

## Role of the Patient Care Coordinator

Stacey Per, LCSW

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Introduction. The Patient Care Coordinator provides a bridge between the medical and the supportive services at the Colorado Neurological Institute's Center for Brain and Spinal Tumors. The medical component is comprised of the various physicians and the medical intervention they prescribe. The supportive care encompasses the Patient Care Coordinator, Program Assistant, and neuropsychologists, as well as the menu of programs offered to our patients and families. The Patient Care Coordinator has many different roles. I am the program ambassador and advocate for patients and families in my care. In addition, I maintain existing programs and create new ones to offer our patients and families different choices to meet their special needs.

Program Ambassador. In the role of ambassador, I move back and forth between the clinics in the physicians' offices and Swedish Medical Center. I speak with the patients, their nurses, the physicians, the social workers and other support staff members. I attend various rounds and communicate with everyone involved in patient care. I introduce the Program to new patients and educate the hospital community about the services offered to the patients in the Program.

For example, patients with benign brain tumors may have an operation and be

discharged from the hospital with only a follow up from their neurosurgeon. As a program ambassador, I meet with these patients during their admission to introduce our various programs and other services. I then assess their needs and facilitate the appropriate referrals. These patients may benefit from supportive services such as meeting with a neuropsychologist or attending our support group. After they are discharged from the hospital, they have the benefit of many different programs, as well as being acquainted with the Coordinator if future needs arise.

In my role as program ambassador, I have worked hard to build a relationship with the neurology floor at Swedish Medical Center where most of the Program patients are housed during part of their hospital admission. Through this relationship, I have given in-services to promote a sense of good will between our team members and the hospital staff.

In the role of ambassador, I am an approachable liaison between the patients and medical professionals who may be less accessible. I bring homemade cookies to patients' families in the surgical waiting room, and bring patients handmade blankets once they reach the floor. Patients are given a friendly face to talk with during their difficult medical crisis. Brain tumor patients show a fear and uncertainty that stems from



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1. Miller L. The other brain injuries: Psychotherapeutic issues with stroke and brain tumor patients. *Cognitive Rehabilitation*. 1991;9(5):10-16.
2. Fawzy FI, Fawzy NW, Canada AL. Psychoeducational intervention programs for patients with cancer. *Psychologische Beitrage*. 2000;42(1):95-117.
3. Salander P. Brain tumors as a threat to life and personality: The spouse's perspective. *Journal of Psychosocial Oncology*. 1996;14(3):1-18.
4. Branka AM, Jakovljevic M, Branimir M. Depression, cancer and religiosity. *Psychiatria Danubina*. 2002;June, 14(1-2):9-18.

the diagnosis of cancer as well as its impact on daily functioning.<sup>1</sup> As a patient ambassador, I am able to “humanize” the medical process so that patients feel they are not just brain tumor patients, but individuals who still have dreams and hopes for the future.

*Patient Advocate.* In my role as patient advocate, I meet with patients and assess their needs. I may assist patients with grant requests or provide resources for community programs and resources. I have helped patients and their families with information on topics that range from finding assisted living to deciding which breed of dog may be best for them. I help patients with disability applications and make referrals to hospice and home health agencies. Most importantly, I am a sounding board, a confidant. I am a person they can share their frustrations with at times, and offer a shoulder to cry on at other times. I gauge patients’ moods and may offer an encouraging word, a joke, or a tissue.

*Support Program Coordinator.* In my role as support program coordinator, I oversee and facilitate a monthly support group. I attend the monthly healing service, plan and oversee a quarterly fun activity, “match” newer patients with more experienced patients and oversee the Heartstrings volunteers. It is paramount for patients to have several choices to obtain emotional support. Based on a review of the literature and authors clinical and research experience, cancer patients may benefit from a variety of psychological intervention programs.<sup>2</sup>

Finally, I keep statistics about how many patients we are treating, what type of tumors they are diagnosed with, and what services they may be receiving. This enables the Program to track its growth and let us evaluate how our services are being utilized.

*Support Services.* The CNI Center for Brain and Spinal Tumors holds a monthly support group for both patients and their caregivers. It is critical that both patients and caregivers feel they are not alone with this disease. The therapeutic benefits of discussing the unique problems of having a brain tumor are immeasurable. Both patients and caregivers need a safe place to decompress and brainstorm about coping strategies. Patients benefit from sharing their stories and not feeling as if they are the only ones embarking on this difficult journey.

So often the caregiver’s needs are overlooked. We address this need by splitting the group into patients and caregivers. This provides the caregivers the ability to share their own stories and to get support through their process. Spouses should be viewed as separate people with their own needs.<sup>3</sup>

In our support group, we start out as a larger group of both patients and caregivers to discuss general issues. We then split up into a group of patients and a group of caregivers. This gives both groups the ability to express the very different frustrations that they are facing. In the different groups, the members can get validation and support in a non-threatening environment.

The group addresses issues of coping, depression, isolation, dealing with friends and families. The group takes a solution-focused approach to these and other issues identified by its members. Physicians who are affiliated with the Program, as well as outside service providers may attend to give a brief in-service to the group. Both patients and caregivers are given the opportunity to learn more about different treatment options related to brain tumors.

*Healing Service.* The CNI Center for Brain and Spinal Tumors addresses more than

just the physical and the psychosocial aspects of having a brain tumor. The interfaith Healing Service addresses the spiritual component as well. Traditionally, the medical model does not address issues of spirituality or religion. By holding a monthly Healing Service, the Program acknowledges the importance of spirituality and fellowship within the community it is treating. A large portion of published empirical data suggests that religious commitment may play a beneficial role in preventing depression and physical illness, and facilitate recovery.<sup>4</sup> As Patient Care Coordinator, I encourage patients and their family members to connect with their spiritual source. I work closely with the chaplain intern from Swedish Medical Center, and encourage patients to get spiritual support.

*Quarterly Leisure Event.* Our patients and their families have identified the need to have group recreation activities as a mechanism to interact with other patients and families in a relaxing, enjoyable manner. To address this issue, we have created quarterly “fun” activities, such as watching movies, having picnics and casual gatherings. The patients and their families are given the creativity to decide what they want to do in the future. One family reported they wanted to make scrapbooks around having a brain tumor. Another family is interested in planning a retreat for couples so they can have some relaxing time together to enjoy life and not have to worry about being a patient for a few days.

*Reflecting the Light.* The CNI Center for Brain and Spinal Tumors has a spring ceremony to reaffirm life and to remember those who have not been as fortunate in the Program. This is a time for people who may

not have seen one another for a period of time to reacquaint themselves with the Program and its current activities. This service includes candle lighting, live music and sentiments of patients, caregivers, and team members.

*Heartstrings Program.* The CNI Center for Brain and Spinal Tumors is fortunate to have a team of volunteers to add warmth and heart to our program. This is facilitated through the Heartstrings Program. We have volunteers who knit and quilt blankets. These blankets are given to patients post surgery. Our volunteers wanted to address the need for support for families while patients are undergoing surgery. We have a loyal troop of cookie bakers who supply our families with fresh, homemade cookies while in the family waiting room during their loved ones surgery. Heartstrings is able, through funds donated to CNI, to help many patients with the financial burdens of battling a brain tumor.

*Peer Support Coaches.* Patients may not feel comfortable going to a group or social activity. They may prefer to speak with an individual on a one-to-one basis, someone who has already undergone various treatments and has been dealing with the same disease for a longer period of time. The concept of having a peer coach is helpful not only for the patient being coached, but for the coach as well. The peer support coach is helped by being able to “give back.” The coaches are able to share their success story and to internalize their unique process. The patient is able to see that they are not alone in this disease process. They are able to identify with the longer term survivor and gain a sense of hope through the outcome of another.

*Conclusion.* The Patient Care Coordinator plays a pivotal role in a unique program at the Colorado Neurological Institute. This role will grow and evolve as the needs of the Program continue to expand. As medical treatments become more complex and more successful, more emphasis will be placed on supportive care. As demonstrated in this article, our Program recognizes this need, and through the Patient Care Coordinator has sought to continue to balance our outstanding medical care with a strong supportive care program.

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