A Summary Report

Cancer Survivorship Throughout the Lifespan

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CANCER SURVIVORSHIP THROUGHOUT THE LIFESPAN: CHALLENGES FOR THE 21ST CENTURY

Overview

Long-term survivorship after cancer is now a reality for millions of Americans. Meeting the complex medical, psychological, social, and spiritual needs of this growing population presents a significant challenge to the healthcare community. As this population comes under study, it has become increasingly evident that the needs of cancer survivors have not been addressed satisfactorily. The thrust of treatment has been to achieve cure and the consequences of the disease process or long-term implications of treatment, physiological and psychological, have remained a secondary consideration. Over time, these issues have become more salient and to varying degrees treatment protocols have been modified so that survival outcomes remain intact or improve, but the effects of toxicity of treatment and other long-term effects continue to be under-estimated.

What appears to be lacking, however, is a reasonably solid database on which models of assessment, treatment paradigms, and preventive strategies could be based. Literature is largely anecdotal and there has been very little integration of knowledge across disease types or age groups. In holding conferences focusing on cancer survivorship throughout the lifespan, our goal was to bring together professionals with different areas of expertise to generate a common agenda for research and to suggest models of clinical intervention.

The first conference, which took place in October 1998, sought to establish the parameters of the field of study. Many who had conducted research or were known for their clinical or advocacy work in the area were invited to present their views, with the purpose of establishing commonalties across diseases and age groups. A range of professionals and survivors shared their research and clinical experiences as they saw both relating to the four specific aims of that conference:

1. To establish a unified definition of survivorship and related issues.
2. To identify common medical, psychological, and social sequelae of the cancer diagnosis and treatment.
3. To acknowledge the need for continuity in the treatment and care of survivors throughout the lifespan.
4. To generate an agenda and models for research and clinical strategies.

Key papers reflecting the contents of those meetings are presented here. Some convergence of views is clearly in evidence. For example, it appears that a lifespan developmental approach is very appropriate as a means to unify the field and to serve as a basic model for research and clinical models. However, it was also clear from this first conference that we still lacked specific direction and concrete avenues for pursuit. Thus, the second conference, held in October 2000, sought to generate common paradigms for research and clinical service delivery. Barriers to quality continuous care to cancer survivors were identified, as well as potential means to overcome those obstacles. Specific objectives of this second conference were:

1. To delineate macro level factors that interfere with optimal medical, psychological, and social treatment of cancer survivors across the lifespan.
2. To explore factors that interfere with optimal medical, psychological, and social treatment of cancer survivors throughout the lifespan.
3. To integrate the continuous care of long-term survivors throughout the lifespan into the broader medical system.
4. To generate an agenda and models for future research and clinical strategies.

In the subsequent pages of this document, findings of these two meetings will be presented. Issues pertaining to an agenda for research and clinical outcomes to be pursued over the next five years were highlighted throughout the conferences and summarized in discussions with experts. There are four areas of focus: applied quality of life, prevention, chronicity, and end of life issues. The summary of these discussions is presented in section IV of this report.

As editors, we made some interesting observations of the available knowledge base pertaining to cancer survivorship. Defining survivorship and beginning to identify key aspects of physical, psychological, and social consequences were reasonably straightforward. Issues were pursued on a global level, and were shown to apply to survivor groups across the life span. Much greater difficulty was encountered, however, when the attempt was made to identify barriers to addressing the diverse needs of cancer survivors. First, it is clear that many of the factors that preclude adequate cancer treatment affect survivorship as well. For example, access to care can be limited severely by geographic or socioeconomic factors, affecting those on active treatment and survivors in a similar manner. It is unclear, however, if these factors affect survivors in some unique ways.

Our speakers on these topics were chosen because they had risen to national prominence in their respective fields. Their presentations reflect the fact that principles that were studied for years among cancer patients were already well developed and validated theoretically, but lacked specific application to cancer survivors. This effort is still in its infancy.

A consequence of these observations is that the material presented in these summary proceedings as suggestions for future endeavors remains fairly global and undifferentiated. It would be wonderful if we could delineate specific agendas for research on defined clinical problems, and barriers to addressing those needs among survivors. This is not possible at present as once the attempt is made to go beyond universal concepts, the data, clinical application, and theory required are lacking. Only interdisciplinary discussion and systematic investigations of diverse survivorship groups can assure the desired level of integration that we consider to be necessary.

Critical themes were identified throughout the discussions and as such represent major influences in the future development of the field of cancer survivorship. These include:

- The lack of research tools and methodologies to document outcomes unique to cancer survivorship in measurable terms. Quality of life measures developed for people on active treatment are not directly applicable to long-term survivors. Because long-term survivorship is a relatively new phenomenon, it is imperative to use heuristic strategies, such as surveillance of survivors over time, to identify important more remote, as well as immediate, outcomes. Due to social implications, researchers must be mindful of important contextual issues, such as patient confidentiality, family relationships, and cultural sensitivity, as the projects proceed.

- Reimbursement of clinical services and long-term follow-up of survivors is inconsistent and problematic. The present reimbursement system focuses on acute illness and interventions. After active treatment for cancer, current billing codes do not accommodate comprehensive follow-up care, even though it is deemed to be important. The preventive and remedial value of long-term interventions must be demonstrated. Once they are, they may be used to persuade third party payers of the necessity for ongoing contact with patients.

- Cancer survivorship needs to be a scientific field of study on its own. It needs dedicated professionals, its own database, and its own sources of funding for ongoing research endeavors. There is more to cancer research than the binary outcomes used to examine survival rates for given treatment protocols. Individuals' quality of life during treatment and after treatment is of paramount importance. Disease survival is extremely important, but the additional question of "at what cost?" must be considered.

- Survivors, and not just the professionals providing their care, must be included in the development of the field. Their perspectives are unique and without them, it is likely that the field will be misguided. The flow of information must be bi-directional. Survivors need greater education about ongoing risks and possible strategies for prevention and remediation so that they can advocate their own needs. In return, they can provide important outcome data to help demonstrate the efficacy of interventions and to help identify other areas of study.

- A lifespan approach is essential. Individuals do not live their lives in defined stages, but rather have a continuous journey over the course of years from diagnosis to death, whatever that length of time might be. If we choose to study issues by linking them to specific age groups, we will never understand the themes that are common over the life course and that affect the quality of life of cancer survivors. The current models of breaking down patient groups by age are limiting and new paradigms for exploration that embrace longitudinal foci must be generated.

The challenge ahead, as we venture forth into the 21st Century, is to define agendas more carefully and to mobilize resources in order to delineate models of research and enhanced service delivery to cancer survivors. It is our hope that the following material is a first step to accomplishing those goals.

Section 1

Defining Cancer Survivorship

Cancer Survivorship:
A Definitional Problem

Elizabeth J. Clark, PhD, MSW, MPH

We are accustomed to considering American Cancer Society projections such as those for 2000 indicating that there will be 1,228,600 new cases of cancer. There will also be 564,800 deaths from cancer. There is a one in two lifetime risk for men and a one in three lifetime risk for women of developing cancer.

It is, however, becoming as important to begin considering the growing number of people who are surviving their cancers. Today, for instance, there are 8.1 million persons living with a cancer history, and 58 percent of them have lived five years or longer. In 2000, one in nine hundred young adults were survivors of childhood cancer. By 2010, this figure is expected to increase to one in every two hundred and fifty young adults.

Cancer survivorship poses enormous definitional problems for both patients and clinicians and therefore for researchers who would study it as a process. Survivorship is a bio-medical concept. As such, it is measured by health care outcomes, such as length of disease-free time, or time from diagnosis, or by longevity. One of the difficulties with survivorship as a bio-medical concept is prognostic ambiguity. This has become particularly difficult with recurrences occurring at later dates and with secondary and tertiary cancers. As a result, it is becoming harder and harder to define who is a survivor solely by the bio-medical concept. The magical five-year point does not have nearly as much meaning anymore, because we are finding that eight years later or ten years later or thirteen years later someone has had a recurrence, or they have developed a second cancer.

Survivorship as a social process requires different terminology. When we talk about cancer survivorship from the social perspective, we have to include both micro and macro phenomena in the definition. At the micro level, this includes the personal experience of the individual with cancer, the construction of reality of that individual, and the framing of personal experience. Because personal experience has an impact on interpersonal relationships, we also have to include the interactions between individuals with cancer, their health care professionals, their families, their friends, and their co-workers.

In the social definition of cancer survivorship, we also have to consider macro phenomena, as well as socio-cultural factors. The social concept of illness includes consideration of all factors outside the individual that influence the illness process.

An example of the macro level or context would be the social world of the institution where the individual is treated. Since it may be a community hospital, a cancer center, or an outpatient clinic, given their institutional differences, it is reasonable to ask whether these differences have an impact on definitions of phenomena, and if so, what are they? One might ask, for instance, what views of survivorship does a particular institution hold on the reasonable assumption that the way cancer and cancer care are approached, can be quite different depending upon the culture of the treatment setting.

We also know that most institutions have formulations about diagnosis and treatments that are based on ideas of what could, should, or might happen at different points in the cancer experience, based on probabilities. We know that clinical profiles of disease are used and clinical profiles are built up after many individual cases are observed and documented. Institutional culture and behaviors, as well as the medicalization of cancer survivorship all have an impact on the social definition of survivorship and an impact on the individual.

There is also the definition of cancer survivorship as defined by the survivorship community. This definition is in the charter of the National Coalition for Cancer Survivorship. That definition reads: "From the moment of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor." This is primarily a social definition that allows all individuals with cancer to be called survivors. This includes persons who do not fit the bio-medical definition, for example, persons with recurrences, those in continual treatments, and those in terminal stages of illness. It gives them a social definition that is useful.

There is another very important consideration regarding definition. We know that defining oneself is an act of power. Think about the difference between the phrases "cancer victim" and "cancer survivor." NCCS has worked for years to get the term "cancer victim" removed from the literature. But while the word "survivor" and the NCCS definition of "cancer survivor" can be very useful for the survivorship community, they are not as useful for the research community. For research, you have to be able to define your parameters in a definite way. Terms need to be precisely defined, and variables must be measurable.

The definitional problems with the term "cancer survivor," exist because the concept is multi-determined and cannot be explained by any single model of interpretation or by a single level of analysis. We know that we have to address the biological, the psychological, and the social bases or levels of explanation, and this may be the reason why quality of life studies have been so popular, because quality of life studies include all of these components.

So what is the status of cancer survivorship research? We have seen quite a lot of research done in the area of cancer survivorship over the past twenty-five years. Sometimes we think this is a new area of inquiry, but you can go back in the literature to Weisman's work, "Coping with Cancer" from the 70s. It is a wonderful piece of work that still has relevance today. Weisman defined behaviors that were positive for persons with cancer, and attempted to describe persons who were vulnerable to negative outcome or poor adaptation.

It appears from the sociology literature that researchers have studied factors that contribute to the onset of cancer and factors that inhibit patients from seeking cancer care in a timely way. They have looked at cultural aspects for pain and social factors that help or hinder adaptation to the illness of cancer. Similarly, the nursing literature has had many wonderful studies on cancer survivorship issues during the last ten or twenty years. An example is the concept of hope. If you go back in the literature, you will find that hope was studied in the 70s, and then the concept fell out of favor for some reason until the 90s. Some of the work being done on hope by oncology nurses today is remarkable.

We could go through the various professional disciplines and list their major areas of study with regard to survivorship. If we did so, we would find several commonalities. First is the fact that very little of this research has been directly applied in our clinical settings. Work that was done, very good work, has just not moved forward in our clinical settings.

Much of the cancer survivorship research has been done in isolation and has not been replicated. You read a really good study and find that, for whatever reasons, no one has ever replicated it, and so it is not considered conclusive. We know that until quite recently, multi-disciplinary and multi-institutional studies in cancer survivorship had been infrequent, and it is only now that we are beginning to see multi-institutional studies looking at cancer survivorship. The establishment of the Office of Cancer Survivorship within NCI in 1996 has helped to bridge many of these gaps. Areas that have been understudied are survivorship across the continuum and across the lifespan. We can look at both cancer and cancer survivorship as a continuum. But first there is the disease continuum of cancer. That looks at diagnosis, treatment, remission, recurrence, dissemination, and death as one continuum, a disease continuum. However, we also know that the pattern can shift – for example, remission, recurrence, remission, recurrence, so it is not always linear progression.

Of this continuum, the areas that have been most studied are diagnosis and initial treatment and the terminal phase of illness. So if you look at the literature on survivorship, much work has actually been done on how persons adapt to a diagnosis of cancer and how they go through the initial treatment. We have also seen literature in the last twenty-five years on terminal phases of the disease. What is still lacking is what happens in between. As we watch cancer survivorship extend across the lifespan, we have to pay more attention to those other categories.

In 1985, Fitzhugh Mullan, one of the co-founders of NCCS, wrote an article called "Seasons of Survival." He listed three stages in his article: acute survival, extended survival, and permanent survival. Acute survival begins with a diagnosis and continues through the initial course of treatment. Extended survival is an intermediate stage, and it includes maintenance therapy and remission. The permanent stage (this is the long-term stage of survival described by physicians) is a state of cure or sustained remission. In this stage, the probability of disease recurring is greatly diminished. Dr. Mullan has always made the point that there are not clear lines of demarcation between these stages, but that it is a continuum. People move in and out of the stages.

Another group, Welsh McCaffrey and her colleagues (1989) also described the continuum of cancer survivorship. They laid out various cancer survivorship trajectories:

- Live cancer free for many years
- Live long cancer free, but die rapidly of late recurrence
- Live free of first cancer, but develop second primary cancer

- Live with intermittent periods of active disease
- Live with persistent disease
- Live with expected death

This model, again, is largely based on the bio-medical definition of cancer survivorship. We need to expand these models from the disease experience to the illness experience, to account for the fact that the cancer experience never actually ends. A person lives with the diagnosis of cancer and that history for his or her entire lifespan.

A theory of cancer survivorship is developing, and there are numerous assumptions that we can already put in place. First, survivorship is a dynamic concept that involves a continuum of events from diagnosis onward. Second, survivorship is experienced in five major ways: physically, psychologically, socially, behaviorally and spiritually.

Survivorship is a highly contextualized social process. It is multi-determined. It cannot be explained by a single model or by a single level of analysis, and survivorship issues have commonalities that cross the boundaries, types, and stages of disease. From past research, we can identify the challenges that seem to cut across all ages of the lifespan.

First, we know that cancer survivors need to regain a sense of control over their lives. They need next to adapt to physical compromise, and they need to manage emotional distress. They need to continue personal growth, and they need to live with uncertainty and fear of recurrence. All of us live in our society with partial knowledge and uncertainty, but there is a difference for the cancer survivor, who has to think about uncertainty of the disease recurring. We also know that cancer survivors need to keep a positive and hopeful future outlook. They need to maintain satisfying relationships, maximize choices, engage in medical consumerism and self-advocacy, and integrate the role of person with cancer into personal identity (Clark and Stovall, 1996).

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Definition of Lifespan in Cancer Survivorship

Gary A. Walco, PhD

In medicine, as well as in many other areas of study, professional training and service delivery are often focused on specific age groups. For example, pediatrics focuses on infants, children, and adolescents. In addition to subspecialties based on age groups (e.g., neonatology, adolescent medicine) there are subspecialties focused on specific organ systems (e.g., pediatric neurology, pediatric cardiology) or disease groups (e.g., pediatric oncology). With increasing specialization, there is often even less of an integrated approach to the context of life span development. Thus, difficult questions arise. When is it appropriate to transfer a patient from a pediatric system of care to an adult system? If a child with cancer has been followed by pediatric oncologists from the time of diagnosis through long-term survival, including diagnosis for late effects, what needs to be done to assure a smooth transition to an adult service?

At the other end of the age continuum, although there are medical specialists for the elderly, few of these are identified as "geriatric oncologists." The implication is that many factors associated with the aging process may not get the attention that is owing to the elderly with cancer. Nor is it clear that medical or surgical oncologists are specifically attuned to such age related changes. Even if that were the case, it would be important to establish how practices vary as patients develop from young adulthood, through early middle age, middle age, late middle age, and into elder hood. Clearly the medical, psychological, and social concerns confronting a young adult are vastly different from those experienced by the elderly.

These issues become crystallized as one examines methodological strategies espoused by developmentalists. In essence, if one focuses on specific age sectors (pediatrics as distinct from adult as distinct from geriatrics), the perspective is cross-sectional in nature and, as a result, continuity between these general stages is lost. In contrast, a longitudinal perspective highlights the development of individuals over time and helps, as a result, to establish this continuity. For pragmatic reasons, however, longitudinal research studies on many aspects of development throughout the life course are lacking. In addition, medical technology has become so advanced that it is unrealistic to expect specialists and subspecialists to address comprehensively aspects of their medical concentration across developmental lines.

There is, however, a methodological paradigm common in developmental psychology that may be quite useful as a foundation for the work so needed in cancer survivorship. During the 1970s, a great deal was written about lifespan approaches to development. The key notion to emerge was that individuals change in somewhat predictable ways over time and that common processes underlying observed changes should become a focus of investigation. Once such functions have been established, individual differences, or deviations from modal developmental tendencies, may also be examined. Thus, for example, it makes no sense to focus on psychopathology as a static disease state. On the contrary, it is preferable to view it in the context of biological predisposition, temperament, personality development, and deviations from normal developmental processes that may lead one to a psychopathological state at some point in time.

Although a complete review of methodological strategies in lifespan development is beyond the scope of the current discussion, it is clear that in order to address the issue of continuity of medical care across ages, a focus on developmental themes and the implementation of such strategies is critical.

Certainly a comprehensive review of the biological, psychological, and social issues related to long-term survivorship from cancer is not feasible here. What follows is a sampling of some issues amenable to a lifespan developmental focus.

Biological Aspects of Long-Term Survivorship

As the number of long-term survivors increase~~s~~, more late effects are being appreciated. It is now clear that treatments potent enough to eradicate cancer also take their toll on multiple organ systems in the body, including cardiovascular, pulmonary, renal and genitourinary, sensory, dental, musculoskeletal, peripheral nervous system, reproductive, and neurological or neurocognitive. In pediatric oncology, chronic disease process, poor nutrition, growth hormone deficiency and other hormonal dysfunction, steroid growth effects, as well as psychological factors all serve to increase the risk of problems with growth and development. Among this array of potential late effects, some are recognized quickly, even while an individual is receiving the treatment (e.g. hearing loss related to cisplatin), while others appear many years after the completion of treatment (increased risk of myocardial infarction and cerebral vascular accidents). As treatment regimens progress and become more aggressive in order to eradicate cancer, there is an increased risk of more late effects and longer latencies until they can be recognized.

Another major area of concern among survivors is the increased risk for secondary malignant neoplasms. Due to such factors as variability in the predominant type of primary malignancy, age at initial diagnosis, intensity and duration of therapy, it has been difficult to arrive at an unambiguous identification of the mechanisms underlying secondary malignancy. It does appear, however, that previous radiation therapy and alkylating agents, as well as the combination of these two, place individuals at increased risk.

Finally, it appears that some patients are “prone” to malignancy. Because in the past, relatively few people survived their first bout with cancer, the opportunity to observe second or third malignancies was absent. Increasingly, however, there are reports of individuals who manifest multiple malignancies of various etiologies, raising significant questions about the nature of genetic predisposition to cancer, as well as difficult dilemmas in treatment approaches.

The biologic realm includes an array of issues that are amenable to lifespan approaches. Chemotherapeutic agents that affect cardiac functioning may have a different impact depending on the age of the patient at the time of administration. In addition, life style changes that may be related to cardiotoxicity add another dimension to what may be observed later on in life. In other words, there may be an interactive effect between cardiac concerns at a young age and the aging process itself that yield observed results later in life. The degree to which these processes parallel cardiotoxic effects seen in adults is an empirical matter that remains to be assessed. However, it is reasonable to assume that knowledge gleaned in one area may have a substantial impact on other areas and the transmission of these data will take place only if a systematic mechanism is put into place.

Psychological Aspects of Long-Term Survivorship

A broad range of psychological issues has been assessed in long-term survivors of cancer. In some cases, the focus has been quality of life, which is typically broadly defined and includes a number of parameters. Although quality of life measures have been developed for specific age groups and specific diseases, there are common elements that are measured. By focusing on themes that are consistent across these measures and evaluating changes over time, major strides may be made toward adopting a lifespan perspective.

There also have been a number of studies on more specific aspects of psychological adjustment throughout the lifespan. These include neurocognitive consequences of chemotherapy and radiation, risk for psychopathology, including posttraumatic stress disorder, social adjustment, models of stress and coping, family issues in coping with cancer, marital concerns and roles of informal caregivers, parental concerns, siblings' concerns, body image, and sexuality.

The latter cluster serves as a good forum to demonstrate the value of lifespan approaches to survivorship. Regardless of age, the disease process of and treatments for cancer have a profound impact on bodily functioning and physical appearance. These factors interact with other elements of psychological coping and have a major impact on adjustment. In contrast, age related domains of the literature have remained fairly distinct. Concerns over the integrity of their body experienced by young children, the sensitivity to physical changes and "marring" evident in adolescent females, preoccupation with body image and sexuality frequent in adult females with breast or gynecologic cancer, and anxiety about their potency in older men with prostate disease have links that may provide a common strategy for investigation.

Social Aspects of Long-Term Survivorship

The reintegration of cancer survivors into normal societal activities has been a challenge, both for the survivors and societal institutions. For children and adolescents, this has included school reintegration and reestablishing peer networks. The parallel in the case of adults is returning to work and resuming a career. In both of these arenas, there are certain preconceived notions and stigma that resist such a transition even to the extent of discriminating against cancer survivors at the workplace and even excluding them from their job. Many survivors of cancer have a great deal of difficulty obtaining health and life insurance. Ethnic and cultural issues have been discussed as related to decisions in cancer treatment, but have not been adequately studied as contextual factors in the reintegration of cancer survivors. As many of these cultural considerations are present throughout the lifespan, the manner in which they interact with developmental forces over time makes them urgent objects of further investigation.

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The Experience of Survivorship: What We Should Know?

Claudette G. Varricchio, DSN, RN, FAAN

The National Cancer Institute (NCI) recognized the need for a research agenda on survivorship. The Office of Cancer Survivorship (OCS) was created to facilitate quality research, identify the healthcare needs of and guide therapeutic decisions for cancer survivors.

Physiological Outcomes of Cancer Therapy

In exploring the physiological outcomes of cancer and its treatment in survivors, we must identify the impact of the disease process and treatment to the extent possible. Research is needed in the following areas:

Specific Late Effects

- Cardiac function (e.g., ischemic heart disease following radiation therapy and cardiomyopathy after anthracycline therapy);

- Renal function (e.g., following platinum-based therapy);

- Deficits in cognitive function (e.g., children who have received craniospinal radiation and/or intrathecal methotrexate).

Reproduction and Sexuality

- The interaction between physiological late effects and pregnancy;

- Incidence of anomalies at birth among the offspring of cancer survivors;

- Possible genetic consequences of having had, and being treated for cancer. Even though the primary cancer did not seem to have a genetic base, did it cause mutations in DNA that might be transmitted to the offspring;

- Pituitary and gonadal function;

- Premature menopause and implications of hormone therapy.

Secondary Cancers

- Descriptive studies of secondary or tertiary malignancies;

- Possible mutagenic effects of the cancer therapeutic agents;

- Studies on the causal direction of observed correlates (e.g., While there appears to be an increase of secondary breast cancer in survivors of Hodgkin's disease who had mantel irradiation, causal factors are not known).

Quality of Life Issues in Survivorship

The complex psychosocial factors that affect the quality of life for cancer survivors must be evaluated and assessed as part of any research or clinical care agenda. Critical issues that must be addressed include:

- Quality of life may be affected by feelings of stigmatization;
- Quality of life may be affected by changes in self concept, including feeling categorically different from peers;
- Psychological distress factors, including fear of recurrence, sexual dysfunction;
- Social reintegration;
- Insurability and employability.

Methodology Issues

New methodologies to measure and assess the long-term consequences of cancer survivorship are needed. These include:

- Optimal tracking systems to indicate what happens to people who have had cancer;
- Assessment tools to validly assess quality of life among survivors;
- Controlled studies to define specific effects using appropriate contrast groups;
- Psychometrically sound measures that are capable of measuring changes in quality of life in longer-term survivors;
- Instruments validated for use in sub-populations of minorities and culturally diverse people.

Populations at Risk

The NCI and other national organizations have identified populations who have either not been studied or given as much attention as other groups or cancer sites or have special needs that must be considered. These include:

- Colon and lung cancer patients;
- Groups identified by culture, income, and age;
- Patients with less common cancers.

Education and Communication

Broad based educational and communication needs must be addressed if we are to move forward in any agenda to improve cancer survivorship through the continuum. Such needs include:

- Decision-making processes regarding treatment, specifically with regard to communication between providers and patients;
- Public education about cancer survivorship aimed at facilitating re-entry and adjustment by cancer survivors;
- Educational interventions targeted to the developmental and literacy needs of the audience;
- Culturally sensitive educational endeavors.

Interventions to Improve the Quality of Survivorship

The development of interventions aimed at improving quality of life for cancer survivors remains a priority for research. Issues to be considered include:

- Potentially preventable problematic outcomes;
- Risk-benefit analysis of each intervention;
- Targeting specific interventions to the identified needs of defined patient groups (i.e., who might benefit from what);
- Data on cost effectiveness;
- Data on appropriate surveillance and follow-up strategies.

Databases and Infrastructure

One possible source of reliable information regarding long-term outcomes are the subjects who were enrolled in cooperative group clinical trials and who are now being followed by those running the cooperative groups. Another source of better information on survivors over 65 years of age is now available because of a melding of the SEER and Medicare databases. Combined, they give a more textured profile of this age group. At the same time, it is worth noting that for all the improvements in the data on those aged 65 and older; information regarding status of survivors under the age of 65 remains inadequate.

The National Childhood Cancer Survivors Study has a database of a cohort of survivors of childhood cancer that is well described. Cancer centers also have cohorts from their treatment studies that they can follow and use as sources of subjects for future research on survivorship. There are state and other tumor registries, which can provide valuable information about survivors. In this regard, advocacy groups should not be overlooked as sources of possible subjects who represent a cross-section of the American public and who might be willing to participate in survivorship research.

In summary, the needs are considerable and include well-described cohorts of survivors, and the resources and the methods to study them. While it is now possible to identify selected subgroups and target the research on them, the infrastructures for tracing cancer survivors and following them over time remains to be developed.

The Future of Survivorship Research

In light of what has been outlined above, it seems clear that survivorship is going to be a fertile field for research. For example, there is a role in cancer prevention trials for people who have had cancer. Some small trials, now under way, are looking specifically at the prevention of recurrence of head and neck cancers, as well as the prevention of recurrence of colon cancers, and other secondary prevention. If these opportunities are to be exploited fully, it is critical to make them known to the appropriate cancer survivors.

Research on the immediate effects of having had cancer, and not only the long-term and late effects, holds great promise. This is particularly true in areas like physical, psychological and psychosocial rehabilitation.

Then there is the question of what happens to the survivors of childhood cancer and young adults who have been cured of their cancer and now are aging and experiencing the normal effects of aging? What, for example, will be the results of the effects of cancer and its treatment as they interact with the normal aging process? At the moment, there are no research findings to tell survivors what they as survivors can expect of a normal aging process.

There are other big gaps in our information on all ages of survivors. For example, there are few data on the differences due to age at treatment, developmental stage, current recurrence, and second cancers.

Working partnerships will be the key to any successful effort to address these issues. To this end, collaboration among the National Cancer Institute, the American Cancer Society, and the National Coalition for Cancer Survivorship is indispensable. Collaboration must also involve consumer groups and foundations that are interested in supporting research that is broadly relevant to cancer survivorship. In a similar vein, a coordinated effort among nurses, physicians, social workers, psychologists, and rehabilitation, and physical medicine practitioners is a priority. The conclusion is indisputable. All of the disciplines that provide health care have to coordinate those of their different practices and research efforts that are relevant to cancer survivors if, as a result of their interventions, the quality of life of those who survive cancer is to improve as it can and should.

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Section 2

Special Concerns in Cancer Survivorship

Sequelae in Long-Term Survivorship

Patricia Ganz, MD

The risk of late effects of cancer treatment depends on several factors, including the tissue treated and the age of the patient at the time of treatment. The level of the dose and the modality of delivery also have a bearing on late effects, as do the type of treatment and its target. Late effects can occur shortly after treatment or many years later, and patients of all ages can be affected.

We know more about late effects in childhood survivors because pediatricians have conducted systematic clinical trials that provide a detailed record of what treatments have been used. However, we still do not know the scope of the problem in middle-aged and older adults.

The degree of risk of late effects to individual patients cannot be predicted. We can treat everybody with the same dose on a protocol and have very substantial variations in late effects. We need to be able to account for these variations in response to the same treatment. We also need to realize that while second cancers are a very important problem in this patient population and account for a growth and expansion of the number of new cancers that we see, there are other disabling conditions to which we need to pay attention.

In the last 20 years, our therapies have become much more complex, and diseases that were once treated with surgery alone are now routinely treated with chemotherapy and radiation, as well. While these advances in treatment lead to higher cure rates, they also lead to greater risk of late effects. Accounting for the range of toxicities of each modality working on its own does not give us the full picture of what happens when the modalities are combined.

Below is a sample of the effects that we can expect from different kinds of treatments.

Surgical Late Effects

- With breast cancer and other diseases in which there is regional nodal staging, there is a risk of lymphedema.
- Amputation leads to functional as well as cosmetic issues.
- With abdominal surgery, potential effects include intestinal obstruction from adhesions and short bowel syndrome.
- Staging laparotomy, which was commonly used to stage patients with Hodgkin's disease, fortunately is being done less frequently in earlier stage disease, but those individuals undergoing it may be susceptible to immune dysfunction and severe bacterial infections.
- Pelvic surgery done in rectal, bladder and prostate cancers may lead to impotence and problems of incontinence.

Chemotherapy Late Effects

- The late effects of chemotherapy include a wide range of renal toxicities. The greatest concern is renal failure. As we age, changes in our renal function occur. These changes may be accelerated by exposure to this agent at a younger age (e.g. cyclophosphamide with toxicity to the genito-urinary tract.)

- Regarding other late effects on the bone, steroids are widely used in leukemia and lymphoma so that avascular necrosis of the hips can be a late effect.

- Anthracyclines and cyclophosphamide can lead to various cardiac problems, including congestive heart failure.

- Pulmonary function declines in all of us as we age. Therapies that we give to patients or survivors may contribute to this in the form of late term effects.

- Steroids contribute to cataracts, as does Tamoxifen.

- Neurotoxicity can occur with changes in the brain and the peripheral nervous system. (Cisplatinum, and taxol in particular cause peripheral neuropathies.)

- Hematological toxicities are well described in the literature, and we know about leukemia occurring, usually within a fairly predictable period of time. But we cannot predict who will get it.

- There are gastrointestinal toxicities affecting liver function and changes, as well as changes in gonadal functioning, with infertility resulting from treatment involving certain agents.

- There has been considerable interest in fertility and sterility issues in the case of survivors, particularly those with Hodgkin’s disease. A similar interest is evident in the case of women with breast cancer being treated with adjuvant therapy. Problems include early menopause and loss of fertility.

Radiation Late Effects

- With radiotherapy, all tissues are susceptible to second malignancies. These cancers usually occur in the field in which the radiation has occurred. Often these are soft tissue malignancies such as sarcomas, but it is possible to see skin cancers or epithelial cancers occurring.

- In the case of effects on bone and soft tissue, children tend to develop short stature, abnormal growth, and deformities. Dental and oral health is also of concern in the case of young children being treated with head and neck radiation.

- We know a lot about central nervous system changes in the case of pediatric survivor groups in the form of neuro-psychological deficits. Much has been done to modify treatment by not, for example, giving whole brain radiation to young children.

- In the case of brain cancer, survivors or people who have received prophylactic radiation as adults, the dysfunction that occurs in a person who is older may be substantial, with dementia and severe neuropsychologic dysfunction.

- Cytopenias can also occur with radiation. Radiation given in the area of the renal artery may cause renal artery stenosis and lead to hypertension or genito-urinary changes.

- Survivors of Hodgkin's disease might be at risk for late cardiac effects from coronary artery damage.

- Late hormonal and sterility effects are related to radiation. They are, consequently, important problems if we are going to think about late and long-term survivorship and the quality of life that may result from ovarian failure, sub/infertility, and sterility.

Psychosocial Late Effects

- It is clear that fear of recurrence and death often remains with patients long beyond their initial diagnosis. Even 15 to 20 years later, visiting the doctor for the annual physical exam may, for that moment, lead to a reawakening of fears and anxieties related to the cancer.

- Individuals have a pronounced sense of being vulnerable once they have been diagnosed with cancer. They may have been doing every thing they could to live a healthy life, only to have a cancer detected early. Understandably, they find themselves asking, "If circumstances failed me once, how can I avoid them failing me again?"

- Many cancer survivors live in a condition of dysfunction and disability. Moreover, they may choose to keep this situation to themselves. After so many years, it becomes difficult to continue talking to people about problems of this kind. As a result, support groups and other kinds of social support may be very valuable to individuals surviving under such conditions.

- With the health care system the way it is, and with people moving around, survivors may not enjoy anything like a long term relationship with the person who initially treated them. If their insurance plan does not allow survivors to have additional visits to the oncologist, it may be the primary care physician who has responsibility for continuing care, even though patients often feels much more secure with the oncology team.

- Depending on when a person gets cancer, the effects of the disease may differ. Consequently, we need to consider where in the life-span the cancer occurs and how this particular timing shapes the way people live, surviving the disease.

- We should not overlook the importance of existential and spiritual issues in survivors. We need to begin to quantify this information and see what role they play in the survivor's experience.

- The psychosocial re-orientation of values and priorities may result, not infrequently, in very positive life changes for individual survivors.

- As noted previously, many of our therapies have toxicities that may have a negative effect on the sexuality, fertility, and intimate relationships of individual survivors, leading in turn to psychosocial consequences.

Lack of Comprehensive Follow-Up

One problem that we face is not knowing who is actually monitoring survivors for their physiological and psychosocial late effects. Some physicians who follow survivors long-term may monitor late effects. But in many settings, oncology specialists are too busy treating people who are under active therapy. As a consequence, treatment of cancer survivors is often relegated to primary care physicians who are not always knowledgeable about the issues that cancer survivors face. Since survivors themselves really need to deal first hand with their survivorship, it is important for them to have their complete medical records and to become knowledgeable about treatments received, together with information about toxicities accompanying these treatments and their consequences.

There is also a role for specialized clinics, which can certainly allow us to collect more systematically the kinds of information that will benefit patients. Pediatric programs do have survivor clinics. Should however, someone now 20 years old, who had been treated for leukemia as a child, come in for follow-up care in the form of health prevention, education, and so forth, it is really hard to bill insurers for those services. Under these circumstances, the possibility of tests for pulmonary function, or cardiac function, for example, detecting something that is sub-clinical and diagnosing someone with the condition becomes a real issue for purposes of insurance reimbursement. Expanded research might allow us to obtain more systematic information about late effects.

Conclusion

How then can we increase our knowledge about some of the more significant late effects? Obviously, we need to do more research. We need to use the cooperative groups in the cancer registries. Because we have systematic data on how people were treated in the cooperative groups, we can begin to look at what drugs and what treatment modalities are contributing to late effects. Establishing survivor clinics and registries is important, but we cannot expect the insurance companies to foot the bill for this until we establish the benefit of these types of monitoring systems.

One of the things we can do is begin to design clinical trials that evaluate treatments with similar efficacy but different toxicities. One example of this is the tamoxifen and raloxifene trial.

Although it is a prevention rather than a treatment trial, it compares two drugs that are likely to possess fairly similar capacities for preventing breast cancer. However, one of them is hypothesized to have a lower toxicity, and therefore, a lower risk of causing endometrial cancer. It is also an equivalency trial, providing the kind of information expected of clinical trials generally that help patients select treatment options with lower toxicity risks.

Why is there an emphasis on prevention now? The growing number of cancer survivors has increased awareness of late effects. For this reason, we need to encourage research about the relationship between treatments and their late effects. Without understanding the etiology of a late effect, it is difficult to know what to do to prevent it.

Providing cancer survivors with systematic information about their treatment and its late effects allows them to be prepared and knowledgeable. We must be frank with patients and disclose the real risks of the treatments they are undergoing. Somebody who is two, three, or five years out from treatment and making the transition to long-term survivorship needs to be prepared so as to understand late effects. In other words, we need to empower survivors by giving them appropriate information and the educational means such empowerment requires.

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Aging, Cancer, and Co-Morbidities

Rosemary Yancik, PhD

Our population is aging, and older persons are most vulnerable to cancer. The latest Surveillance, Epidemiology and End-Results (SEER) data, from 1993 to 1997, indicate that older people have eleven times greater cancer incidence rates than younger people. With respect to mortality, the rates are fifteen times greater for the older population. We know that cancer is primarily a disease of older persons, and that mortality rates follow a steep curve after age 45 or 50.

SEER is the monitoring system that we use for tracking cancer rates. Although individual cancers occur at different rates in this age group, SEER data show that for all sites of cancer, about 60 percent occur in the 65 and older population. Even some of the tumors that one might expect to occur primarily in younger persons, such as breast cancer and ovarian cancer, occur in a much higher proportion in the older age group.

<u>The 47 Year Trend</u>, published by the SEER Program of the NCI, compares mortality rates in different groups from 1950, 1975, and 1996. The study showed that mortality is going down for the younger age groups and increasing for the older age groups. There are profound changes taking place that clearly point to an increase that goes from 1450.7 deaths per 100,000 to close to 1800 per 100,000. This finding demonstrates indisputably that this important segment of our population demands much greater attention.

Trends in aging allow us to see how big a problem cancer in the aging population may become in the future. The US Bureau of Census Data reflect the growth of our population from 1900 through 2030. In 1900, approximately 4 percent of the population was over age 65 years. In 2000, 12.7 percent of the population was 65 years or older. In 2030, as the “baby boomers” mature, one in five individuals will be 65 years or older. As public health continues to improve, we are going to have more and more individuals living beyond 65 years. In 1900 life expectancy was only 51 years for women and has now increased to 82 years. Life expectancy for males was 47 years in 1900 and has also increased, although not quite as much as for women.

Health status changes with age and adverse events start to increase. Physical alterations are taking place, as different kinds of physiological decline set in. Vulnerability to geriatric syndromes, such as falls, osteoporosis, incontinence, and general frailty increases. At the same time, co-morbidity is superimposed on all of these other problems. The Co-Morbidity Burden Study focused on six population-based SEER geographic areas. It used medical records to identify a large number of co-morbidities for each of the cancer patients. In constructing a co-morbidity profile of our older age cancer patients, we found several things. Although we were able to tally the total number of co-morbid conditions by age, this figure does not reveal the magnitude of the problem. For example, if a person has a severe co-morbid condition and a mild co-morbid condition, it is possible to capture some, but not all, of that data in the medical record. For our group of 1610 cancer patients, we found that co-morbid conditions do increase with age.

Of course, some people in the 75 years of age and older group had no co-morbidities, while others in the younger age groups had three, four, or even ten or more.

Our aim at the National Institute of Aging (NIA) is to promote research on co-morbidity in greater depth. The NIA established certain priority areas for purposes of research, including (1) breast cancer, (2) aging, race, and ethnicity in prostate cancer, and (3) multiple primary tumors. The NIA is now funding some clinical trials through cooperative groups as a result of a special initiative with these groups and in collaboration with the National Cancer Institute.

In reviewing the issue of co-morbidity, we have come to recognize the need for long-term data on older cancer survivors, in particular, data on their quality of life, their level of activity and their different lifestyles. Moreover, it is important to develop data on selective outcomes comparing the older patients to other age groups. The NIA recognizes that a cooperative effort with the National Cancer Institute would be in the best interests of the success of this research.

In addition it is important to explore the SEER data to gather more accurate information about the prevalence of older cancer survivors with non-active cancers, the burden of other diseases in older survivors, and reliable information on recurrence of cancer in late life. Clearly if one adopts a lifespan approach to cancer survivorship, the needs of older adults bring important lessons to all of us and cannot be overlooked or forgotten.

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For a complete catalog of SEER reports, see http://seer.cancer.gov.

Childhood Cancer Survivorship: A Family Affair

Gerald Koocher, PhD

As we contemplate the basic areas of focus for interventions with survivors of childhood cancer, it is important to maintain an appreciation of human development as a trajectory that combines movement with conscious direction. Under normal circumstances, human development amounts to movement in a certain direction and at a certain rate over time. However, with a diagnosis of cancer, this trajectory may be seriously compromised, depending, for example, on the physiological and psychological impact of the disease on the patient. In addition, cancer may affect the process of socialization and its accompanying accomplishments already underway, as well as the manner in which patients are going to meet the goals already set for their lives. Inevitably, a diagnosis of cancer means, at the very least, adjustments with, if not significant changes to the developmental trajectory.

For children, a key phase in their trajectory is attendance at school. Cancer can interrupt this just as, in the case of more mature cancer patients, it can interrupt work and other aspects of life. But since school is the primary socializing agent for children in our society, providing the occasion of academic accomplishments that lead to high school success, followed usually by college success and then successful employment; the implications of this interruption must not be ignored or underestimated.

Another important area to be considered in this context is peer relationships, and with them, the possibly altered self-perceptions that often are not far behind. How these altered self-perceptions may become part of one's everyday life, shaping its content, and influencing its direction, needs careful consideration. Nor should we overlook some of the very interesting sex differences that occur in the way girls who survive cancer and boys who survive cancer may be treated.

Another interesting area for consideration is the traumatic stress that may accompany cancer. There have been a growing number of articles recently attempting to link theories of traumatic stress with interventions for people with cancer. This trend may be questionable for two reasons: First, the category of posttraumatic stress disorder itself is, in my estimation, no more than a diagnostic maneuver that is too often applied without justification. The second and possibly more telling reason is that when traumatic stress does affect a child with cancer, it actually affects the parents before it affects the child. In other words, more often than not, it is children's reactions to parents’ stress that is the source of this issue.

Since childhood cancer is quintessentially a family affair, it is important to highlight some of the consequences to the family of childhood cancer. One obvious consideration here is the time working parents may lose from their job. This time lost can certainly entail financial loss or costs for parents' careers, when for example, they have to take extended time off to care for their sick child. People often overlook the major impact that meeting the needs of a sick child has on one’s work life. In addition to employment status, coping with childhood cancer affects marital life and causes an array of stresses in interpersonal relationships.

Financial difficulties and limitations of insurance policies are also factors that may contribute to the risks of stress. There are situations where people cannot fill prescriptions and may be too proud as a caregiver to admit it to anyone. Fortunately, care of childhood cancer in the United States is set up so that generally there are a number of charities and other agencies that make it possible for children to receive good care when they are in the hospital. This does not always translate into equally good care on an outpatient basis, where families may not have the resources to provide some of the comforts, or even some of the clinical necessities, that may help the child to cope at home.

Another important issue to consider is the medical "costs" for which there is no reimbursement. These include the time that has to be spent away from home, which can also lead to marital stresses and can be the cause of distress for siblings. There is substitute childcare that might be required for the siblings of the sick child if parents are spending time in the hospital or taking the sick child to clinics. There are parking and transportation costs, which in urban settings in particular, can be quite burdensome. There are additional stresses if it happens to be a situation involving a single parent; especially in the case of a single parent of more than one child. Consideration of the extended family can be a mixed blessing. There are many members of the extended family who could be helpful and supportive in a variety of ways. Unfortunately, there are also members who can be difficult and who can get in the way.

Traditionally, far too little attention has been paid to the distress experienced by siblings. Depending on the age of the siblings and their ability to understand the family situation as it is being affected by cancer, the developmental course of their lives, both long-term and short-term, can be disrupted. For example, does a sibling forego an opportunity to attend college because of economic demands made on the family as a result of cancer? Does the sibling become unduly "parentified" in the sense of wanting to assume parental roles or to help with the care of the sick brother or sister? Does a sibling become so anxious as to not want to go to school, preferring instead to stay at home to be sure that everything is in order?

Another set of considerations highlights the adjustment that faces children diagnosed with cancer. In this regard, it is useful to consider risk factors that involve adjustment. One of them certainly is a high-risk diagnosis, simply because such a diagnosis leads to more intense therapies and more immediate uncertainties. We know that the invasiveness of the therapy and the longer the duration of therapy, the more intensified are the stresses accompanying that treatment. The longer the course of therapy, the greater the likelihood that disruptions will be experienced in the developmental trajectories discussed above. The toxicity of therapy is another important factor in any consideration of adjustment. We should not overlook the degree to which residual handicaps can pose problems for adjustment.

Unlike some psychological distress, this particular distress in this population does not diminish very easily with habituation. In fact, many patients experience an increase in their anxiety as the number of visits to the hospital increases. Pre-existing social or psychological problems in the patient or in the nuclear family are another significant risk factor. It is hard enough if things are going well and if there is an adaptive family system to support the child. If, however, a parent has a significant mood disorder, or if there is a family member with a significant substance abuse problem, hopes for successful psychological adjustment in the child's family are seriously diminished.

We also know that language and culture can be a source of problems. This is particularly true when the language and culture of the patient and the patient's family differ from those of the primary caregivers and where, as a result, the social expectations of both parties are not necessarily in harmony.

With regard to interventional strategies to address these risks, nothing short of a comprehensive therapeutic approach from the day of diagnosis will be enough. Obviously, the first goal is to cure the cancer. No less obvious is the second goal, which should be ~~is~~ to secure an acceptable quality of life for the patient. For this we need the kind and quality of care that from the first day integrates the psychosocial and the medical needs of patients and families. These treatments cannot be pursued on parallel tracks as though they were unrelated, the approach must be integrated and comprehensive. There must be routine monitoring of the quality of the life of patients, their psychological status, and the well-being of their families.

We need programs that help children resume their developmental trajectory, including their formal schooling. School reintegration includes contacting the school, letting school officials know that the child is coming back, and assisting school personnel to meet any special medical or other needs of the child. It is also critical to give the school the information it needs such as, providing warnings about the dangers of contagious diseases (e.g., chicken pox or other health related problems). We also need to help the school prepare itself to meet the complicated academic needs of these children, including addressing learning problems that may develop related to cancer treatment.

Finally, it is important to pay special attention to symptom control and to other difficulties that result from treatment. In other words, if the health care team has a mindset that says, "We have won this battle, we cured your cancer, and we are just going to check you every couple of months to be sure the cancer has not come back," then we are likely to overlook important symptoms that really affect the quality of life of the patient. It is also at this juncture that we probably need family members to advocate for children or teenagers who may not be able to do so for themselves. The highest quality care is evident when the same people that provide the acute care are offering long-term care too. Included in this notion is care that involves systematic follow-up so as to meet the needs of the patient over the long run, not just during the acute phase of treatment.

The Forgotten Factor in Healthcare – Spirituality: What Does Research Find?

David B. Larson, MD, MSPH, FAPA

Many Americans turn to spirituality during times of personal crisis, stress, or medical illness. Although important to many in the United States and many coping with medical illness, issues of spirituality have infrequently been considered by health care professionals in research, training, and clinical care.

The clinical research literature has been found frequently to overlook spiritual and religious factors, so that they are seldom included in studies published in leading health and mental health journals. In addition, the majority of published studies that include a spiritual or religious variable frequently inadequately measure religion or spirituality. For example, in studies sampled in systematic reviews of the published research, of those assessing religion, nearly 50 percent assessed only the patient's religious denomination, a somewhat irrelevant clinical variable. In addition, only one in five studies that included a spiritual or religious variable used more than a single question to assess the levels, or frequencies of spiritual or religious practices, attitudes, or beliefs. Finally, a very small minority of published studies assessed spiritual or religious commitment using the most salient approach, a previously tested, multi-item measure that can assess various dimensions of spiritual and religious practices, beliefs and attitudes.

In earlier research containing spiritual variables, the inadequate measurement of spirituality was not the only methodological problem found. First, less than one in four clinical studies assessing spiritual or religious commitment were found to have at least one relevant research citation. In addition, spirituality was rarely included in studies as a major dependent or study outcome variable. Finally, when spirituality was studied, it was generally treated as a minor peripheral independent variable, and thus, minimally relevant.

Furthermore, when a spiritual variable has been included in a research study, hypotheses have been infrequently made, and even when made, findings were seldom reported in the study's results section. Similarly, the implications of the findings were seldom included in the discussion section. Finally, only a minority of studies can examine the potential cause-and-effect relationships between spirituality or religion and clinical status, since most spiritual variables are included in cross-sectional or single-time design studies. However, when included in retrospective or prospective clinical studies, spirituality has shown much promise as an important predictive clinical factor-whether as something clinically beneficial, as in most cases, or less frequently as something clinically harmful. It should be noted that studies published in the last few years have design and measurement strengths that have begun to reverse these past methodological deficiencies and problems.

What is perhaps most unfortunate about the state of affairs of spiritual variables in clinical research is the lack of awareness that researchers, medical educators and clinicians have concerning the importance of spirituality to patients. Likewise, there is little awareness of the frequently positive and infrequently negative associations of spirituality with clinical status to be found in the published research. Despite the methodological problems noted earlier, generally positive associations, implying clinical benefit, have been found even when spirituality is measured with minimally acceptable research standards.

When measured more adequately in studies with improved research designs; spirituality and religiousness have been found to have even greater promise of clinical benefit in: (1) illness prevention, (2) coping with illness (particularly for those with severe medical illness, such as cancer), (3) recovery from surgery, and (4) potentially improving treatment outcomes, particularly in the case of those who see themselves as more spiritually committed. Areas that need further attention and show clinical promise for purposes of research include: stress, depression, suicide, substance abuse, alcohol disorders, cardiovascular disease, cancer, coping with chronic illness, dementia care, and longevity. Finally, the relation between religion, and in particular, the relation between feelings of alienation from, or rejection by God and negative clinical outcomes requires much more research. In passing, one might note that where there are signs of negative religious coping, a chaplain consult is usually advisable.

In order to understand better the role of spirituality in health, including mental health, clinical researchers and educators are now taking important steps to remedy past neglect and inadequate assessment of spirituality in clinical care. These include building on already published research that links spirituality to health status, the ability to cope with illness, and the determination of clinical outcomes. The work of remedying previous research neglect and addressing the deficiencies and flaws in research methods is an important first step. Properly taken, it should improve subsequent research. In turn, this should yield broader clinical understanding of how and when to integrate what is a very prevalent characteristic of patients, their spirituality, in clinical research, clinical education, and treatment, management and care.

All involved in these conferences want to express our sincere condolences to the family, friends and colleagues of Dr. Larson. He was a major pioneer in the area of health and spirituality. He will be missed.

SECTION 3

SURVIVORSHIP ACROSS THE LIFESPAN

Implications for Clinical Populations:
Pediatric Oncology

Beverly Ryan, MD

While there are over a million new adult diagnoses of cancer per year, children have fewer than 10,000. However due to slightly increasing incidence rates and significantly increasing cure rates with decreasing mortality, the survivor population is expanding. It is projected that by 2010, it's possible that one in every 250 adults between the ages of 18 and 45 will be a childhood cancer survivor. Their health care needs will require special consideration by primary care providers. Ongoing studies of outcome sequelae surveying a large survivor pool are needed to assess who among survivors are at greatest risk of long-term effects.

Survivorship is a concept that begins at day one of diagnosis for adults as well as children. But while adult survivors must strive to maintain what they have already achieved in their lives, children are still developing. In pediatrics, the goal is to allow these children to meet their normal developmental, intellectual, social and emotional milestones while undergoing therapy. They need to reconnect with their achievement trajectory at some point following therapy. One of the objectives of our long-term effects survivorship program is to determine whether our childhood survivor is achieving his/her full potential.

In 1996, the International Society for Pediatric Oncology recommended developing guidelines for establishing comprehensive follow-up clinics for childhood cancer survivors. Nowadays, 50 percent or more of large pediatric cancer centers have a separate survivorship clinic for childhood cancer survivors.

Last year, the Tomorrows Children's Institute established a survivorship clinic in a separate location from the hospital. A pediatric oncologist, nurse and social worker staff the program. The social worker possesses both adult and pediatric counseling skills, because the parents are still part of the equation of our survivors even years after diagnosis and therapy.

Since January of 2000, we have done about 100 assessments at our clinic. Survivors and their families do have questions even years after treatment. We are asking questions on their behalf. What impact will genetics and environment have on late sequelae such as second malignant neoplasm? Have we fast-forwarded the aging process by using growth-inhibiting drugs in children? Can we provide early intervention to offset possible late effects? Will surveillance make a difference in outcome? Who will pay for such surveillance? Finally, what is the mortality data for childhood cancer survivors once they are five years past diagnosis?

If we can show that the mortality of pediatric cancer survivors is the same as for their peer group without a cancer history, it would be important information for employment and insurance purposes as well as an important quality of life issue for the survivor. Several studies on mortality have been published. It seems that beyond five years, deaths from the original primary tumor recurrence still occur. In fact, two-thirds of deaths are from the primary malignancy. One-third are due to other reasons, but second malignant neoplasms head that list. The reassuring news is that the overall numbers are small and that after fifteen years without recurrence, the mortality rate may be that of the general age-matched population.

A growing body of literature has shown that as many as 40 to 50 percent of people attending pediatric survivorship programs have some problem or side effect attributed to their past diagnosis or therapy. Problems include endocrine disorders, growth disturbances, sexuality, fertility issues, pubertal development, and self-esteem concerns. In the survivorship program, we address these issues and educate survivors in ways that will empower them for their future health needs.

One of our goals is to teach about healthy lifestyles. The literature, as well as our experience, indicates that the survivor may take risks. For example, young adults with a past history of chest irradiation may smoke, even though smoking is potentially extremely hazardous. We try to teach choices that lessen the environmental risks of second malignant neoplasms such as not smoking. They can also consume alcohol inappropriately and neglect to wear seat belts. We try to teach how to make choices for a healthy and safe life.

In addition, we have to develop a mechanism to transition these young people to the adult world of medicine. As pediatric oncologists, caring for these survivors is a great affirmation of what researchers and clinicians have accomplished for the child with cancer. We also need the outcome data they provide to know whether adjustments to current protocols can avoid late effects. Parents and survivors still feel comfortable many times in long established doctor/patient relationships. Sometimes the barrier to transition is that the survivor is also lost to us, preferring to forget they ever had a cancer diagnosis or afraid of finding out they have a new problem. Barriers exist because often adult oncologists are too busy to develop a survivorship program and primary care providers may not be aware of the long-term risks of certain therapies.

In our survivorship program, we call the survivor or family prior to the visit to ask their concerns or issues, in order to be better prepared to address them at the visit. We have learned of problems with self-esteem, school issues and emotional problems through these conversations. At a pre-meeting of the team, we are able to share this information so that we have an appropriate professional present at the visit to address the issue raised. A post visit team meeting insures that appropriate follow-up action is taken. Consultants who are part of our survivorship team include an educational liaison, a pediatric psychologist, a child-life specialist, and a creative arts therapist.

The ultimate goals of the survivorship program include: (1) to learn and teach the proper medical surveillance based on the previous diagnosis and therapy, (2) to teach a healthy lifestyle and to empower survivors with that information, (3) to prepare a treatment summary with total cumulative dose of chemotherapy and radiation for the survivor, in order to know their history and learn of possible long term effects and (4) to transition to adult primary medical care. We have considered having an adult advanced practice nurse as a transition mechanism between adult and pediatric oncology as a method of moving the survivor forward while still capturing the important health outcome data these survivors provide.

Our mandate is to have our pediatric cancer survivors fully assimilated into society as productive, healthy adults who are not discriminated against because of having had cancer as a child.

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Implications for Clinical Populations:
Adult Oncology

Dean H. Gesme, Jr., MD, FACP

The relationship between cancer survivors and providers requires a sense of respect for one another. This is an absolute necessity for a productive patient/physician encounter. Cancer care providers are expected to have a wealth of scientific knowledge and experience in all areas of cancer care. Our system of healthcare has done an excellent job in assuring this. Unfortunately, the communication skills necessary to cultivate a trusting and respectful relationship have not always been taught or adequately valued among care providers. Greater attention to this key element can only improve patient compliance, increase patient satisfaction, and most probably, help individual patients to enjoy better health.

Compliance with treatment recommendations remains a concern for optimizing outcomes in cancer therapy. In adult oncology care, many of the therapies provided, including intravenous chemotherapy and radiation therapy, have been directly administered to the patient, and hence, compliance is assured. The advent of less toxic and highly effective oral drugs will emphasize the essential role of compliance in optimizing patient care. It is well known that many patients are poorly compliant with the dosing instructions for many oral medications. Noncompliance may be motivated by attempts to save money, reduce toxicity, exert self-control, or may be due to simple forgetfulness. These behaviors, which bring about an alteration in the therapeutic regimen, may have serious adverse consequences that only become known weeks, months, or years after the noncompliance occurs. Clinical research has given little consideration to these factors as most research studies are done under carefully controlled situations where high compliance is demanded. Hence, greater emphasis will have to be placed on patient compliance. Achieving this will require improved communications between patients and providers.

The information explosion is another challenging area in treating adult oncology patients. Cancer survivors are by nature inquisitive about their disease. Studies have shown that many patients are expanding their information sources beyond the traditional medical establishment to include print and broadcast media along with Internet sources. The reliability and validity of these sources are often subject to question. More important, the task of assimilating these enormous data resources and applying them to individual circumstances can challenge the ability of patients, leading, as a result, to misinterpretation and confusion on their part. Our healthcare system and each provider must rise to meet this challenge so that patients are assisted in locating and selecting appropriate information outside that provided directly by healthcare providers. Harnessing the wealth of information available to them can make for patients who are better informed, and therefore, better able to make wise medical decisions. That, in turn, can help healthcare providers and patients achieve the goal they all have of improved cancer care.

The aging population is an under-estimated trend that will shape the future of cancer care in our country. Many aged Americans encounter greater challenges in gaining access to the current healthcare system and demonstrate less ability to use resources outside the traditional healthcare system. Elderly individuals often have multiple health problems that may interact, creating greater challenges in diagnosis, treatment planning, and decision-making. The rising cost of healthcare and the anticipated contraction of future governmental funding may seriously compromise efforts to provide services fairly within our system of healthcare.

Follow-up care for cancer survivors remains a controversial subject. It is not simply a matter of observation for signs of cancer recurrence. The importance of dealing with psychosocial, financial and employment issues that may arise as a result of the cancer experience is of great importance to many survivors. Preventive strategies to reduce the risk of second malignancies will be needed on a growing scale as new preventive interventions are approved for use with patients. The identification of late effects and long-term consequences of prior treatment is also important to survivors, and yet, is frequently poorly understood by primary care providers. For that matter, these areas of concern are not always well integrated in the traditional oncology follow-up clinic. It is important that each patient be carefully assessed for follow-up needs and be empowered to obtain assistance with long-term follow-up that will optimize well-being and long-term productivity.

The expanding knowledge of, and the serious consequences related to cancer, place a heavy burden on cancer patients and providers. It is expected by patients, friends, and family that the system will rapidly and comprehensively take into account not only the individual medical factors but also spiritual, psychosocial, financial, and the ethnic factors. Effective communication on all levels regarding these issues is desired in order to develop a care plan rapidly after a diagnosis of cancer has been made. These demands can overwhelm the cancer patient and indeed, often overwhelms the ability of healthcare providers to meet the sweeping and immediate needs. Our healthcare system would do well to cultivate resources outside of the immediate healthcare team, including psychologists, social workers, nutritionists, spiritual counselors, friends, family, and community members. The prevailing expectation that the doctor and nurse will meet all demands is certainly unrealistic. In addition, it overlooks an opportunity to expand the patient's network of support. Unfortunately, our current healthcare system has considered these areas to be “optional” supports. As a result, they tend to remain unfunded. Incorporating these areas could improve healthcare outcomes, and perhaps, improve efficacy, even as it lowers the overall cost to the healthcare system.

Today, opportunities for improving our system of cancer care delivery abound. The history of development of our healthcare system suggests that these improvements will be incremental and each of us must play his or her part in continually improving the quality of our system. Cancer survivors and cancer health providers should consider themselves to be in the best position to achieve success in this endeavor.

Implications for Clinical Populations: Geriatric Oncology

Martine Extermann, MD, PhD

For most part, cancer is a disease of old people. Two issues have particular relevance to older people and older survivors. The first one is independence. Older people are interested in living long years, but they are even more interested in living independently and being able to do things. Everybody wants to live long; nobody wants to get old.

The second issue is fragmentation of care that they receive. With older people, this fragmentation of care becomes a serious problem. Recently, we have completed a pilot study with geriatric cancer patients who had early breast cancer. Patients were receiving adjuvant treatment and the extent of fragmented care was clearly demonstrated. This is a simple cancer treatment, and yet, care is almost completely disjointed. Imagine what might be happening to somebody with metastatic disease.

Clearly, improving survivorship of cancer for older people depends on integration of care. Fortunately, models already exist that do this well. For example, geriatricians have been working with this approach for at least twenty years. To date, they have developed comprehensive geriatric measurements that comprise a multi-disciplinary intervention to assess and follow older people. This is an extremely important intervention. It has the potential to decrease dependence along with the potential to decrease mortality in the same proportion as adjuvant chemotherapy for breast cancer. According to the findings of Stuck's meta-analysis, the comprehensive geriatric assessment reduces mortality by 14 percent, proportionally. By comparison, adjuvant chemotherapy for breast cancer reduces mortality by 15 percent, globally. In post-menopausal women, the rate of reduction is more like 8-12 percent.

In other words, there is an available effective way of managing cancer patients that integrates the care they receive. We do not just do oncology. Instead, we treat the tumor while taking into account all the various co-morbidities, functional impairment, and sub-clinical mental problems that the patients might have. We need to begin to pay more attention to this systematic way of thinking when dealing with the older cancer patient.

If a 67-year-old patient does not function as well after treatment as he/she did before ~~it~~, and has not recovered after eight weeks, the chances of recovering are poor. We may undermine the condition of patients when we treat them in the acute care setting by not accounting for the whole situation presented by the patient. If so, then the long-term consequences of this oversight may well be harmful in the form of dependence and major problems with recovery. In contrast, an integrated approach demonstrates great promise for benefit.

Of course, the integrated approach has challenges. It takes a multi-disciplinary team, or some way of arranging it in a multi-disciplinary fashion that accounts for some case management issues, and provides someone to ensure continuity of care for these patients. At the present time, any integration of care is very poorly reimbursed and this is a very serious obstacle. Geriatric studies that have assessed cost-effectiveness clearly show that it is a very efficient approach that reduces costs and improves outcomes.

Much remains to be developed in geriatric oncology care. It is an important area of research and promises much in the way of clinical implementation. In this regard, it parallels the treatment of prostate cancer where we know several things work. However, we still do not know exactly which treatment is best or what order of treatment is preferable. Uncertainty of this kind is not a reason to refuse to reimburse for these various treatments. The challenge is clear. We have to continue with research and develop evidence based treatment techniques for geriatric patients. We must refine them and make them even more cost-effective. Then, health insurers will see that the integrated approach to treating older adults with cancer is the best approach.

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A SURVIVOR’S VIEW OF CANCER SURVIVORSHIP

COL (Ret) James E. Williams, Jr. USA

As a 9-year cancer survivor who has served in the military and worked with national organizations like US TOO, I think the most important advice that I can give is that we need to introduce new ways of thinking when dealing with cancer survivorship.

For Example:

- In Eastern Medicine, the physician’s job is to keep the patient in good health and “balanced.” In our culture, doctors treat illness and disease. The patient community is recognizing the need for a more holistic approach to our health, so wellness is encouraged. But, this will require new ways of thinking for many of us.

- Men, especially minority men, are difficult to reach in our present health care system. Distrust of this system is common. Traditional methods of communication like newspaper ads, reminder letters, etc. just do not work. A more personal approach that builds upon relationships and encourages trust is needed.

- Survivors helping survivors represents an untapped strategy that can make a difference. Churches and faith-based organizations provide opportunities to tap into minority communities. Seventy percent of those involved with black churches are women. Perhaps, women need to mobilize men so they take care of their health. The community health advisor is another person who may open doors to better communication and relationships.

- Our research has focused on increasing quantity of life. While this is important, we need to also pay attention to improving the quality of life for cancer survivors. We need to support more behavioral and psychosocial work. In addition, research that looks at complementary and alternative medicine is important.

- Non-scientists, especially patients and survivors, should be brought into the research process early on so their perspectives are included in studies.

- We need to make it simple and bring all the resources together. Integrated services aimed at taking care of the whole person should be a priority for our health care system.

So, if there is one thing that I have learned from all my experiences as a fighter…..in Vietnam and against cancer…..its that you need to be creative and sometimes turn the picture upside down to find the answers.

Section 4

Barriers to Continuity of Care

Cancer control and cancer treatment start with prevention for healthy individuals and continue through end of life care. Although quality cancer care is available, it is not equally accessible to everyone. Even when services are both available and accessible, they will not necessarily be used. Cultural, economic, and geographic factors prevent many people from receiving necessary health care.

Many barriers to continuity of care exist among under-served populations in both urban and rural areas. Minorities, the poor, the uninsured and under-insured, and people living in rural areas often have limited access to, and awareness of, services that are available to them. The health care professionals who seek to serve these populations are similarly at a loss to know how to reach them.

Whether access to care is inhibited by poverty, culture, illiteracy, fear, or geographic isolation, the education of these underserved populations, and the health care professionals who serve these populations, is the key to fostering the communication that is necessary for continuity of care to exist. So that programs offering cancer screening and treatment can be successful, people need to be reached where they live. People need to understand and trust the messages they are receiving, and they need to be treated with respect.

The following section provides a summary of key points from a panel of national experts who addressed significant barriers to the continuity of care for cancer survivors. The bullets identify critical issues that have significant impact on our ability to provide quality care for cancer survivors. Any research agenda or clinical care models will need to consider these barriers if progress is going to be made.

Barriers to Continuity of Care
Cancer Control in Appalachia: Geographical Barriers & Rural Outreach

Gilbert H. Friedell, MD

- Many people in rural communities are not sufficiently literate to deal with the health care system.
- Even if people have health care services available to them, it does not mean that they will use them.
- Since there is very little public transportation in rural areas and many people there do not own cars, residents can be far from the services that they need.
- Even if a family owns a vehicle, another family member may need it to get to work or there may be no money for gas.
- Many people have childcare responsibilities that prevent them from getting to a clinic or doctor's office to receive consistent treatment and follow-up care.
- Older residents are not easy to recruit for cancer screening.
- Some people do not realize that they are in need of health care services or how or where to find these services.
- People who do not have insurance or money to pay for services cannot always receive the proper treatment.
- Social and cultural barriers to treatment go unrecognized by the health care system.
- There are too few healthcare professionals in many rural areas.
- Programs to educate people about healthy lifestyles are not readily available.
- Programs to reach out to the community to bring people in for treatment are not readily available nor are mobile screening units that go into the community to provide services.

Barriers to Continuity of Care
Poverty

Elmer Huerta, MD

- Poor people are often so focused on the struggle to survive today that they cannot be concerned about the future.

- People who do not expect to live very long anyway tend not worry about developing cancer.

- Educational messages disregard the understanding level of the intended audience or they meet with suspicion by those they reach.

- Health education and health care programs are not ethnically sensitive.

- Fatalism regarding cancer prevents people from seeking care.

- People are afraid that if they were diagnosed with cancer they would be unable to afford treatment.

- People are concerned that a diagnosis of cancer would place undue financial or emotional strain on their families.

- People avoid medical care because they are afraid that a doctor might find something wrong with them.

- The poor know very little about cancer and are not knowledgeable about health in general.

- The media bombards the community with entertainment rather than with educational messages.

- Many of the working poor are employed in jobs that do not provide health insurance.

- Lack of understanding of the medical system prevents people from seeking care and immigrants from countries with socialized medicine may not understand differences in the American medical system.

- The under-served are not aware of risk factors for the most common forms of cancer, nor do they understand that early detection improves survival.

Barriers to Continuity of Care
Sociocultural Factors

Lovell Allan Jones, PhD

- The lack of understanding of minorities' knowledge, attitudes, and practices regarding cancer, results in inappropriate approaches by healthcare workers.

- The insufficient knowledge of ethnic/cultural practices in minority populations, in the medically under-served, and in populations in certain geographic areas undermines health care services.

- The unavailability of health care services where minorities and the medically under-served actually live leads for all practical purposes to a lack of access.

- Financial constraints prevent patients from receiving costly diagnostic procedures and medications.

- Follow-up care is time-consuming, and minorities and medically under-served individuals can rarely afford to take time off from work or time away from children to receive it.

- Lack of bilingual providers and translators inhibits communication among patients, their families, and providers.

- The concept of "guinea pig" is still prevalent and mistrust of the health care system is common.

- Physicians' lack awareness of existing needs and concerns of the community they serve.

- It is time-consuming for physicians and staff to explain and/or translate why care should be continued.

Barriers to Continuity of Care
Managed Care, Uninsured, Underinsured

Pamela J. Haylock, RN, MA

- Managed care, in many cases, is not being managed in the best interests of people with cancer.

- The health care delivery system is often dissatisfying to consumers, with managed care increasingly contributing to problems.

- The financial burden of cancer can be substantial even for people who are covered by a health plan.

- Most people whose jobs do not provide health insurance cannot afford to pay for it.

- People who are between jobs may have lapses in health insurance coverage.

- People who are uninsured have less access to cancer screening and limited access to specialists, risk later diagnosis, and experience lower survival rates.

- People who are uninsured or under-insured have difficulty maintaining needed follow-up care.

- The health care system takes a disorganized and fragmented approach to cancer care.

- While governmental safety nets exist, many people still fall through the cracks.

- While non-governmental resources are available to cancer patients, a person who is ill may not have the skills or strength to research these options.

- Health care professionals and patient advocates may not be aware of all the programs that are available for cancer patients.

Section 5

Models of Service for Cancer Survivors

If the complex physical, psychological and social needs of cancer survivors are to be met, the health care system must recognize and respond to these needs by developing new models of service. A successful health care model will require an integrated approach that is multidisciplinary and adopts a “lifespan” continuum. Clinical interventions that address the complex medical, psychological, and social needs of cancer survivors with clinical efficiency and cost effectiveness are required. Measurable outcomes and evaluations must be included so that reimbursement issues and fiscal inadequacies may be tackled. Finally, clinical studies must include quality of life criteria; so that the evidence needed to make sound clinical and reimbursement decisions may be made.

Summaries of several key models of service including outpatient and home care, reimbursement for services, standards for long-term follow-up and access to clinical research follow. A panel of national experts outlined the inherent challenges that such models face and offered some direction for future development.

Models of Service
Outpatient Care: Assuring the Continuity of Care

Catherine D. Harvey, DrPH, RN

Challenges in Outpatient Cancer Treatment

- A great deal of variation in the quality of outpatient care exists.
- Differences in the cost of treatment for a particular disease occur.
- There are changing expectations of payers depending on network and geographic region.
- The public must be made more aware of the needs for continuity of care.

Cancer Care Today

- Eighty percent of cancer treatment is community based.
- There are 10,000 physicians who offer clinical trials, many within their local communities.
- Most patients would rather be treated close to home, so that they can be near their friends and families.
- With more information available today, patients are more concerned than ever to identify the best physicians and the most appropriate treatments.
- Patients dealing with cancer for the first time are increasingly concerned with what they can expect as survivors.

Outpatient Data and Research

- Office-based research must include the study of efficacy of therapy, survival, morbidity, and use of second-line chemotherapy.
- Symptom management considered in terms of side effects, interventions, psychosocial support, pain and suffering, and end of life care; should be assessed.
- Patient satisfaction and communication are important factors in recruiting patients for research trials.
- Access to research is an important criterion to include when setting guidelines for successful practice.

Decreasing Hospital Admissions

- Calling to check on patients, rather than waiting for them to call when they have a problem, results in the need for fewer admissions to hospital.

- People who are treated on Thursdays and Fridays, but then have problems over the weekend, do not want to bother their physicians or call the office for help.

- More patients are admitted to hospitals on Mondays and Tuesdays, after trying to take care of themselves over the weekend.

- Patient education is indispensable, but will not take place without some system in place to achieve it.

Patient Satisfaction

- Physicians should take time to explain a proposed treatment to their patients and listen to their concerns.

- Reliable data on patient satisfaction are necessary to assess the quality of outpatient treatment.

- Physicians and other medical office staff should show a caring attitude and make care easily available.

Models of Service
Home Care

Barbara Given, PhD, RN, FAAN

Challenges in Home Care

- With the population aging and with improved cancer treatments, there are growing needs for home care for long-term survivors.
- Eighty to ninety percent of home care is provided by family members.
- The number of hours of family home care provided during active treatment is equivalent to a half time job.
- The home is where most cancer care is provided and the patient relies on the family to provide care.
- The value and effectiveness of informal home care are not well recognized nor financially supported.

Current Models of Home Care

- Assume that discharge plans for home care actually result in care.
- Assume that the professional judgment and decision making necessary for care can easily be translated to home care.
- Do not consider family time for care as a resource nor consider the "family's" needs in assessing home care.
- Do not tailor information to patient and family needs nor offer formal assistance with care.
- Do not consider how to integrate formal and informal care.
- Do not assess the quality and effectiveness of family home care.
- Results in a disjointed care setting where family caregivers acquire skills by trial and error.

New Model of Home Care:

Should acknowledge that:

- There are many phases and stages of cancer care, including improvement, stability, and deterioration of the condition of the patient.
- Family members provide the majority of cancer care at home.
- The response of patient and family to the demands of care varies.
- The skills and information needed to provide care vary over time.
- The capacity and willingness of family members to provide care vary.
- Family members need training and guidance in providing care.
- Partnerships between formal and informal systems need to be developed and maintained.
- Quality of care and any expected clinical outcomes for the patient are influenced by home care.
- The health care needs of family members must be accounted for, as well as those for the patient.
- Patients and family members are the coordinators of cancer care.
- Family members are involved in all aspects of care, including symptom management, pain control, medical care procedures, monitoring of disease and treatment, coordination of care, as well as assistance with self-care, household tasks, emotional support, transportation, and financial management.

Models of Service
Standards of Care for Long-Term Follow-Up

Rodger J. Winn, MD

Challenges for Long-Term Follow-Up

- Detecting recurrent disease or second primary tumors at an early stage so that intervention will lead to clinical benefit.
- Validating scientifically appropriate test panels and schedules for most tumors.

A Need for Guidelines for Long-Term Care

That:

- Assist the patient and practitioner in making decisions.
- Result in more consistent treatment.
- Use both evidence-based and consensus data.
- Provide tumor-specific data on all cancers.
- Will be multidimensional and will require additional elements beyond those found in follow-up guidelines now available.
- Secure compliance on the part of primary care physicians, oncologists, supportive care providers, and patients.

The Dimensions of Survivorship

Require:

- Clinical surveillance to detect recurrence of disease or second malignancies.
- Symptom management of the long-term effects of cancer and cancer treatment.
- Consideration of the psychosocial impact of cancer and cancer treatment.
- Management of the legal and economic impacts of cancer and cancer treatment.
- Accounting for the genetic implications of cancer and cancer treatment.

Clinical Surveillance of Cancer Patients

- Is disease and stage specific.
- Requires knowledge of the natural history of disease, including risk and sites of recurrence.
- May require developing specialized clinical skills.

Early Detection and Routine Follow-Up Visits

- Seventy to eighty percent of recurrences are detected because of symptoms, not as a result of routine evaluations.
- Recurrent disease found in routine examinations is a less threatening, slower moving disease.

Risk Assessments in Survivorship Guidelines

- Require a screening instrument.
- Need to categorize patients as normal or high risk across all domains.
- May require triage paths.

Patient Perceptions of Basic Follow-Up

- Indicate that a regular clinical examination is the most highly valued component of routine follow-up.
- Indicate problems with being handed off from one set of experts to another.
- Indicate that they want to be thoroughly informed.
- Indicate that they want well-defined clinical guidelines.

Models of Service
Clinical Trials

Robert Comis, MD

Challenges to Clinical Trials Participation

- Patient awareness of the clinical trial option is extremely low and ~~is~~ hindering enrollment.

- The inability to recruit adequate numbers of patients to participate in clinical trials is slowing the development of new treatments for cancer.

- More than eight out of ten patients do not even consider participating in clinical trials for the treatment of their cancer.

Attitudes towards Clinical Trials

- Patients who are aware of the clinical trial option for experimental treatment still do not participate because they feel that standard treatment would be more effective or fear that they will be given a placebo in place of treatment.

- Patients are afraid that they will be treated like guinea pigs in clinical trials.

- Many patients believe that their insurance plan will not cover the cost of treatment in clinical trials.

- Physicians believe that clinical trial participants receive the best possible care and that outcomes are at least as good as for those patients receiving standard treatment.

The Role of the Physician

- Patients who choose to participate in clinical trials are far more likely, than those patients who choose not to participate, to have heard about the possibility of participating from a doctor.

- Trial participants are more likely to have had a doctor inform them about the pros and cons of participating and assist them in finding an appropriate trial.

- Although many primary care physicians and oncologists believe that more patients should participate in clinical trials, they do not uniformly encourage participation.

- Many physicians do not persist in encouraging patients to participate once a patient has expressed reluctance.

- Physicians identify strict eligibility requirements and the amount of paperwork they need to fill out as factors that limit their efforts to recruit patients for clinical trials.

Patient Satisfaction

- When members of the general public are asked whether they would consider a clinical trial if faced with cancer, eight out of ten say they would.

- More than two-thirds of Americans would be willing to participate in a clinical trial designed to prevent cancer.

- Most patients who do participate in clinical trials feel that they are treated with dignity, and respect, and that they receive excellent care.

- More than three out of four who participate in clinical trials would recommend participation to other cancer patients.

Section 6

Summary of Group Discussions

A series of group discussions were held during the conferences and the findings of these discussions follow. Audience participation was encouraged and wide ranging deliberations occurred. However, four major subheadings were identified including applied quality of life; prevention; chronicity, and end of life concerns. For each of these four topics, a similar format was used for discussion and reporting. The first objective of the workshops was to define the area and list major concerns. From that, agendas for key areas of research were to be generated. It is recognized that in order to achieve research objectives, some important policy issues, often reflecting macro-level factors, need to be addressed. For many of these major topics, more basic local grassroots and advocacy pursuits were also identified. Finally, strategies for achieving the desired outcomes were discussed. It is recognized that many of the recommendations are broad strokes and will require additional refinement and development. They do, however, represent a starting point for future consideration.

Applied Quality of Life: Outcomes for the Next 5 Years

The notion of "quality of life" has been applied to individuals with cancer to address their physical, psychosocial, and spiritual well being. Once treatment is over and one begins to confront the "new reality" (so labeled by Wendy Harpham), quality of life issues need to be examined across multiple circumstances and contexts. It is our contention that key outcome variables in survivorship research revolve around the notion of applied quality of life, and therefore it is of high priority to generate definitions, means of assessment, and research paradigms to capture the essence of these factors.

Concerns:

- Assuming that quality of life group data applies to the individual;
- Time-intensive nature of quality of life research and lack of time by clinicians;
- Storing data and maintaining confidentiality over the long term;
- Identifying valid and measurable indicators of quality of life;
- Correlating functional status with quality of life.
- Lack of reimbursement for full spectrum services (including surveillance, psychosocial care, and follow-up).
- Offering long-term follow-up, including psychosocial interventions across the continuum.

Research Issues:

- The application of current quality of life research to clinical setting;
- The construction of systematic quality of life studies across the continuum of care;
- The need for valid instruments that are culturally relevant and language appropriate;
- The development of quality of life databases that allow for easier identification and recruitment of subjects so we can move beyond opportunistic samples;
- The need to share knowledge between survivor and professional groups.
- Demystifying the psychosocial research process for the practitioner.

Policy Issues:

- New strategies to provide better integrated cancer care and follow up;
- The need to incorporate quality of life data into outcome requirements for health care programs (i.e. clinical trials and protocols);
- Standardization of long term follow-up and care;
- The need to explore development of a “profession” to assist in educating cancer survivors.

Grassroots/Advocacy Issues:

- The need to see survivors as members of the treatment team/care plan;
- The inclusion of survivor input regarding educational needs and follow-up;
- The development of holistic curriculum development as part of health care professional training;
- The need to educate insurers so they make quality of life services available in contracts;
- The development of cancer survivors for an “owner’s” manual that includes guidelines for long-term follow-up and a wellness plan.

Strategies for Achieving Outcomes:

- Educate health professionals about the value of quality of life in patient assessment and care;
- Develop better case management procedures;
- Use paraprofessionals in clinics to assist with survivor issues;
- Adopt a multidisciplinary approach to share knowledge about quality of life issues;
- Adopt care plans for comprehensive follow-up and continuity of care;
- Use quality of life data that are both community and culturally sensitive;
- Include quality of life assessments in a medical history and develop distress indicators as measurements of quality of life;
- Incorporate quality of life as part of all clinical trials and care plans;

- Collect outcomes data routinely;
- Collect data on “outliers” (qualitative data).

Prevention:
Outcomes for the Next 5 Years

By recognizing deleterious long-term consequences of the disease process and its treatment, the potential exists to make modifications that will lower individuals' risk. The same is true for factors that may increase risk for recurrence of primary disease or secondary malignancies. Clearly we would benefit from longitudinal research that would show antecedent-consequence relationships and correlations that may increase or decrease risk. Only with such a definition may we target preventive interventions and minimize negative outcomes.

Concerns:

- The need for educational strategies as preparation for survivorship at the onset of treatment;
- The impact treatment and prevention has on families;
- The need for financial support for follow-up assessment and research;
- The lack of insurance coverage for integrated quality of life care.

Research Issues:

- The different risk factors for different age groups;
- The assessment and role of co-morbidity in prevention strategies;
- The impact of complementary and alternative medicine on survivorship;
- The "who, what, when, and where" of follow-up care;
- The clinical implications of genetics for the cancer survivor;
- The development of prevention and interventions for remediation;
- The need for research on risk factors in cancer survivors to incorporate developmental issues.

Policy Issues:

- Financial support needed for ancillary services that are currently not reimbursable;
- The need for improved education of professionals to work with cancer survivors;

- The education on cancer survivorship of other primary care providers, specialists and other health professionals.

Grassroots/Advocacy Issues:

- Empowering survivors to be their own advocates;

- Providing risk and preventive information to survivors of different ages (e.g. who, what issues, etc.);

- Educating the public about early detection and the availability of cancer screening.

- Using survivors to inform researchers and clinicians.

Strategies for Achieving Outcomes:

- Develop guidelines for early detection and screening of secondary malignancies that are evidence based and consensus driven;

- Formulate descriptive studies that follow survivors longitudinally—organ systems and quality of life (e.g. in clinical trials).

- Improve access to, and use of tumor registry data to promote availability of survivors for studies of survivorship.

- Develop a comprehensive survivor database;

- Study the interaction of risk factors with age;

- Incorporate data on the use complementary and alternative medicine by patients into studies;

- Apply knowledge of genetic issues for prevention;

- Create a portfolio summarizing history and treatment to use prospectively;

- Include incidence of late effects and secondary cancers in clinical trials.

Chronicity Issues:
Outcomes for the Next 5 Years

It is now most reasonable to view cancer as a chronic illness with an uncertain outcome. Transitioning from a mindset of an acute illness with a fatal outcome to a condition that may be endured over time has significant implications for promoting physical, psychological, and social well-being. Models of coping with ongoing "stressors and hassles" may be invoked to understand the psychological impact of the illness. Social issues, such as the continuity of healthcare coverage, become very significant, as does the impact of the illness on families.

Concerns:

- Legitimizing survivorship issues around chronicity;
- Providing insurance coverage for multidisciplinary care;
- Specifying the transition of patient care across the lifespan;
- Exploring the predictability of interventions;
- Applying new technology and interventions to long term cancer survivorship.

Research Issues:

- Lifespan transitions, especially with children/adolescents and the elderly;
- Co-morbidity;
- Lessons to be drawn from existing models of other chronic illnesses;
- Comparison studies of those diagnosed early in life vs. those diagnosed later;
- The impact of new technology and interventions on survivorship;
- The generalizability of existing studies.

Policy Issues:

- Education of those in the public sector about long-term survivorship;
- Educating professionals, schools, and the community regarding needs and late effects of long-term survivors;
- Continuity of insurance coverage (COBRA/Disability) and financial support for integrated care;
- Education of employers about the needs of cancer survivors.

Grassroots/Advocacy Issues:

- Empowering survivors to advocate for the rights of cancer survivors;
- Increasing collaboration between advocacy groups and health care professionals;
- Educating parents, patients, and families in negotiation and advocacy skills;
- Developing common goals and increasing collaboration among site specific survivor/advocacy groups;
- Conducting "snapshot" focus groups with advocacy groups and providing the feedback used for care planning;
- Seeking increased research funding for long-term survivorship issues by professionals and patients;
- Involving survivors, policy makers, researchers, clinicians, communities, schools, employers, payers, and families in advocacy efforts.

Strategies for Achieving Outcomes:

- Make payers part of the health care team;
- Develop translational interventions using research data to design programs;
- Demonstrate cost-effectiveness of interventions and include measurable outcomes;
- Promote multidisciplinary research and collaboration;
- Move from disease site focus to a holistic approach in research;
- Use case managers to support patients with limited income or insurance coverage;
- Include survivors/consumers in the planning of clinical trials and research programs;
- Establish an enhanced role for nurses in chronic care;
- Integrate research in, and reimbursement for chronicity;
- Use comparison groups (other diseases) in future studies.

End of Life Issues:
Outcomes for the Next 5 Years

A cancer survivor has been defined as an individual living with cancer from the moment of diagnosis until death. Unfortunately for some, death comes sooner rather than later. Nonetheless, it appears that facilitating quality of life at the end of life, using various palliative care interventions, is an extension of other quality of life endeavors. Attention must be paid to the physical comfort, socioemotional adjustment, and spiritual well-being of survivors, as they cope with their illness and treatment, as they make the transition to long-term survivorship, and as they confront their own mortality.

Concerns:

- The development of better tools/measures of comfort, socio-emotional adjustment and spiritual well being;
- The integration of palliative care throughout the continuum of treatment;
- The redistribution of health care monies to include “end of life” needs and palliative care;
- The cultural and generational differences in people’s attitudes about death, dying and end of life issues;
- The link between professional legal liability and inadequate pain control;
- The general under-treatment of symptoms at the end of life;
- The inconsistency of the Hospice benefit with the skilled care benefit in nursing homes, leading to inadequate palliative care;
- Broader insurance coverage for palliative care services.

Research Issues:

- The conflicting needs of patients and families at the end of life;
- Spirituality, in particular its definition and meaning to patient/family;
- Professional training, including professional differences/common knowledge;
- The impact of loss, grief, and burnout on professional caregivers;
- The impact of professional trauma for professionals working in end of life care settings;

- The transition of patients between active treatment and palliation within the health care system;

- Efficacy/benefit studies of complementary therapies and creative arts interventions at end of life (e.g. musical thanatology);

- Optimal timing for end of life discussions as part of professional training;

- Flexibility in adopting “commonsense” components of palliative care and formal research;

- Exploring personal/professional attitudes on death and dying and their impact on interventions to better understand counter transference issues.

Policy Issues:

- The education and training of physicians regarding regulations and attitudes about palliation and end of life;

- The inadequacy of the six-month limit for hospice (Medicare waiver);

- Specialists “handing” patients back to family physicians for pain symptom control when patient reaches end stage;

- Publicizing Patients’ Bill of Rights for Pain Control in all care settings;

- Bereavement leave for employees;

- Inadequate reimbursement for dying at home;

- Increasing understanding about futile care (still giving chemo in ICU when patient is dying);

- Assigning staff of the same ethnic group as the dying patient;

- Hospice programs' focus on cost containment and resulting limited choices for patient care/palliation;

- Funding for complementary therapies and other supportive services;

- Reimbursement for home health aides other professionals.

Grassroots/Advocacy Issues:

- Education for patients about end-of-life (advance directives/physician-assisted suicide/power of attorney);
- Public awareness for patients and families regarding pain control, addiction fallacies, and fear;
- Partnering health care professionals with faith communities to provide better education for clergy regarding end-of-life issues;
- Providing evidence based physical and mind/spirit interventions;
- Incorporating non-traditional models of care like the creative arts, spirituality and other supportive services.

Strategies for Achieving Outcomes:

- Assist patients to become better self-advocates;
- Dispel myths about death and dying, using patients as teachers;
- Enable therapeutic outcomes to inform clinical interventions;
- Provide broad public and professional education regarding advance directives, living wills, palliative care and death/dying;
- Develop unified definitions and a scientific knowledge base to advance research on palliative care and end of life issues.