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What are the core elements of oncology spiritual care programs?

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ABSTRACT

Objective: Tending to the spiritual needs of patients has begun to be formally recognized by professional spiritual care providers, health care councils, and health delivery systems over the last 30 years. Recognition of these programs has coincided with evidence-based research on the effect of spirituality on health. Palliative care has served as a forerunner to an integrated professional spiritual care approach, recognizing the importance of addressing the spiritual needs of the dying from its inauguration within Western medicine almost 50 years ago. Oncology programs have also begun to recognize the importance of spirituality to patients along the cancer continuum, especially those who are approaching the end of life. Although standards and best practice guidelines have been established and incorporated into practice, little is known about the actual factors affecting the practice of spiritual care programs or professional chaplains working within an oncology setting.

Methods: Participant observation and interactive interviews occurred at five cancer programs after we conducted a literature search.

Results: This study identified underlying organizational challenges, cultural and professional issues, academic program development challenges, administrative duties, and therapeutic interventions that determined the success of oncology spiritual care programs in practice.

Significance of results: Although spiritual care services have developed as a profession and become recognized as a service within oncology and palliative care, organizational and operational issues were underrecognized yet significant factors in the success of oncology spiritual care programs. Spiritual care programs that were centrally located within the cancer care center, reported and provided guidance to senior leaders, reflected a multifaith approach, and had an academic role were better resourced, utilized more frequently, and seen to be integral members of an interdisciplinary care team than those services who did not reflect these characteristics.

KEYWORDS: Spirituality, Health services research, Cancer program development, Chaplaincy, Organizational design

INTRODUCTION

Tending to the spiritual needs of cancer patients has become recognized as an essential component of health care delivery systems, emerging from the confines of local faith communities and becoming embedded within the provision of care by interdisciplinary teams and professional chaplains. These teams and individuals seek to address the spiritual needs of a heterogeneous patient population. Concurrent with the integration of spiritual care services within mainstream cancer care, recent research on the effects of spirituality on health have provided early biomedical evidence of the additional value to a

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health care delivery system when spiritual aspects of health and illness are systematically addressed (VandeCreek & Burton, 2001).

Historically, palliative care has evolved from a predominately cancer focus, with much of palliative care research and practice rooted in an oncology setting, broadening its mandate to the care of those living with any life-threatening illness (Sinclair et al., 2006*a*; World Health Organization, 2008). In both the cancer and noncancer domains, palliative care has helped to normalize death and dying within the historically death-denying culture of cancer care (Zimmermann & Rodin, 2004). Extensive research supports best practices in multidisciplinary palliative and end-of-life care. Within this perspective spiritual care has been characterized as being integrally important (Saunders, 1986, 1993; Wald, 1986; Kearney & Mount, 2000; World Health Organization, 2008).

Although spiritual care falls within the ambit of all health care professionals (Sinclair et al., 2006*b*), for several centuries professional chaplains have traditionally functioned as leaders in the provision of spiritual care within health care settings (VandeCreek & Burton, 2001; Cadge et al., 2008). Recently, the *profession* of chaplaincy has evolved from a strictly voluntary denominational model to an institutionally funded, multifaith service with standards of practice and a code of ethics (Association of Professional Chaplains, 2000; Canadian Association for Pastoral Practice and Education, 2008).

Caring and respecting the spiritual needs of oncology patients and their family members is understood to be an integral component of holistic care. Whether spirituality takes the form of a long-standing commitment to a religious tradition or is embedded in a more individual connection with that which brings a person meaning and purpose, spirituality is widely understood to represent an important component of inner healing and strength when one is facing the reality of cancer, especially when there is no cure. The importance of spirituality and religion to health has been extensively explored in the literature (Larson, 1993; Larson et al., 1997, 2000; Harris et al., 1999; Moadel et al., 1999; Koening et al., 2000; Larson & Tobin, 2000; Freedman et al., 2002). A diagnosis of cancer is understood to commonly draw patients to face their own mortality, whether their cancer is curable or incurable, raising issues of meaning and purpose. Cancer patients with an enhanced sense of spiritual well-being are described as being able to cope more effectively with the process of living with cancer and having a greater quality of life (QOL; Chochinov et al., 1999; Fryback & Reinert, 1999; Cohen & Leis, 2002; Fisch et al., 2003; Lin & Bauer-Wu, 2003). There is a growing body of literature documenting patients' desire to have their spiritual needs openly discussed and supported by their health care providers, especially when they are facing a diagnosis of a potentially incurable disease (Ehman et al., 1999; Balboni et al., 2007). Although addressing the spiritual needs of oncology patients may be a legitimate activity for a number of health care professionals, the professional chaplain or spiritual care provider possesses advanced training and experience in addressing spiritual needs of cancer patients from a variety of spiritual backgrounds. Professional standards and competencies (National Hospice and Palliative Care Organization, 2001; The Pallium Project, 2005; National Health Services Scotland, 2007) provide a template for spiritual care best practices.

Although the professional standards and competencies for professional chaplains are emerging in concert with growing maturation of this domain of patient care, little has been published about operationalizing spiritual care best practices within actual spiritual care programs based within cancer centers. How do they operate as programmatic partners of care? We were curious to understand the range of approaches used by cancer programs to integrate spiritual care within their structures and functions. Therefore, we undertook a literature search on the topic and visited five major cancer programs in order to characterize the elements, culture, and integration of spirituality within mainstream oncology care. The intended outcome of this report is to explore and characterize key components of spiritual care services within an oncology setting and to foster discussion within the broader palliative care and spiritual care community on best approaches to position and nurture spiritual care services within formal integrated oncology programs.

METHODS

Literature Search

We conducted a literature search in PubMed, CINAHL, PsycINFO, Web of Science, and Atlas meshing the key terms "spiritual," "religion," "chaplain," "oncology," "cancer," "program," "health services," and "department." Although a handful of articles were identified from both the literature search and via manual searches in bibliographies and referred by peers, an analysis of these individual papers yielded essentially no data on the specific topic of interest. A search of the gray literature identified publications and policies outlining standards of practice and core spiritual care competencies as determined by practicing chaplains (The Pallium Project, 2005; National Health Services

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Scotland, 2007). Although standards of practice, code of ethics, and best practice guidelines have been formulated by professional spiritual care organizations (Association of Professional Chaplains, 2000; VandeCreek & Burton, 2001; Canadian Association for Pastoral Practice and Education, 2008), national health councils (National Hospice and Palliative Care Organization, 2001; The Pallium Project, 2005; National Health Services Scotland, 2007; National Consensus Project, 2009), and researchers (Hunt et al., 2003; Ferrell et al., 2008), we were unable to identify research investigating the key factors that enhance or inhibit the development and success of formal spiritual care programs within an oncology setting.

Following this literature search, we were left with several pressing but unanswered questions:

1. How do oncology program administrators' understanding of spiritual care and placement within the reporting structure affect the success of a spiritual care service?
2. How is the value of spiritual care reflected monetarily and spatially within a health care institution providing care for oncology patients?
3. What services and therapeutic interventions have spiritual care providers found helpful in reducing the burden of cancer within their specific setting?
4. What considerations are important when designing a sacred space or chapel within a health care organization?

Site Visits

As a separate initiative, one of the authors (S.S.) arranged site visits to spiritual care programs within five leading cancer centers. The plan was to investigate what are the explicit and also less tangible yet essential components that characterize successful spiritual care programs that have been well integrated and institutionalized within busy oncology care settings.

The project occurred over a 1-week period at leading cancer centers in the state of California. Convenience sampling was used based on geographic proximity to facilitate visits to a concentrated number of cancer centers within the area.

Six sites were chosen from the National Cancer Institute's list of designated cancer institutes (National Cancer Institute, 2008) and by personal recommendations from academic spiritual care colleagues whom we contacted. The designated spiritual care program leader at each of the six cancer centers was approached about accommodating a site visit. One cancer center declined involvement because of recent staffing changes. A list of guiding questions was forwarded to each site to help individuals prepare for the visit.

The five participating sites' spiritual care programs consisted of two programs that were exclusive to a comprehensive cancer center and three programs for which the cancer center was one service within a larger academic health delivery system.

Data Gathering

We used a qualitative approach to understand the key elements of spiritual care programs within large cancer centers. Two techniques were used to gather data: participant observation and unstructured interactive interviews. Participant observation and interactive interviews were chosen based on the supposition that people's comprehension and behaviors can only be understood in context (Boyle, 1994, p. 162). Participant observation also allowed the researcher to make obvious what had become ordinary to participants in the field, because individuals' cultural knowledge is often unknown and taken for granted by them and is often more easily recognized from the perspective of an outsider (Germain, 1993, p. 245; Morse & Richards, 2002, p. 49). Finally, participant observation provided the researcher with an opportunity to see whether what was said about the importance of spiritual care was reflected in the physical setting. The location of chaplains' offices and meditation rooms and the aesthetics of each center were recorded in field notes to evaluate whether "what people say they do and what they do in reality tally" (Mulhall, 2003, p. 308). Although an interview guide was constructed in order to provide consistency among interviewees and to serve as a guide to the researcher, interviews were open and explorative, placing control in the hands of the interviewee rather than the interviewer, differing from a more structured approach to qualitative interviews. Although concepts from previous interviews helped inform future conversations, most interviews were free flowing, covering the various topic areas spontaneously, with the interviewer rarely having to interject directive questions.

Data Analysis

Data analysis occurred concurrently with data collection in a reciprocal, back-and-forth process (Morse & Richards, 2002). Themes that emerged from the initial interviews were incorporated and explored in subsequent interviews allowing for unidentified themes to develop and be validated throughout the data collection process. Field notes and interview data were transcribed and analyzed, out of which

preliminary themes were named. Transcripts were then read through twice and participants' perspectives were highlighted. The unit of texts and observations were underlined and coded within each of the transcripts before being compared between transcripts. Codes were formally organized into themes from which four formal elements of oncology spiritual care programs then emerged (Tesch, 1990).

RESULTS

We found four core elements of oncology spiritual care programs.

Sacred Spaces in Public Places: The Bricks, Mortar and Governance of Spiritual Care Programs

It has been inferred by some that the "real" mission statement of any organization is the annual budget. Although we were not privy to this information, the same could be argued spatially, namely, the value to a particular component of health or health service is reflected in its organizational reporting structure and, more concretely, its physical location within the institution it functions.

The spiritual care service reporting structure varied within each of the five sites ranging from the vice-president level ($n = 2$) to directors of community relations and supportive service programs ($n = 3$). The level at which spiritual care services reported reflected two main factors according to participants: its perceived importance by the administration and the comparatively small size of the service compared with the many staff and extensive budgets of other programs within the hospital. There was a strong preference among all participants for spiritual care services to report as high up the organizational chart as possible, as that was seen to be reflective not only of the importance of the service but of its ability to provide direction to the values of the organization upon which policy was grounded. Although the placement of spiritual care in the organizational chart varied across sites, those spiritual care departments which were recognized as a free-standing department with an assigned director were utilized more frequently and seemed to garner additional respect from other health care providers. When the spiritual care service was subsumed or consolidated within a larger multipurpose department or service, innovation, professional recognition, and personal job satisfaction were negatively effected.

The location within the site of the sacred space or chapel and the spiritual care services offices strongly correlated with the success of the service. Sacred spaces or chapels that were in an easily accessible, central location were associated with robust and well-integrated services. Sacred spaces adjacent to a major thoroughfare of the institution were used far more extensively by patients than those that were relegated to an obscure hallway or, in one instance, a renovated utility room. The term "chapel" was usually associated with older and faith-based institutions, being adorned with Judeo-Christian imagery, whereas "sacred spaces" or "meditation rooms" were less easily identifiable with a particular faith tradition and were a feature of more contemporary institutions. Althought the décor of the space remained anchored within the era it was built; efforts were made by all spiritual care services to be as inclusive as possible. This included the absence of religious symbols and the incorporation of universal symbols such as water fountains and mosaic stained glass. The use of water fountains in the sacred spaces of cancer centers provided a unique challenge that was easily identifiable by the overpowering smell of chlorine that filled these spaces, which, although ensuring sterility, diminished serenity.

Spiritual care offices at some centers were centrally located and at others they were not. Locating the spiritual care offices within cancer centers was even a challenge in this project. In some instances they were located in the institution's basement, ranging from renovated mail rooms to an odd-shaped office where attention to administrative duties was routinely interrupted by the sound of flushing urinals in the adjoining washroom.

Professional Issues in Spiritual Care: Faith Based versus Multifaith Services

Although sacred spaces reflected the era and beliefs of the institution at the time of building, the model of spiritual care at each site was more related to the current administration's and the service's own perception as being either a denominational/religious service or a multifaith/spiritual service. One center was a faith-based institution and boasted a heavily resourced service; in other secular institutions, spiritual care programs that were multifaith and nondenominational thrived and seemed to be used more extensively than those which reflected a specific faith-based service.

The tension between providing an inclusive service on the one hand and a service that could draw upon the strength of a particular tradition on the other was a prevalent challenge. Those individuals who were rooted in a strong faith-based approach were quick to inquire about the researcher's own faith background, whereas those who were not were less inclined to do so. Participants who reflected a strong faith-based approach shared their concerns

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about the perceived growing tendency within chaplaincy to reflect a multifaith perspective, as they felt it provided a diluted form of spiritual care. This same tension was also evident in multifaith service models that were apprehensive about hiring faith-specific chaplains (e.g., Roman Catholic chaplain or Jewish chaplain), as they felt it truncated the breadth of the service and, in some instances, increased the possibility of proselytization. Services that held an explicit faith-based approach used the term "pastoral care" more readily than "spiritual care" in the name of their service.

Finding a balance between an open and inclusive approach to spiritual care and an approach that was grounded within a faith tradition was a tension of both individual practice and of overall service delivery. Faith-based models of spiritual care, while serving as a point of unity for patients of that particular faith, also created restrictions with patients who did not identify with that particular tradition.

The spiritual care services that were more faith based in approach were readily identified by administration as a representative of their faith-based institution rather than a professional attending to an important aspect of universal human health. At one of the sites this principle was evident in the funding model for their relatively large chaplaincy service: it received no funding from the institution. Aside from the perks of free parking and a free daily meal ticket, the oncology chaplain was required to visit local parishes for salary support, which was further subsidized by a large number of funeral service honoraria.

Institutional funding and a nondenominational/multifaith approach were important professional issues in determining the success of the spiritual care service within an oncology setting. A service that understood its mandate as tending to the spiritual needs of the diverse clientele of its institution was more likely to be recognized as a formal service by health care staff and in monetary support by the institution.

Academic Spiritual Care Programs

Research and education represented important components in insuring an integrated spiritual care service. Educational activity ranged from clinical in-services, formal university-based lectures within the faculties of nursing and medicine, and clinical pastoral education programs. The importance of providing educational opportunities to differing disciplines within the workplace and the university setting was seen as a significant factor in the service being recognized as an integral member of the interdisciplinary team by both current and future health care professionals. Participants at each site identified the establishment of an accredited clinical pastoral education program as a marker of premiere spiritual care programs. A formal clinical education program was seen to create a culture of excellence, providing a forum for clinical best practice and research while also increasing operational capacity, integrating the service throughout the center. The two sites in this project that were accredited teaching centers not only benefited from the students in their service but boasted a higher number of full-time employees than centers who did not have an education program, as many positions were created after staff witnessed the benefit of the service provided by a student.

The value of research to the vitality of the spiritual care program at each of the sites was always emphasized, yet evidence of research activity, such as protected time, research training, grants, and publications, was essentially absent. None of the programs in this project had protected research time. Engaging in research-related activities was cited as a vital component to individual practioners' own practice and the profession, as it established a community of experts and innovation within the academic health care delivery systems that cancer care was heavily rooted within. A strict focus on a service delivery model of spiritual care was characterized by participants as being focused on the operation and funding of the service rather than on innovation and growth.

Although environmental factors, such as space and place within the organizational chart, were major determinants of the success of an oncology spiritual care service in an academic, biomedically oriented milieu, chaplains themselves identified a range of approaches that aided in the integration of spiritual care among their fellow health care providers. Although most of these interventions were therapeutic in nature, allowing staff to witness firsthand the importance of addressing spiritual needs, some were specifically aimed at caring for staff. These ranged from formal debriefing sessions following a death to informal opportunities to reflect on the nature of working in an oncology setting. One chaplain developed "Tea for the Soul," a time for staff to enjoy a cup of tea while informally sharing their own sense of well-being in the workplace. Participants spoke of a strong connection between staff's perceived need of the spiritual care service for patients and staff's own appreciation of the service. Maintaining an ongoing and visible presence within the clinical areas was an important success factor, as it served as a tangible reminder of the importance of this often intangible service. In summary, gaining the trust and respect of their colleagues was a key factor in insuring the success of the service over the long

term. A chaplain who had earned the respect of his or her colleagues was more likely to be utilized in direct patient care.

This project also allowed an opportunity for oncology chaplains to share their therapeutic repertoire in the provision of spiritual care to oncology patients. Independent of the administrative structure, function, or values of the spiritual care program, there was a great deal of consensus on the practice of spiritual care. Much of the collective wisdom of practioners came in the form of open-ended questions designed to elicit the spiritual world of those they were caring for. These included: Cancer is described as a journey; where do you see yourself in the journey? How are your spirits? Is God a part of the equation? Where do you get strength from?

Academic cancer care and palliative care programs have championed the use of standardized tools to assess patients or their cancers. In striking contrast, none of the oncology chaplains used formal spiritual assessments, preferring to develop a personal repertoire of questions that were validated through their own practice being utilized contextually. In inquiring further about the lack of administration of formal spiritual assessments, chaplains felt that they carried an impersonal and clinically latent tone that did not reflect their own practice. The single greatest identified therapeutic intervention escaped language, being referred to as "silence" or "presence." Although oncology chaplains did not deny the need for skilled questions, they felt that the spirit in which questions where asked and comfortability with silence were equally or more important than the content of such inquiries.

An additional factor described by oncology chaplains in the development of a successful spiritual care program was the broader faith community that used the cancer service. Community faith networks included volunteer visiting programs, advisory committees, faith leaders education days, ecumenical memorial services, and mail-outs highlighting the service. Volunteer community faith representatives who were endorsed by their faith communities to visit were accommodated by those sites that had the resources to train, orientate, screen, and monitor this large group of individuals. Although they provided many benefits, including the development of a denominational on-call list, the time commitment required for educating these members of the faith community was substantial, ranging from 14 to 40 hours per month. Screening interviews, shadow visits, security checks, and orientation classes were identified as the most resource-intensive aspects of such volunteer programs. Disciplinary actions for volunteers who were deemed to be acting in an unprofessional manner were infrequent. However, they were identified as an onerous process that drained both time and energy from within the department and within the interdisciplinary teams affected by such events. When dealing with disciplinary matters such as proselytization where it was deemed that the termination of a volunteer was warranted, spiritual care providers also attested to the difficulty in terminating someone who was not an employee, mandating explicit policy to support the program through such difficult circumstances. Although volunteerism conjures the notion of a pro bono service, those individuals responsible for coordinating this service were quick to point out the costs that are often associated with supporting and managing such a heterogeneous group of individuals.

Mundane Rituals and Temporal Tasks

Although the clinical focus of most spiritual care providers and their departments centered around the search for meaning and purpose among patients, their families, and the cancer center's staff, a significant amount of time was spent tending to mundane rituals and temporal tasks. Spiritual care providers, some of whom were one-person departments, were responsible for these routine yet important administrative tasks ranging from fielding and responding to phone and e-mail requests to the entry of workload statistics. Although individually these tasks were not time intensive, when taken collectively they often eroded clinical hours. The tension between the demand for attention to these temporal tasks and the extensive training of the spiritual care staff led to a considerable amount of moral distress for chaplains who were a part of this project. as they felt torn between what they were trained to do and their administrative duties.

Several participants also highlighted their extensive obligations to committee and organizational initiatives. Although these activities enhanced their service's profile in the organization, they also had the potential to drain an already resource-limited service. Although staff and administrative recognition of spiritual care services was essential to the vitality of the service, it also fostered an influx of requests for committee work and other organizational initiatives that could quickly overwhelm thinly resourced spiritual care services. Spiritual care providers cautioned against the tendency to overextend themselves in important but labor-intensive committees and initiatives. These included hospital ethics committees, grief support initiatives, community advisory committees, palliative care committees, new staff orientation, memorial services, and debriefing sessions.

DISCUSSION

During the past few decades, cancer care has seen the emergence of an interdependent, complementary professionalism within the context of multidisciplinary teams. The institutionalization of team-based care has challenged traditional approaches to spiritual care and has called on cancer programs to explicitly support the codification of spiritual care within the academic, biomedical model. As spiritual care increasingly joins the ranks of other professional groups in formal cancer programs, there are clearly some early successes:

- Integration of spirituality as an important component of holistic health and the integration of spiritual care as part of routine team-based cancer care
- The creation and location of ecumenical sacred spaces within multifaith cancer programs
- The evolution from a faith-based model of chaplaincy to a nondenominational, multifaith, professional approach to patient-centered spiritual care
- The expansion of the discipline from a strict service-based profession to an integral member within the senior leadership of the organization, providing influence on matters of organizational ethics and policy development and fostering the organizational soul.

There nonetheless remain many challenges. Spiritual care services need to more effectively carve out an academic role for themselves, including research and research methods, advocate for appropriate budgetary prioritization, better characterize their role as distinct but complementary to psychosocial oncology, and, through strength of partnership, demonstrate measurable value added to overall team-based cancer care. There are also several opportunities that need further exploration:

- Determining the role of chaplains in cultivating the expression of organizational values within decision support frameworks and committee structure
- Discovering effective ways for spiritual care providers to best meet the needs of health care staff as they work within a personally challenging clinical environment
- Achieving formal recognition and monetary support by cancer institutions for professional multifaith spiritual care as an integral component of individual health within a multidisciplinary academic health care delivery system
- Performing further research exploring the function of spiritual care services on the ground (operationally) in order to further establish the key organizational factors affecting the success of the service.

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