

HEALING BEYOND THE BODY

The Princess Margaret Hospital of the University Health Network developed an innovative volunteer program called Healing Beyond the Body (HBB) in order to address the gaps in psychosocial service commonly found in cancer care. Healing Beyond the Body significantly expands the traditional role of volunteers in hospital settings by enabling them to provide more extensive and intensive psychosocial support to patients and their families. Within this Program, volunteers provide targeted intervention focusing on meeting the emotional, informational and capacity building needs of the patient, and assisting with the identification of patients requiring professional service. The Program thus augments professional psychosocial services thereby increasing system capacity. It also extends the continuum of psychosocial care available to patients by creating new service options and allowing for a better fit between need and type of service best suited to meet that need as some patients prefer and benefit from volunteer based rather than professional services. Additionally, the Program assists in improving the referral rates to professional psychosocial services for those patients requiring that level of intervention. Healing Beyond the Body, then, builds on the long-standing dependence of the hospital sector on the contributions of volunteers but re-invents the concept of volunteerism to offer a solution to the significant system deficit related to distress.

PROGRAM DESCRIPTION

HBB Vision

The primary vision and expected outcome for this strategy is to reduce the negative psychosocial impact of life with cancer for both patients and supporters. To achieve this, the specific goals of the program are to provide support for patients and their caregivers in order to: make the hospital experience less confusing and overwhelming; reduce barriers to patient participation in their own care; and, increase self-management of the psychosocial impacts of this illness.

Systemic implementation

Given the ambitious nature of this new model, successful implementation of the Program into hospital-based cancer care required its integration into the organizational structure of the hospital and its key strategic initiatives such as patient centered care. Aligning with the purpose and priorities of the organization facilitated institutional support of the Program and allowed quality and risk management issues to be more easily addressed. Prior to roll-out of the program and with a view to ensuring consistency, quality and efficiency, an operational framework for the program was developed to reflect the new expectations and responsibilities of this role. This operational framework describes the formal processes for all key elements of program management.

The program is comprehensive and hospital wide. It is designed to provide service for patients and their caregivers in all clinics and areas of the hospital throughout the trajectory of their treatment. By creating such a comprehensive program it avoids a

piece mail approach with its inherent redundancies. Therefore, the model facilitates program management by enabling resource efficiencies, simplifying quality assurance processes and fostering the coordination of services across the multiple clinics that patients attend to ensure that patient need is seamlessly addressed across the trajectory of care.

This program is also built on a strong and dedicated research platform to guide implementation and address the gaps in the literature by attempting to answer the outstanding questions around volunteerism. Such strong resource allocation for research is rare for volunteer based services leaving gaps in understanding about this potentially powerful new human resource and how best to develop such a volunteer based program. Among the issues requiring further exploration is the need to better understand the full potential of volunteers to meet patient need while maintaining quality and patient safety, best practices relating to roles suitable for volunteers, training and supervision processes; impacts on staff; outcomes for patients; overall cost for service delivery. Consequently, this research will provide evidence-based protocols toward the development of similar programs in other settings for those functions found to be feasible through the volunteer role and could influence the broader system.

Operational Implementation

One of the first elements defined was the **scope of the HBB volunteer role**. The primary activity of volunteers under this model is to invite patients/supporters into conversation about their current psychosocial challenges. The goal of each contact is to facilitate the patient/supporter's development of an increased sense of control and ability to cope, and to ease the stress of facing cancer. This is accomplished through the provision of several services, under the broader categories of informational, navigational and emotional support:

- Supportive conversation that allows patients and supporters to express their emotional, relationship, practical and spiritual reactions, questions or concerns
- Sharing of generic information related to treatment, hospital procedures, services available in the hospital and broader system, practical tips to deal with treatment, and, coping/stress management strategies
- Skill building by engaging in problem solving about a specific issue raised by the patient/supporter, helping the patient prepare for the questions they want to ask during medical appointments, and, providing assistance to gain skills in information seeking
- Confidence building through validation, encouragement and by tapping into the patient/supporters own strengths
- Triage and encouragement to access patient education and professional psychosocial service
- Liaising with staff to ensure that necessary information is shared and care is coordinated.

The next step was to define the type of positions in which this type of support was to be offered. The positions articulated include:

- *Waiting room support* (peer and non-peer) to assist patients during their clinical visit
- *New patient orientation* to assist patients prior to their first visit
- *Mentor* which is a peer position linked over the long term with an individual patient to guide them through their treatment trajectory
- *Telephone support* to provide assistance between hospital visits
- *Group volunteer* to provide supportive and educational services
- *Volunteer team leader* to partner with HBB staff to assist with training and supervision
- *Program advisor* to provide direct program input, as well as, assist with engaging patients/supporters to provide input.:

Since this new volunteer role and volunteer positions require extensive responsibility, careful attention was paid to the **selection and preparation** processes. Competencies desired for the successful performance were defined under 3 dimensions: knowledge, skill, attitude, while recognizing that there is overlap and mutual influence between these three constructs.

Knowledge

Role of program

Role of volunteer:

Helping: listening and partnering to find solutions

Not friendship but a purposeful helping relationship

With exception of mentor role, no contact outside of the hospital practical help

Psychosocial impacts

Practical (housing, insurance, work/school, transportation, child care, money, medications)

Emotional (worry, sadness, fear of pain/death/treatment/for loved ones, depression, nervousness, self-image, body image, cognitive/memory)

Relationship (role changes, conflict, talking to children, stigma/loss of friends)

Spiritual/meaning of life: alterations in faith, questions about meaning

Medical information:

Role of surgery, chemotherapy, radiation therapy, main side effects

System:

Princess Margaret Hospital and community cancer support, general community resources (transportation, CCAC, housing, income assistance, assistance with cost of medications, community information lines)

Information:

Practical knowledge for dealing with cancer (financial aid, transportation, aid for medication costs, wigs, handling well wishers calls/emails etc)

Coping strategies:

Breathing, diversion etc

Warning signs of difficulty:

Depression, anxiety, significant conflict, suicide ideation, financial crisis

Attitudes:

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Empathy
Genuine
Respect,
Cultural sensitivity
Nonjudgmental
Confidentiality
Boundaries
Objective/client centered
Self-aware: know own triggers/baggage
Non-reactive/mature
Comfort engaging with emotions and letting person stay in their pain
Open to learning/receiving feedback, engaging in self-reflection related to volunteer role
Self-care, managing stress in own life
Commitment/reliability

Skills/techniques

Communication/Interpersonal skills:

- Active listening
- Empathic listening
- Response techniques: minimum prompts, reflecting, paraphrasing, open-ended questions, summarizing, seeking clarification, seeking more information, using neutral responses, silence
- Non-verbal communication
- Encouraging patients to share feelings, normalize feelings

Providing resource information: PMH, community

Providing information or experience with prioritizing, assertiveness, self-care

Providing information seeking skills: asking questions in appointments, web, Patient Education

Screening, the first step in selection and which commences with an interview takes into consideration the role, the scope of practice, the range of positions, the required competencies and functions, and the demands of the training requirements. Using accepted volunteer management and human resource practices and procedures, it is a multi-tiered process within HBB that doesn't end with the initial interview, health screening, and reference checks but continues through the 3 step training process.

The **training modules** were also developed based on the defined competencies and functions. Prior to contact with patients, all volunteers attend 2 group sessions. The sessions provide the necessary knowledge, begin the skill development, and provide an opportunity to continue assessing for the necessary attitudes. Training is offered a number of times per year, and are offered jointly rather than offered as site-specific modules. The training sessions begin with a didactic presentation of material and progress into more interactive opportunities to provide for practice in implementing the required skills. The first group training session is offered to all volunteers in Oncology and highlights the following:

-PMH orientation

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- Psychosocial issues faced by cancer patients and their families
- Basic skills (active listening, empathy, response techniques, nonverbal communication)
- Basic PMH resources

The second group training session, offered initially by 2 staff, but once the program has the capacity by 1 staff person and 1 volunteer highlights the following:

- Continuation of communication skills training
- Self-management skills for patients
- Resources available to patients in the hospital (cont'd) and in the community
- Basic treatment information

Role play becomes key to this training, building scenarios based on:

- Information learned during PMH training and contained in reference/training manual
- Demonstrating expected reactions versus extreme reactions that require referral
- Strong emotions, such as despair
- Family conflict
- Distress over decision making, disease progression
- For peers: ability to share their own journey while staying focused on patient needs

Following the group modules, volunteers receive supervised on-site training. This element entails 2 mandatory shadowed shifts in the volunteer's designated clinic, with extension offered if sufficient proficiency has not been demonstrated. This phase offers the opportunity to review knowledge learned in the group modules, offers information about the volunteer's own clinic, and focuses mostly on interacting with patients with opportunity for immediate support and feedback. :

After the completion of the training, volunteers work autonomously within their chosen clinic. To ensure **maintenance of competence and best practices**, and that volunteers don't add to the workload of clinic staff, Healing Beyond the Body's psychosocial staff provide support and supervision on an ongoing basis to the volunteers. Supervision includes continual monitoring of volunteer behavior and liaison with clinic staff to seek their feedback. Additionally, HBB staff are available to connect via telephone, email or in person with volunteers for non-urgent matters, and are on pager for matters requiring immediate attention. Volunteers also are required to attend a minimum of 3 group debriefings per year. Finally, volunteers undergo an evaluation process each year that provides a formal opportunity to provide feedback and take corrective action if required.

Two other key elements in the operational plan are **recruitment and retention**, with a particular focus on the need to ensure and maintain diversity in the volunteer pool to optimize the program's ability to reflect the diverse mix of people affected by this illness. This increases the chances of providing the type of support best suited to the unique patient need. Given the extent of investment in each volunteer at the front-end, efforts at recognition and acknowledgement also are addressed to maximize the satisfaction

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levels of volunteers and increase retention rates, thereby decreasing the need to recruit new volunteers.

For HBB, **marketing** strategies are directed not only to external groups to recruit volunteers but also to internal staff and patients. Because this is such a new role, both staff and patients need to be educated about its capacity and limits. The patients require active marketing as they have not experienced this type of volunteer in a hospital setting before, and will not avail themselves of the available support unless informed. Oncology staff need this information to ensure that they understand the role, accept this new volunteer on their team and take full advantage of their skills for the benefit of patients.

The final element of the operational plan for this program is evaluation and **research**. This research platform is integral to the success of the program in the hospital setting success within PMH, as well as, the program's capacity to inform the broader community about the viability of such an endeavor and provide recommendations to guide implementation in other settings. Evaluation requires attention to a number of factors beyond the traditional patient satisfaction measures, including screening, training, supervision processes; ensuring that the needs met are those seen by the patients' as most crucial; referral rates to professional psychosocial services to evaluate the triage component; patient outcomes related to distress and capacity to self-manage, data to evaluate resource needs for such a program and to demonstrate cost effectiveness. Additionally, this research will provide evidence-based protocols toward the development of similar programs in other settings for those functions found to be feasible through the volunteer role. This research is intended to answer the many outstanding questions about the full potential of this role to meet patient need while maintaining quality and patient safety.