## IN BRIEF

Psychosocial support is a significant component of comprehensive cancer care. In this article we provide information about building a psychosocial oncology program within an academic cancer center. Program development is described through the integration of three foundational components: clinical service, research, and training. We describe the importance of these components and use the examples of distress screening and cancer survivorship to illustrate their intersection. Emphasis is placed on initiating program development with existing resources and expanding as experience and resources allow.

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# Growing a Psychosocial Oncology Program within a Cancer Center

The subspecialty of psychosocial oncology developed as a response to the unique psychological, social, and spiritual issues related to a cancer diagnosis and its treatment.[1] However, in 2008 the Institute of Medicine (IOM) issued a comprehensive report that indicated cancer providers often fail to adequately address the psychosocial needs of their cancer patients.[2] The groundbreaking IOM report outlined a theoretical model for providing psychosocial care built around five key elements:

1. Identification of psychosocial health needs
2. Linkage of identified patients to appropriate professionals
3. Support of cancer patients in managing illness
4. Coordination of psychosocial and biomedical care
5. Follow-up to determine effectiveness of services offered.

The IOM report also provided examples of programs that use this service delivery model. The literature has provided guidance for targeted issues, including distress screening and assessment[3,4] and interventions for specific problems such as depression[5] or patient navigation.[6] Despite this growing literature base, few resources outline the processes necessary to build a psychosocial oncology program.

This article highlights three foundational components necessary for program development—clinical service, research, and training. We discuss each component toward the goal of an integrated psychosocial oncology program. To illustrate coordination of these components, we focus on the intersection of clinical service, research, and training in efforts to enhance distress screening and cancer survivorship services within our own psychosocial oncology program at UT Southwestern Harold C. Simmons Cancer Center, an NCI-Designated Comprehensive Cancer Center in Dallas, Texas.

## Program Goal 1—Clinical Service

In 1983 a multicenter, cross-sectional study demonstrated that up to 47 percent of all cancer patients experience distress at a level of intensity sufficient to meet criteria for a psychiatric diagnosis.[7] Subsequent reports have estimated that approximately 25 percent of cancer patients report significant depressive and/or anxious symptoms.[8] While cancer patients and their family members often have substantial and diverse psychosocial needs best addressed by clinician experts in psychosocial oncology, even the most integrated cancer centers are challenged to fully staff a psychosocial oncology program.

A comprehensive psychosocial oncology program must address multifaceted needs in order to treat the "whole patient" while remaining efficient and cost-effective. To do so, the psychosocial oncology team must first identify patients who need services and then have an effective process for triaging those patients to the appropriate psychosocial professional. The most efficient method to meet these goals is through distress screening. Once patients are identified through a distress screening mechanism, clinical intervention must be comprehensive yet frugal. The Psycho-Oncology Consultation Model (PCOM) is one clinical model that allows programs to achieve these often divergent goals.[9]

The PCOM is grounded in the consultation-liaison model of clinical care and assumes limited contact with the patient. The psychosocial clinician must achieve patient evaluation, treatment planning, and intervention often in a single visit.[9-11] This form of therapeutic intervention also follows a symptom management model in which evaluation determines a specific patient concern (i.e., symptom) and interventions target that symptom. The patient returns for follow-up appointments if the intervention impact is less than desired or if a new symptom emerges.

Although single-visit efficiency may suggest a lack of treatment effectiveness, a randomized study of 100 women with gynecologic cancer demonstrated that patients who had a single meeting with a psychologist (intervention) not only demonstrated decreases in anxiety, depression, and overall distress, but had greater improvements in physical, emotional, functional, and overall well-being.[12] It is important to emphasize that the PCOM does not prohibit follow-up appointments; instead it recommends follow-up appointments based on patient need and successful completion of specific therapeutic goals.

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The takeaway message: when building a psychosocial oncology program you must balance comprehensive patient care with efficient use of limited resources. Efficiency can be achieved through systematic screening of all cancer patients, thus generating appropriate referrals followed by a psychosocial consultation model of care to maximize therapeutic time.

### Program Goal 2—Research Integration

In recent years, psychosocial oncology literature has focused on the experiences of cancer patients and the evaluation of clinical interventions. A convergence of psychosocial oncology research training, research funding options, publication outlets, integrated cancer centers, and transdisciplinary partnerships has fostered an environment in which basic and applied psychosocial oncology research has flourished.[13]

For example, descriptive research in psychosocial oncology has addressed cancer risk and screening, psychosocial distress, and disease and treatment symptom management, often with integration of social psychological and health promotion theories. Intervention research has focused on efficacy and effectiveness of psychosocial techniques (e.g., cognitive-behavioral modalities, supportive-expressive therapy) and behavioral strategies (e.g., physical activity, yoga) for cancer patients, often integrating evidenced-based principles of psychotherapy and behavioral interventions with unique characteristics of oncology care. Although more and better interventional studies are needed, evidence-based recommendations derived from existing work are being developed for cancer patients across the diagnosis and treatment spectrum.[14,15]

Despite the growth of psychosocial oncology research, concerns exist about disconnects in the translation of empirical work to clinic practice.[16,17] To address these gaps, Jacobsen has described a "push/pull" infrastructure model focused on "pushing" evidence from research into the clinic while "pulling" the demand from clinicians and patients.[18] Within a psychosocial oncology program, a highly integrated research program allows alignment of goals that can optimize patient care through such a "push/pull" process.[19] For psychosocial oncology team members, research integration promotes scholarship and expanded recognition of member contributions through transdisciplinary collaboration, presentations at professional conferences, peer-reviewed publications, and inclusion on grant applications. In addition, psychosocial oncology research activities and intramural and extramural funding can complement clinical goals by providing support for novel or expanded service provision, additional staff members, and increased program visibility across the cancer center and the community.

On a larger scale, integration with research links a psychosocial program to greater priorities of the cancer center. Traditionally, most major cancer centers have active research programs in basic and laboratory (e.g., genetic, molecular) and clinical (e.g., therapeutic clinical trials) sciences. Over the last decade, increased focus has been placed on enhancing cancer control and population science research, particularly within NCI-Designated Comprehensive Cancer Centers. Broadly defined, cancer control and population science research focuses on epidemiology, behavioral sciences, health services, surveillance, and cancer survivorship and can take either basic or applied forms.[20] Indeed, designation as an NCI-Designated Comprehensive Cancer Center requires a commitment to population science and cancer control research, and achieving status as an NCI-Designated Comprehensive Cancer Center requires significant funded population science research and transdisciplinary collaboration.[21] Psychosocial oncology program members can facilitate these population science goals and ensure their integration with patient care and other institutional priorities.

For community cancer centers, the development of this type of research program may seem unattainable. Within a community oncology setting, psychosocial professionals' clinical and administrative demands combined with a potential lack of research expertise within the organization often limit ability to generate fundable psychosocial research. In such cases, psychosocial professionals can reach out and develop relationships with researchers at local universities, academic medical centers, and NCI-Designated Comprehensive Cancer Centers. Although these relationships may take work to initiate, they can be successful and mutually beneficial. Community cancer centers obtain the benefits of well-established research programs, such as additional funding, research expertise, and peer-reviewed publications; academic centers obtain access to an untapped oncology population for study accrual. For example, the NCI-sponsored Community Cancer Centers Program (NCCCP) explicitly seeks to align community hospital cancer centers with larger academic research partners, recognizing that most patients are treated in community settings. Furthermore, competitive grant applications in psychosocial oncology increasingly focus on collaborative, multi-site, and multi-level research questions.

## Program Goal 3—Training & Education

Growth of psychosocial oncology has been accompanied by the need for well-trained clinicians and researchers. In recent years, graduate programs in counseling and clinical psychology, psychosocial nursing, and clinical social work have partnered with cancer centers to increase depth and breadth of training within psychosocial oncology. Some programs place these opportunities within a larger framework of behavioral medicine or health psychology specialization with strong didactic preparation. Other programs provide psychosocial oncology training as "stand-alone" opportunities. More intensive training can be gained during clinical internships with psychosocial oncology rotations and during post-doctoral fellowships with a central focus in psychosocial oncology. Such specialized post-doctoral training is increasingly becoming an integral part of preparation for a position within a psychosocial oncology program.

As demands for training have grown, psychosocial oncology programs are put in the unique position of creating educational opportunities in clinical practice and research that benefit trainees but are also useful for the program and the institution. Training agreements set up without knowledge and careful planning of trainee experience, content requirements, supervisory needs, and funding obligations risk draining time and resources for all involved. However, training partnerships developed through thoughtful collaboration on these issues can provide a "win-win" scenario for trainees, institutions, and supervising professionals. The pre- to post-doctoral professional receives the necessary experience to advance skills through exposure to what is often a new population (i.e., cancer patients). Institutions benefit by having well-trained and well-supervised additional psychosocial staff available for patient needs. Psychosocial oncology professionals stand to benefit from the presence of newly trained professionals to stimulate new clinical developments and/or new lines of research.

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When building the educational component of the psychosocial oncology program, two separate growth directions may be available. The first is to develop a post-doctoral fellowship and provide training for that level of professional. The benefit of this growth process is the training and experience level of the post-doctoral fellow. Such a trainee may quickly take on an advanced clinical load and/or provide strong research assistance, as well as play a role in pre-doctoral and intern supervision. As an added benefit, successful post-doctoral fellows may naturally progress to post-training roles as staff within psycho-social oncology programs.[18] A barrier to this growth plan is the financial commitment to provide the needed time, salary, and benefits to post-doctoral fellows. Even the most supportive and well-funded cancer center is unlikely to single-handedly and continually fund post-doctoral training within psychosocial oncology. Instead, post-doctoral traineeships may be funded through various means, including extramural training, research grants, or philanthropic funds. Any discussion of developing a sustainable post-doctoral training program will need to include funding sources and additional potential benefits to the institution.

The second growth plan for education is to begin with pre-doctoral trainees and work toward a post-doctoral fellow component by establishing relationships with a well-respected training program at one's own institution or other local universities. Many programs are eager to have another practicum site for clinical work and/or research. For pre-doctoral students with interests in behavioral medicine and health psychology, working with cancer patients may be of great interest and an essential preparation for internship and post-doctoral placement. For a psychosocial oncology program, benefits to having a strong pre-doctoral training component include a sustained relationship with quality training programs, an infusion of trainee energy, and mentorship opportunities. Inclusion of pre-doctoral trainees may also demonstrate to cancer centers the benefits of having additional psychosocial providers, supporting a program request for more staff. Despite these clear benefits, supervision of pre-doctoral trainees is time-consuming for program staff and there is often variability in students' time commitment, prior training, comfort with the oncology setting, and professional maturity. Depending on the structure of the home pre-doctoral program and the student's time commitment, short- or long-term funding issues may also need to be addressed.

A final training issue for psychosocial oncology programs involves continuing education for already-established professionals and community members. For example, programs may develop or partner in introductory training for psychology or social work professionals interested in expanding their work to oncology patients. Continuing education may also take the form of more advanced topics geared toward one's own staff or even a national audience of psychosocial oncology professionals. Overall, these types of programs may be eligible for continuing education credits in specific fields and may attract a larger audience. Educational sessions for community members may generate new connections for program building and enhance a program's status and visibility within local areas. Such opportunities allow program staff to remain up-to-date on current practice and research and interact with other professionals and interested community members. Ultimately, a strong continuing education component can help a program and parent institution develop well-recognized specialties and elicit speaking invitations at national and international conferences and other events.

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## Intersection of Program Goals

In our view, the three important components of psychosocial oncology programs (clinical service, research, and training) have the greatest impact when they are well integrated. However, we also recognize that few emergent psychosocial oncology programs will simultaneously have these strong, intact building blocks. Therefore, we recommend that programs initiate development with existing resources and then expand as experience and resources allow. Not all activities of an emerging program must involve all three foundational components. It is often useful to start with one foundational component and integrate other areas in a long-term plan. To illustrate these concepts, we discuss two examples from our experience as a growing psychosocial oncology program—distress screening and cancer survivorship. In the following section we describe how we focused on component integration and built off existing program strengths.

Our psychosocial oncology program is affiliated with the NCI-Designated UT Southwestern Harold C. Simmons Cancer Center (SCC). The SCC is unique in that the overall cancer program not only includes the university hospital and oncology clinics but also the county safety-net hospital (Parkland Health & Hospital System) and a private not-for-profit children's hospital (Children's Medical Center of Dallas)—primary teaching facilities for the university medical school. The SCC is also affiliated with the Moncrief Cancer Institute, a community-based cancer prevention and support center in Fort Worth. SCC is a matrix cancer center, with faculty membership from a number of academic departments. For example, faculty focused on psychosocial oncology are appointed in the Division of Psychology within the Department of Psychiatry and the Division of Behavioral and Communication Sciences within the Department of Clinical Sciences.

Despite the overall cancer program's reach across hospitals, the clinical structure of psychosocial oncology has traditionally been separate for the adult and pediatric settings. Our psychosocial team focuses on adult oncology patients and is primarily housed within the cancer center's Supportive Care Department, whereas pediatric psychosocial oncology clinicians are organized under the umbrella of the children's hospital. This results in two clinical psychosocial oncology programs (adult and pediatric) that have traditionally been independent although their goals are similar. Recent efforts have allowed us to collaborate on converging clinical issues, such as cancer survivorship. Greater integration across pediatric and adult psychosocial oncology is being achieved within research and education endeavors, project collaborations, and consolidation of several aspects of pre-doctoral training.

## Distress Screening

In 2009 the International Psycho-Oncology Society endorsed psychosocial distress as the "6th Vital Sign" in oncology care.[22] NCCN has published guidelines on distress screening. Further, programs accredited by the American College of Surgeons Commission on Cancer (CoC) must meet new standards on distress screening by the year 2015.

Distress screening has an important function in oncology clinical service; it provides a real-time assessment of psychosocial and other supportive care needs and allows for prompt clinical response. At our cancer center, clinical use of distress screening has grown rapidly, building the base for emerging training and research endeavors. Our adult psychosocial oncology team developed and implemented a distress screening protocol that provides opportunity for oncology patients to report types and intensity of their psychosocial symptoms, as well as request consultation with a member of the Supportive Care team (i.e., psychologist, social worker, dietitian, financial advisor, pastoral care provider).

Consistent with NCCN guidelines, our protocol employs a screening tool that has been validated in oncology populations. Although we now use paper-and-pencil format, our goal is to integrate distress screening into our electronic medical record (EMR).

We currently only screen within our university hospital outpatient setting, but our goal is to expand screening to the inpatient setting and to the county hospital as our program grows. Outpatients are screened at each medical or surgical oncology appointment; the screening instrument is collected and evaluated daily by a team member. Patients whose responses are above a cutoff score or who ask to speak with a team member are contacted by phone for further assessment and consult. We collect between 1,200-1,400 psychosocial distress screeners each month.

Within our program, we have begun to integrate training goals into our distress screening protocol, leveraging it as an important component of education and training. Among pre-and post-doctoral trainees, distress screening helps promote understanding of the PCOM and other relevant care models by focusing clinical attention on the most intense symptoms reported by patients. Through this focused approach, trainees learn how to integrate screening data into their evaluation process, thus reducing the time necessary for evaluation and increasing clinical efficiency.

With appropriate supervision, our trainees can follow up with low-intensity screeners, effectively increasing staff consultation hours and providing trainees with a safe patient contact experience. If during this contact it is determined that symptom intensity is greater than the trainee's clinical skills, we may use the opportunity for focused supervision or modeling of an intervention. In addition, distress screening provides an opportunity for psychosocial professionals to educate other oncology colleagues in the cancer program. Within our setting, these educational opportunities have ranged from informal (e.g., on-the-fly conversations) to more formal (e.g., presentations at grand rounds and faculty meetings) interactions. Breadth of educational topics that come from screening can include:

- Difference between screening and assessment
- Psychometric qualities of screening instruments
- Empirical basis of cutoff scores
- Ethical considerations associated with screening and follow-up.

These topics are important to all team members and oncology distress screening provides a platform for psychosocial professionals to demonstrate our unique professional knowledge.

In addition to promoting clinical goals and training opportunities, distress screening can be an important element within a psychosocial oncology research program. Although research on distress screening has grown in recent years, gaps in knowledge still exist. As noted in a recent special issue in the journal, *Psycho-Oncology*, investigations are needed to address such issues as: distress in under-represented groups, translation of findings, and measurement refinement.[22] A member of our team recently published on distress symptom frequency and intensity data from understudied patients in a community cancer center setting.[23]

Within our psychosocial oncology program, we are developing research endeavors focused on distress screening that capitalize on our large clinical screening program, our trainee involvement, and the unique features of our cancer center population. Of particular note is our cancer program's expertise in lung cancer care (as evidenced by an NCI-funded Special Program of Research Excellence and world renowned experts) and our diverse patient population. These features have allowed us to focus research projects on distress among lung cancer populations and ethnic and cultural considerations in distress screening.

## Survivorship

Improvements in early detection and cancer treatment have allowed a greater percentage of individuals diagnosed with cancer to live longer. In fact, recent figures estimate almost 12 million cancer survivors (defined as living individuals ever diagnosed with cancer) live in the United States.[24] This growing survivor population has brought about a number of challenges for cancer centers in general, and for psychosocial oncology programs in particular, to broaden scope of care beyond active treatment. In addition to treatment-related side effects and physical late effects, cancer survivors may have unique psychosocial concerns, including: [25]

- Uncertainty
- Fear of recurrence
- Adjustment to physical limitations
- Sexual and fertility issues
- Existential and spiritual concerns
- Fatigue
- Cognitive impairment.

Many cancer centers are evaluating models for addressing the growing needs of cancer survivors. A recent survey of LIVESTRONG Centers of Excellence in Survivorship Care noted a number of care models, including separate survivorship clinics, integration of survivorship services into disease-oriented teams, and consultative services.[26] Within these models psychosocial clinicians have various roles, ranging from integration in multidisciplinary survivorship teams to a more consultative model of service provision. At our cancer center, the psychosocial team currently provides survivorship services to disease-oriented teams within a consultative framework. However, continuing discussions are focused on expansion of survivorship care and greater integration of supportive services. Another psychosocial clinical goal is partnership with the pediatric oncology team at the Children's Medical Center to coordinate survivorship transition among young adult survivors of childhood cancers.

The growing number of cancer survivors reinforces the importance of understanding psychosocial needs and evaluating interventions. Facilitated in part by the NCI's Office of Cancer Survivorship and other organizations focused on survivorship funding, such as LIVESTRONG, there has been an exponential growth in cancer survivorship research in recent years.[27]As detailed by recent cancer survivorship overviews, a number of necessary inquiry topics have emerged. These include addressing psychosocial issues among aging and underserved groups of survivors, assessing economic outcomes within survivorship, and translating research into clinical care.[28]

As the clinical care for the psychosocial needs of survivors evolves within our program, we have built on our research and training infrastructure to further cancer survivorship research. Led by one member of our psychosocial oncology team, we have organized a transdisciplinary group (including both adult and pediatric researchers) to foster partnerships in research and training related to cancer survivorship issues. Monthly meetings that include both faculty and trainees (pre-doctoral and post-doctoral) allow both a discussion of projects and educational opportunities for attendees. From these discussions, collaborations have developed that have resulted in extramural funding for projects focused on lung cancer survivorship, contextual factors in treatment decision-making, and surveillance decisions among high-risk patients. In addition, pre-doctoral trainees from this group have received extramural funding and successfully conducted dissertation research focused on psychosocial issues among cancer survivors.

A number of our research endeavors have focused on patients seen at the county safety-net hospital, Parkland. Many of these patients are low-income, minority, and under- or uninsured individuals who have been traditionally under-represented in psychosocial and behavioral survivorship research. Projects focused on the needs of these individuals aim to fill a gap within survivorship research.

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## ACKNOWLEDGEMENTS

The authors would like to acknowledge Simon Craddock Lee, PhD, Celette Sugg Skinner, PhD, Cassidy Cisneros, and Rachel Funk for their contributions to this manuscript. Acknowledgement also goes to Catherine Taylor, whose support has helped build the psychosocial oncology program at UT Southwestern Harold C. Simmons Cancer Center.

## FUNDING

This work was supported in part by the National Lung Cancer Partnership and its North Carolina Chapter (Young Investigator Research Grant) to H.A.H.