Implementing a Primary Healthcare Framework:
The Importance of Nursing Leadership in Developing and Maintaining a Brain Tumor Support Group


Background: Although brain tumor support groups have been available internationally for many years, Liverpool Hospital in Australia has not traditionally provided this service. As a leadership initiative, the development of a brain tumor support group that incorporates a primary healthcare framework is a sustainable approach that showcases the role of nursing leaders in changing attitudes and improving outcomes.

Objectives: The purpose of this review of the literature and reflection of clinical experience is to explore nursing leadership within brain tumor–specific support groups.

Methods: This article will showcase a nurse-led group that incorporated a coordinated approach to delivering patient-centered care.

Findings: The initiation of activities and interventions that reflected the five tenets of primary health care resulted in improved outcomes for individuals and their family caregivers throughout the trajectory of their illness. Vital to the success of this project was moving from a standalone leader to building collective and collaborative leadership more conducive to facilitating change. The support group successfully demonstrated that individuals and family caregivers may see ongoing and long-term improvements during and following treatment.

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The care of individuals and their families following the diagnosis of a brain tumor is multifaceted and complex. This article explores the success of a brain tumor support group within the Australian healthcare setting, where a primary healthcare (PHC) framework was implemented as a strategy for achieving care coordination and support for patients with neurologic cancer at the systemic, organizational, team, and individual levels.

As a philosophy of care, the PHC framework has been applied to a variety of healthcare settings, including cancer care (McMurray & Clendon, 2010). The five principle tenets of the PHC framework—appropriate technology, collaboration, accessibility, health promotion, and public participation—have emerged repeatedly throughout the literature when exploring the coordination of cancer care. Although not specifically addressed or incorporated as a principle framework of practice, the five tenets are addressed and presented in a variety of contexts and associated with positive outcomes for individuals and families (Nichols, 2014). Embedding PHC principles into practice encompasses a broad spectrum of activities that focus on recovery from illness, guard against deterioration of health, and provide restorative and rehabilitative care (Starfield, 2006). Within this setting, the PHC framework offers a more inclusive approach to care that recognizes the social determinants of health, working toward prevention or early recognition of health issues, health promotion, and a system focused on attainable goals.

In 2003, the consultative report Optimising Cancer Care in Australia (McAvoy, 2003) became the blueprint for cancer care...
reform in Australia, acknowledging that poorly integrated systems were a major failing of modern healthcare systems. The National Service Improvement Framework for Cancer (National Health Priority Action Council, 2006) further highlighted the optimal cancer service as being seamless, coordinated, continuous, and integrated. In response to these reports, the cancer care coordinator (CCC) role rapidly emerged as a solution to achieving system reform and improving patient outcomes (Yates, 2004). The role of CCCs is to coordinate patient care, provide access to appropriate services, support multidisciplinary care, and act as a resource for information and education (Cancer Institute of NSW, 2011). Prior to the introduction of such roles, and in settings that do not have dedicated CCCs, other advanced practice nurses (e.g., clinical nurse consultants, clinical nurse specialists) have included the coordination of cancer care in their existing roles. The difficulty is that the CCC position has been poorly defined and its role within the healthcare system can be varied, with duties ranging from administrative and acute ward-based roles to community-based positions. Subsequently, seamless and integrated care has been recognized to require a broader systems approach that is sustainable but not the sole responsibility of an individual practitioner (Evans, 2008; Yates, 2007). Although neuro-oncology nurses have identified with and developed the role of the CCC, Lapum, Chen, Peterson, Leung, and Andrews (2009) highlighted the need for an increased focus on the identification of nurses as leaders and PHC providers, making them fundamental to developing the social structures that support the CCC role. Successful leadership in nursing has far-reaching implications that often underpin the success or failure of a project. As a leadership initiative, improving patient outcomes through the development of a brain tumor support group that incorporates a PHC framework is a sustainable approach that showcases the role of nursing leaders in coordinating cancer care and changing attitudes, behaviors, and practices. Brain tumor support groups provide the ultimate platform for nursing leadership to flourish because they address the needs of individuals and family caregivers at the community level.

Oncology support groups offer an opportunity for patients to share experiences, information, and emotions and can contribute to improved quality of life following the diagnosis of a brain tumor (Ahlberg & Nordner, 2006; Catt, Chalmers, & Fallowfield, 2008). The Liverpool Hospital brain tumor support group is a senior nurse clinician–led leadership initiative that was established in 2003. Liverpool Hospital is a single, 875-bed healthcare facility within a local health district in southwestern Sydney, Australia. The facility is a principle tertiary teaching hospital and services a population of about 1.35 million people. Liverpool Hospital has an extensive cancer therapy service and sees about 6,000 new patients annually. The neuro-oncology patient population is a small group of about 300 patients at any given time.

Developing the brain tumor support group structure involved a coordinated approach among various hospital departments, neurosurgeons, oncologists, allied health staff, and consumers. The group offers a forum for people to meet and learn from others who have had similar experiences. The group is provided at a local level and is accessible to the people of southwestern Sydney and beyond. In line with the principles of PHC and the notion of wellness and how to live well, the broad aim behind starting the group was to cater to the special needs of individuals with a brain tumor (malignant and benign) and their family caregivers by providing practical and emotional support. Special needs and relevant topics of this group were identified with focus groups and brainstorming sessions with key stakeholders. Initially, a 10-session program was designed. During the past 11 years, regular and ongoing evaluation has seen the program evolve and now includes presentations covering 31 different topics, with presentations given by 38 different guest speakers, as well as the maintenance of a stimulating social event program.

**Nursing Leadership**

Effective leadership involves taking a broader approach to issues, and the five tenets of PHC provide a benchmark to develop and evaluate initiatives such as brain tumor support groups. Leadership in nursing is fundamental to encouraging and guiding others to recognize that PHC is not a new concept and that implementing the tenets of PHC is not a revolution; rather, implementing these tenets is a refocus of practice (Besner, 2004). Changing practices through the development of leadership initiatives involves moving away from hierarchical systems and transactional leadership styles that focus on the planning and organization of the healthcare system (Faugier & Woolnough, 2002). The brain tumor support group initiative is an example of transformational leadership, in which the focus has been on changing and improving practices through influencing change and the provision of a sense of direction for individuals diagnosed with a brain tumor and their family caregivers (Cook, 2001). Through the development of the brain tumor support group, nurses have engaged in and responded to the challenge of change in a proactive way that includes consideration of the political and organizational issues that affect it (Bowden, 2005).

**Model Implementation and Sustainability**

Vital to the success of this project was moving from the position of a standalone leader to building collective and collaborative leadership that was more conducive to facilitating change. Key players that built and have sustained the foundation of the Liverpool Hospital brain tumor support group include the clinical nurses and multidisciplinary clinicians who were invited to present and were selected on the basis of their expertise in neuro-oncology. They were able to communicate complex information in plain English and lead new and innovative practices in health promotion, wellness, and managing health with a neuro-oncology diagnosis. Breaking down the vision into smaller goals has seen outcomes, including improved communication and networking postdischarge, increased community referrals, and improved information transfer with care providers within the community. Broadening the collaborative focus also has involved improving communication with nongovernment organizations and other key stakeholders. In line with this collaborative approach of PHC, the Liverpool brain tumor support group is registered with regional, state, national, and international cancer care services (e.g., International Brain Tumour Alliance), and referrals from these organizations are welcomed.

The development of a multidisciplinary brain tumor support group has initiated innovative projects. These have included
inaugural research addressing the cognitive and behavioral sequelae of adults with a brain tumor, which has been shown to help them, their families, and healthcare professionals, with interventional methods and written information on topics that have never been addressed before (Whiting et al., 2010). This written material has been disseminated nationally and internationally and translated into other languages by overseas brain tumor advocacy groups. Because of the success and achievements of the Liverpool Hospital brain tumor support group, the coordinators are contacted regularly by nursing and social work colleagues in other area health services and states across Australia to provide expert advice, guidance, and resources to set up and facilitate similar groups. The early and ongoing work of this group has been widely presented and shared and has been instrumental in the development of other brain tumor groups in Australia.

The diagnosis of a brain tumor is associated with a direct effect on functional and social abilities and quality of life for the individual diagnosed and family caregivers. The care needs are complex and constantly changing and extend beyond cancer treatments. Following the diagnosis of a brain tumor, the focus is often on the individual, leaving family care needs unmet (Schubart, Kinzie, & Farace, 2008). The trajectory is emotionally distressing, and information and support are vital because many family members feel unprepared for their role as care providers (Northouse, 2012). The Liverpool Hospital brain tumor support group recognized the needs of family caregivers early in program development and included specific “carers only” sessions within the program to address family needs and topics that are continually refined based on group member requests and evaluations.

The support group has demonstrated that ongoing, long-term improvements can be made for individuals diagnosed with a brain tumor, as well as for their family caregivers, during and following treatment. The ownership and bottom-up approach to change is fundamental to the success of such projects. Outhwaite (2003) highlighted that, by allowing individuals to develop aspects of a project, ownership is instilled and the leadership skills of others are developed. Examples include the initiation of a biannual evaluation of the brain tumor group and feedback focus groups, which have led to continual refinement of the program content, resulting in new topics. Baum, Bégin, Houweling, and Taylor (2009) considered this process vital because supported, well-informed individuals are less likely to delay medical treatment, reducing catastrophic events and emergency interventions. With a healthcare system that is increasingly stretched for resources, modern nurse leaders must be flexible and adaptive in developing creative solutions to managing patient care (Drenkard & Cohen, 2004). Epping-Jordan, Pruitt, Bengoa, and Wagner (2004) maintained that achieving patient-centered care involves healthcare models that promote health and address immediate and long-term needs.

**Initiatives**

**Health Promotion**

Following the diagnosis of a brain tumor, appropriate and timely information is vital to informing decision making, increasing health literacy, and building capacity and skills of resilience. From this, an increased level of control and overall health can be obtained (Hancock, 2009; Koutoupoulou, Papathanasiou, Katapodi, & Patiraki, 2010). Extensive and substantive information often is provided without assessing an individual’s ability to process and understand this information. The brain tumor support group promotes health literacy through the dissemination of information in easy-to-understand terminology. More importantly, the group provides a setting for patients and family caregivers to process and understand information, enables active listening and discussion, invites sharing of personal experiences, and answers questions in a supportive environment. The support group setting provides a forum for dialogue and interaction. Navigating information should begin early (Gilbert et al., 2011), to ensure that individuals make informed decisions and to provide support during the early diagnostic stage, survivorship, and palliative care. In addition, Marbach and Griffie (2011) noted that individuals feel that the dissemination of information is understudied, highlighting that information should be sensitive to the preferences and needs of survivors.

**Interdisciplinary Collaboration**

Effective nurse leaders recognized and understood the entire picture, the interrelationships within an organization, and how needs could be met through the development of a support group. The brain tumor support group involves experts from diverse sectors, including the hospital setting and nongovernment organizations. Representatives from these agencies are often guest speakers at support group sessions. Building collaboration at an intersectoral level involves the participation of all stakeholders who have an interest in the care of individuals diagnosed with a brain tumor and their family caregivers. Examples include involvement with Cancer Council Australia, state carers associations, and Brain Tumour Alliance Australia. Assistance is provided through support networks, psychosocial support, telephone support, and assistance with navigating services, transportation to care facilities, and financial issues.

**Appropriate Technology**

Technology can open access to healthcare systems through the use of telecommunications as a conduit between individuals and healthcare professionals (Catt et al., 2008; Lapum et al., 2009). Postdischarge telephone and electronic support is invaluable. The period following diagnosis is often unsupported, and appropriate technology allows information to be shared with patients and families and promotes early intervention for adverse events. The provision of an email contact with group coordinators allows transfer of knowledge and additional resource provision. This includes connecting individuals with valuable and scientifically sound information. Although knowledge is power, the Internet can be distressing in terms of the significant amount of unfiltered information. From a PHC perspective, the support group ensures health equity for this vulnerable population by assisting with navigation of electronic material.

**Accessibility**

Accessibility is focused on social justice and the provision of equity through the elimination of social, environmental, and economic disadvantages (McMurray & Clendon, 2010). Fundamental to this are improved delivery and access to services (Guilfoyle
The Liverpool Hospital brain tumor support group provides this forum at a local level and increases accessibility to people of the southwestern Sydney region. The group recognizes that individuals face isolation at a number of levels. For example, the prescription of oral chemotherapy isolates patients from oncology outpatient clinics. Coupled with cognitive losses and the restriction of not being able to drive, many individuals become isolated from care and are at risk for adverse events.

**Participation**

Central to PHC is public participation in the brain tumor support group. This participation contributes to the success of the group and recognizes healthcare professionals as partners with patients rather than leaders within the group setting (Hollenberg & Bourgeault, 2009; McMurray & Clendon, 2010). The brain tumor support group empowers individuals and the community to build on existing assets and strengths for decision making (Whitehead, 2007). The group connects vulnerable individuals with broader networks, increasing confidence in health choices (Aston, Meagher-Stewart, Edwards, & Young, 2009). Understanding how participation varies throughout the trajectory of illness is essential to meeting the needs of individuals diagnosed with a brain tumor and their family caregivers (Boon, Verhoef, O’Hara, & Findlay, 2004). A focus on individual experiences facilitates the identification of issues and challenges and highlights potential topics and areas for future support group development and direction. Therefore, individuals and families have input into the support group program in partnership with nurse leaders. Within the support group, the formal task-oriented and restrained hospital setting is replaced with a sense of normalcy (Rosenblum et al., 2009) and a safe, nonclinical environment in which wellness can flourish.

**Barriers to Nursing Leadership**

New and innovative nursing practices and models of care, such as brain tumor support groups, are potentially vulnerable to the reality of workloads and the dominance of the biomedical setting. Nursing shortages, skill mix, and ongoing budget cuts are significant challenges to innovative models of care, such as that of the brain tumor support group (Bonsall & Cheater, 2008; Davidson, Elliott, & Daly, 2006). Maintaining sustainability is a significant barrier to projects like this, and this can be addressed, in part, by a clear project plan, appropriate leadership, and a multidisciplinary cofacilitation model. Caldwell, Chatman, O’Reilly, Ormiston, and Lapiz (2008) maintained that, often, the implementation, not the intervention, is inappropriate. Implementing a PHC framework naturally has allowed a change in the culture, with areas of practice being broken down into smaller components with achievable goals using the five principle tenets of PHC. Using this methodology, along with the principles of practice development and transformational leadership, the Liverpool Hospital brain tumor support group is believed to be the longest and most consistently conducted group of its kind within Australia, with the inaugural nurse leader still coordinating the group. Setting up the structure of the support group in line with PHC principles also has allowed focus to be maintained and all staff to be engaged in all aspects of the project and to undertake components of the group sustainability that suit and develop their leadership skills.

The coordination of care for patients with neurologic cancer is vulnerable to becoming focused on acute care, with limited postdischarge interaction. However, the focus of the Liverpool Hospital brain tumor support group is providing a forum to support individuals and their carers so the individuals remain as healthy as possible outside the hospital setting. Advocating a broader systems approach to the coordination of care for patients with neurologic cancer is vital, and all nurses, regardless of their positions and roles, have the potential to lead and influence individual care and promote excellence in nursing approaches to supportive care. Although the Liverpool Hospital brain tumor support group structure is a selective model of PHC, it focuses on a specific high-risk group of individuals. However, the group embraces the tenets of comprehensive PHC, building on an intersectoral, participatory, and empowerment framework, and demonstrates these concepts in practice via the care coordination of patients with a brain tumor and their caregivers.

**Conclusion**

CCCs, who have proven valuable in addressing the needs of patients with neurologic cancer, cannot be relied on as a single solution. Vital to the success of this project was moving from a standalone nursing leader to collective and collaborative multidisciplinary relationships that are more conducive to facilitating change. A PHC framework is a strategy for achieving care coordination and support for patients with neurologic cancer at the systemic, organizational, team, and individual levels. The health needs and inequality associated with being diagnosed with a primary brain tumor are vast. From an acute care perspective, PHC initiatives for patients with brain tumors and their family caregivers were lacking and inadequate. Activities and interventions that reflect the five tenets of the PHC framework result in improved outcomes for individuals and their family caregivers. The success of the Liverpool brain tumor support group highlights that optimal outcomes are achieved when dynamic nurses practice transformational leadership and have the passion to make a shared vision a shared reality.

**References**


