

Caring for the Caregiver



Developing a self-care and resiliency program for oncology professionals

Research shows that medical providers who care for seriously ill patients encounter a high risk for diminished well-being that can include burnout, moral distress, and compassion fatigue.¹ The daily care of critically ill patients combined with multiple losses is a recipe for burnout in any clinical setting, and oncology is no exception. Clinicians who work with seriously ill patients with cancer have increased rates of physical and emotional exhaustion, cynicism, and inefficacy.²

Although oncology providers experience high job satisfaction overall, the intensity and emotional rigor of the work can contribute to people leaving the field early. Thus, it is imperative for cancer programs to develop effective strategies to prevent burnout and increase resiliency among providers and staff.

At Providence St. Joseph Health, Eureka, Calif., our pledge to staff is, “to create an environment where you are respected, appreciated, and given opportunities for personal growth and development.” Our rural Northern California cancer program took this pledge to heart through the creation of a holistic Self-Care and Resiliency Program for providers and staff that fully supports their physical and emotional well-being.

Here’s our story.

Defining and Addressing Caregiver Burnout

The term *burnout* was coined 30 years ago to describe a physical and emotional state of fatigue experienced by health and service workers. Burnout syndrome is defined as, “a multidimensional process with three central constructs: emotional exhaustion, depersonalization, and reduced personal accomplishment.”³

“Oncology nurses and caregivers who bring a unique passion to patients are also uniquely at risk for compassion fatigue,

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cumulative grief, and burnout due to how professionally close and how frequently they interact. Compassion fatigue occurs when caregivers unconsciously absorb the distress, anxiety, fears, and trauma of the patient.”⁴ Cumulative grief follows the caregivers’ journey alongside patients and families as they go through cancer treatment.

Burnout due to compassion fatigue and cumulative grief is now recognized by the World Health Organization as a codified legitimate medical diagnosis related to employment or unemployment.⁵ Physicians can now diagnose someone with burnout if they meet the following symptoms:⁵

- Feelings of or energy depletion or exhaustion
- Increased mental distance from one’s job, or feelings of negativism or cynicism related to one’s job
- Reduced professional efficacy.



Oncology Nurses Maureen Bell (L) and Ivy Brewster (R) enjoy a glass blowing lesson.



Oncology Nurses prepare for a local race.

Rural providers can be especially vulnerable to burnout. Rural patients face many challenges in receiving cancer care, including transportation barriers and financial challenges.⁶ Like many rural community cancer programs, St. Joseph Hospital serves a population of patients with multiple psychosocial challenges, including health disparities, lack of transportation, mental health issues, and substance abuse. Providers and staff who work with these patients have an increased need for substantial self-care programs to help improve provider well-being and retention.

Though much research exists on the topic of caregiver burnout, significant studies identifying evidence-based practices to combat burnout among healthcare providers in a clinical setting remain sparse. Common recommendations for increasing oncology staff self-care include:

- Creating oncology provider and staff support groups
- Hosting education and training on stress reduction
- Providing retreats for oncology professionals.

Evidence-based blueprints for all-inclusive comprehensive self-care programs are rare, and it was this need for evidence-based solutions that inspired and fueled the development of St. Joseph Hospital's Self-Care and Resiliency Program.

The Beginning: Remembrance Ceremonies

Our accredited cancer program began five years ago, and from its inception one of our oncology nurses understood that providers and staff needed an outlet to process their unresolved grief due to the death and dying of patients. The first step on our journey was implementation of bi-annual patient remembrance ceremonies for providers and staff. Master's-level social work students and chaplains planned and implemented the ceremonies together. The ceremony format included nurses and social workers reading names of the patients who had passed away, prayers and eulogies read by the chaplains, and a time for the staff to share memories of the patients as a group. The ceremonies were held during work hours, so clinics would close early so that staff could attend.

After the ceremony, staff were provided information about our Employee Assistance Program, and the oncology social worker and chaplains were available for more comprehensive grievance counseling if needed. Though these ceremonies were an effective way to help process grief, only about 40 percent of staff attended. Over time it became apparent that some staff never attended, whereas others were in attendance every time. Of staff who attended, many commented that they were able to process their grief after being part of the ceremony, and they looked forward to these services as a time where they could remember patients who had passed and share fond memories with others in a supportive setting.

Despite the success of the remembrance ceremonies, it was obvious that more intervention was needed to meet the self-care needs of the full oncology staff. Providers and staff commonly voiced complaints about feeling burned out, tired, and emotionally drained. Some staff members quit because of the high intensity and stress of their work environment. It was at this point that April Alexander, clinical oncology social worker, and Larry Beck, senior chaplain, began to discuss more effective ways to support oncology staff self-care.

Identifying Staff Preferences

The next step on our journey was to create a support group specifically for oncology caregivers; this group was co-facilitated by our oncology social worker and chaplain. The goal of the support group: to increase caregiver resiliency through debriefing and support.

These informal support groups were held a few times a month after work hours and generally included education around self-

care, such as mindfulness activities, followed by a group discussion. These sessions became a time where caregivers could discuss the stresses and concerns of their day and receive emotional support from co-workers and psychosocial staff.

Though the support group setting was helpful for some staff, it became apparent that the activity needed to be held during work hours. The main challenge: members of the care team—clinic nurses and staff who provided direct patient care throughout the day—could not get time off to attend.

Our next step was to leverage scheduled staff meetings to provide self-care and resiliency education. Our oncology social worker conducted some mindfulness-based training with staff, such as breathing exercises and relaxation techniques, and facilitated discussions around basic self-care activities. Our chaplain also began working with the oncology department, attending the infusion clinic, support services, and medical oncology clinic staff meetings to offer additional self-care strategies. Staff were educated about the signs of pre-burnout and how to develop a personal self-care plan and encouraged to practice self-care on a daily basis during their workday to increase resiliency and decrease burnout. Ideas for self-care during the workday included walking outside during breaks, use of alone time during breaks and lunch, practice of relaxation breathing techniques during times of stress, and debriefing with staff when needed.

Feedback about this education revealed that some staff were more conducive to this type of self-care education than others. It was clear we needed to diversify our self-care education and activities. Figure 1, right, offers a high-level overview of the growth of St. Joseph Hospital’s Self-Care and Resiliency Program.

Unique Needs of Oncology Nurses

We learned quickly that oncology nurses have unique needs when it comes to self-care due to the kind of patient care they provide and the subsequent daily emotional toll it takes on them. We have found that nurse-led activities are generally much more effective and better attended by nursing staff. This may be because nurses have a better understanding of the activities they need to increase their own self-care. We also discovered that nurses commonly debrief with one another in the break room and outside of work hours, so forms of unorganized self-care were already occurring in this population.

Working as an oncology nurse includes forming close relationships with patients and their families during treatment. Though this relationship building can result in positive feelings of helping others, the loss of a patient can intensify feelings of compassion fatigue, a phenomenon of stress resulting from exposure to traumatized individuals.⁷

Compassion fatigue is compounded in our small community where nurses interact with surviving family members in other settings, such as the grocery store, church, and social gatherings. Witnessing repeated death and dying along with grieving family members can result in personal grief and exhaustion for nurses.⁶ The emotional impact of working with patients with cancer is well known to nurses, who must practice self-care in order to provide ongoing safe and compassionate care. Balancing the

Figure 1. Components of St. Joseph Hospital’s Self-Care and Resiliency Program



demands of work and having energy to invest in nurturing the self allows nurses to continue to nurture others.⁸

We interviewed our infusion nurses about how they manage stress at work and what activities they engage in after hours to relieve this burden. All provided examples of positive coping methods, such as exercise, spending time with family and pets, and prayer and spirituality.

A recent nurse-led pilot program included education promoting awareness about compassion satisfaction and fatigue, as well as health and wellness tips, grief and bereavement activities, and access to a respite room for meditation.⁹ A systematic review of strategies to promote nurse resilience (Figure 2, page 42) revealed these best practice components:¹⁰

- Social activities
- Education on work-life balance
- Continuing education on self-care
- Structured forums for discussion
- Professional counseling and/or debriefing
- Bereavement rituals.

On-site workplace interventions that address emotional strain on nurses can be effective in reducing compassion fatigue, including:¹¹

- Counseling
- Support groups
- Debriefing
- Art therapy
- Massage
- Bereavement interventions
- Attention to spiritual needs.

It is important to recognize what nursing staff in the infusion clinic are instinctively doing right to combat stress at work. Several

Figure 2. Best Practice Self-Care Strategies for Oncology Nurses⁸



research-based recommendations currently available and used by our staff include the remembrance ceremonies, social activities, and access to counseling. The care for the nursing team is evident in their work. The closeness and support of this team was recently celebrated when a cancer patient nominated the entire nurse team for the prestigious DAISY nurse award, which was given early in 2019. The teamwork and camaraderie of our nurses extend beyond work as staff regularly get together in social settings and at each other’s homes for holiday parties and birthdays and for physical activities such as kayaking, roller skating, and biking.

We suggest that social workers and/or chaplains assess the unique needs of nursing staff and design educational opportunities targeted toward these needs. Our social workers and chaplains provide nursing staff with additional resources to help promote positive self-care, including staff education, debriefing opportunities, support groups, and self-care resource lists. Nurse-led educational activities scheduled during monthly staff meetings may be a good outlet for training on preventing compassion fatigue and burnout, balancing work-life needs, mindfulness, and meditation.

Integration of Spiritual Care

The integration of spiritual care was vital to the development of our Self-Care and Resiliency Program. From partnering together to develop education and training to assisting staff in comforting grieving patients, our chaplains have played a pivotal role in the program. In the sidebar on page 45, Senior Chaplain Larry Beck describes in his own words how he helped develop St. Joseph Hospital’s Self-Care and Resiliency Program.

Getting Creative

One of the biggest lessons we learned: creating a Self-Care and Resiliency Program for oncology providers and staff is not a one-size-fits-all proposition. For example, after our oncology

social worker and chaplain followed up with various staff members about the self-care education offered during staff meetings, it became clear that there was a significant need for a wider variety of self-care options. To address these needs, we implemented a pilot study of a “Self-Care Tip of the Week” email specifically for medical oncology clinic staff. This weekly email included graphics or bullet points with vetted self-care activities, psychosocial information, self-care apps, and ideas staff could implement during their workday to help relieve stress. Pilot feedback about this resource was extremely positive. Staff like that it is optional; they can choose to read or delete it. After the success of the pilot program we rolled this email out to the entire medical oncology staff.

Our Self-Care and Resiliency Program also began to schedule monthly events outside of work for staff, which generally include dinner and an activity; for example, biking or rollerblading. These group activities offer staff a chance to socialize in a self-care activity with their co-workers outside of work in a fun, relaxing setting. The process is ongoing, and we continue to look for ways to incorporate self-care into our staff’s lives through education, events, and emotional support. Figure 3, right, offers a high-level view of our Self-Care and Resiliency Program model.

Gathering Feedback

We recently sent out a survey about the various events and activities available within our Self-Care and Resiliency Program. From the 50 surveys sent, we had 18 anonymous respondents who provided insightful information about the efficacy of our Self-Care and Resiliency Program, as well as areas for improvement.

Overall, feedback about the activities and education we instituted was positive, with our remembrance ceremonies, self-care presentations, and self-care tip of the week email being the most popular (see Figures 4, right, and 5, page 44). One of the main things we learned from survey feedback is that many staff are not even aware of the self-care activities offered. Additionally, some staff indicated that they would prefer that certain activities were optional and not included in mandatory staff meetings.

We are taking the feedback into consideration as we grow and improve our Self-Care and Resiliency Program. We also plan on doing a better job educating staff about existing self-care activities; for example, implementing a marketing plan to staff and providers about the Self-Care and Resiliency Program to raise awareness of all available events and activities.

Pitfalls and Pearls

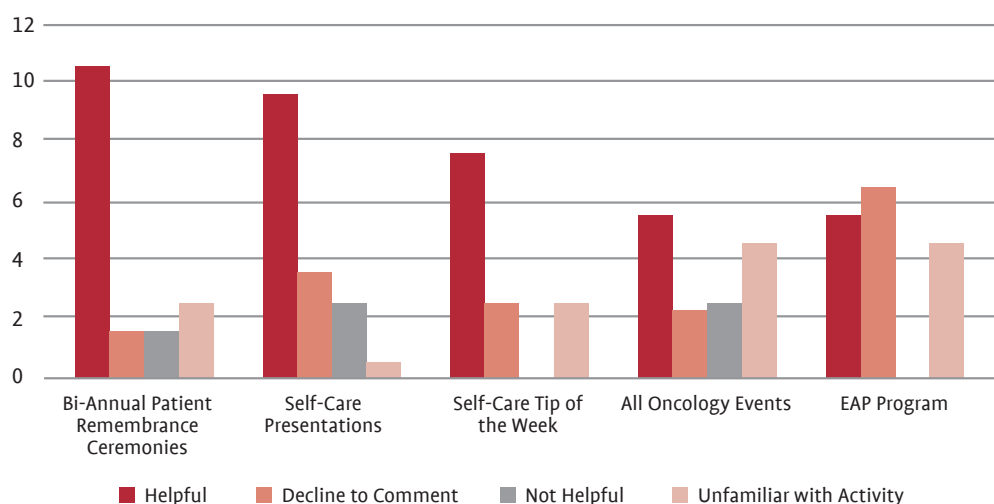
Along the way, we learned many valuable lessons about the development of our Self-Care and Resiliency Program, and we continue to learn through trial and error as we expand services. Here we share some pearls for cancer programs looking to develop a similar program:

- Collaboration between spiritual services, psychosocial staff, and clinical staff is vital.
- Ongoing communication with administration and leadership is key.
- It is important to offer a wide range of activities from in-person events to digital communication, like apps.

Figure 3. St. Joseph Hospital’s Oncology Self-Care Program Model



Figure 4. Survey Results for St. Joseph Hospital’s Self-Care and Resiliency Program



- Activities outside of work are an essential component.
- Recurring patient remembrance events are effective for processing grief.
- Self-care education should be optional for the staff; some will need these resources, whereas others may have a robust support system in place.
- Community resources on self-care, including webinars, workshops, and live events can help diversify and/or expand the program.
- Employee Assistance Programs are a good resource.
- To ensure the success of the program, you need to continually gather staff feedback—informally (at events) and formally (through surveys)—and then use the feedback to improve the program.
- If staff are not aware of the program, they will not participate and benefit from it.
- The program should be holistic in nature, incorporating body, mind, and spirit.

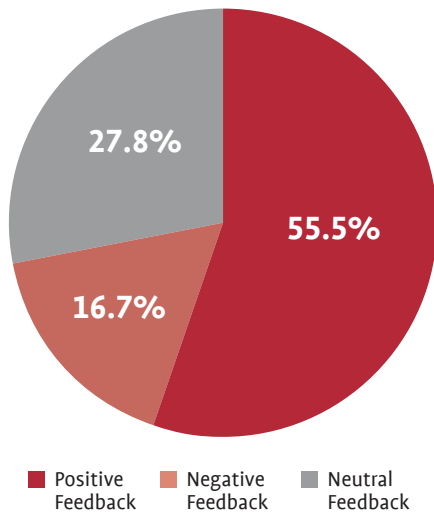
- Often, you will need to help staff overcome an element of “guilt” around self-care needs.
- Self-care is not “one-size-fits-all.” Self-care programs are not static; change is inevitable and programs will evolve with the needs of providers and staff.

We would be remiss if we did not point out that processes and/or issues exist within all organizations that cause stress for staff, and some of these issues cannot be fully remedied through self-care education and activities. For these changes to take place, discussion and teamwork will need to happen at the administrative and operational levels.

Future Plans

Our oncology social worker will partner with an oncology nurse to plan and create a “self-care binder” for all oncology professionals. The binder will include self-care resources, such as mindfulness exercises, self-care plans and tips, self-care events, and self-care and caregiver resiliency education available through our

Figure 5. Satisfaction Survey Results of St. Joseph Hospital's Self-Care and Resiliency Program



Self-Care and Resiliency Program and in our community. New oncology staff members will receive the binder upon hire so that they are aware of the resources that our Self-Care and Resiliency Program provides. Additionally, this oncology nurse is starting a self-care education curriculum geared specifically to meet some of the unique needs of oncology infusion nurses discussed previously in this article.

Opportunities for Research

More evidence-based research on self-care programs for oncology providers and staff is necessary to provide successful holistic models. Continued input from all members of the multidisciplinary cancer care team, including physicians, nurses, social workers, chaplains, oncologists, nurse practitioners, palliative care professionals, and other staff and administration, is needed. Holistic programs that address the whole person (body, mind, and spirit) need to be further developed and studied to test for efficacy and sustainability. Spirituality needs to be explored because preliminary research findings show that it is an effective intervention for healthy self-care. Because each oncology program has its own unique needs, each program will need to tailor its model and education to adequately support self-care and resiliency for its providers and staff.

Closing Thoughts

Oncology programs are beginning to realize that self-care is not optional. Patient care and staff retention are dependent upon the ability of the staff and providers to administer care amid death and grief, long working hours, staffing challenges, and provision of care for patients with significant psychosocial issues. Additionally, the ever-changing face of healthcare with its internal and external demands will continue to put an added stress on providers. Addressing these issues with administration and policy-makers will be mandatory for reducing caregiver stress and burnout. Therefore, more research is needed to explore how policies and internal structures impact self-care and burnout in oncology professionals and which interventions will be effective in reducing the negative impact on caregivers.

Though this task may seem overwhelming, we need to be willing to take the first steps to provide effective self-care that will create resiliency in our oncology programs. The mental and physical well-being of staff and providers is vital. If we allow the physical and emotional toll of our work to reduce personal accomplishment and cause emotional detachment and depersonalization, it can have a negative impact on patient care and, ultimately, patient outcomes.

Through the development and implementation of our Self-Care and Resiliency Program, we are finding new and novel ways to provide self-care for ourselves and the people we work with. The process takes patience and persistence. There will be challenges along the way, yet if we remain open, we can change and innovate.


“Owning our story can be hard but not nearly as difficult as spending our lives running from it. Embracing our vulnerabilities is risky but not nearly as dangerous as giving up on love, belonging, and joy—the experiences that make us the most vulnerable.



All Oncology Department Bike Ride Outing



Chaplain Larry Beck prepares for a patient remembrance ceremony.

Only when we are brave enough to explore the darkness will we discover the infinite power of our light.” This quote by Brené Brown, clinical social worker and researcher, eloquently describes the internal process that we should embrace as we move forward, both individually and organizationally, into the realm of self-care, providing the highest level of care for our patients while also caring for our caregivers. 

April Alexander, MSW, LCSW, OSW-C, ACHP-SW, is clinical oncology social worker; Larry Beck, BCC, is senior chaplain; and Maureen Bell, RN, MS, BSN, OCN, is an oncology nurse at Providence St. Joseph Health, Eureka, Calif.

References

1. Sanchez-Reilly S, Morrison LJ, Carey E, et al. Caring for oneself to care for others: physicians and their self-care. *J Support Oncol*. 2013;11:75-81.
2. Grunfeld E, Whelan TJ, Zitzelsberger L, et al. Cancer care workers in Ontario: prevalence of burnout, job stress and job satisfaction. *CMAJ*. 2000;163:166-169.
3. Allegra CJ, Hall R, Yothers G. Prevalence of burnout in the U.S. oncology community: results of a 2003 survey. *J Oncol Pract*. 2005;1:140-147.
4. Bush NJ. Compassion fatigue: are you at risk? *Oncol Nurs Forum*. 2009;36:24-28.
5. Prior R. Burnout is an official medical diagnosis, World Health Organization says. Available online at: cnn.com/2019/05/27/health/who-burnout-disease-trnd/index.html.
6. Charlton M, Schlichting J, Chioreso C, et al. Challenges of rural cancer care in the United States. *Oncology (Williston Park)*. 2015;29:633-640.
7. Figley CR. *Compassion fatigue: coping with secondary stress disorder in those who treat the traumatized*. New York, NY: Routledge; 1995.
8. McSteen K. Compassion fatigue in oncology nursing: a witness to suffering. Available online at: oncologynurseadvisor.com/home/departments/ce-courses/compassion-fatigue-in-oncology-nursing-a-witness-to-suffering. Last accessed June 1, 2019.
9. Sullivan CE, King AR., Holdiness J, et al. Reducing compassion fatigue in inpatient pediatric oncology nurses. *Oncol Nurs Forum*. 2019;46:338-346.
10. Gillman L, Adams J, Kovac R., et al. Strategies to promote coping and resilience in oncology and palliative care nurses caring for adult patients with malignancy: a comprehensive systematic review. *JBI Database System Rev and Implement Rep*. 2015;13:131-204.
11. Boyle DA. Countering compassion fatigue: a requisite nursing agenda. *Online J Issues Nurs*. 2011;16:1800-1804.

Chaplain Larry Beck: In His Own Words

Do you remember the adage, “All work and no play makes Jack a dull boy?” A more appropriate adage for today’s work culture should be, “All work and no self-care makes Jill and Jack burned out!” As a certified chaplain working at a 154-bed hospital in Northern California, I share spiritual care responsibility with 1 other staff chaplain and 11 volunteer chaplains. Our Spiritual Care Team advocates self-care to groups and individuals and facilitates emotional debriefs in all areas of the hospital. We advocate for self-care with the goal of promoting resiliency and happier caregivers and patients, while reducing staff turnover.

Up until two or three years ago, our Spiritual Care Team had encouraged self-care in all areas of the hospital through nurse huddles, self-care facilitations, spiritual care baskets, and debriefs when trauma or crisis occurred but very little spiritual care within the confines of outpatient oncology. Unless a physician consult for patient referral was sent, we had little contact with oncology caregivers. That situation began to change shortly after I was invited to participate in a remembrance ceremony for patients who died while in cancer treatment or while completing the treatment. Once I started hearing the patient stories told by caregivers, I soon realized that we had a self-care opportunity for these outpatient oncology nurses and caregivers.

At the bi-annual oncology remembrance ceremony held in our chapel to remember all those who died within the past six months from cancer, we placed chairs in a circle around a large vase and candle. My fellow chaplain began with an opening prayer. Our oncology social worker, April Alexander, and another caregiver took turns reading each of the approximately 100 names of the deceased, ringing the bowl bell between each. About 20 caregivers joined the remembrance. After the final name was read, we paused in silence.

Then caregivers randomly offered informal testimony about the deceased. It was heartwarming to hear stories of the people and the personalities who touched their lives and the reward of caring for them. One such story was about a patient who would come in for therapy with a brown bag over his face; he called himself the unknown patient after the unknown comic.

Looking toward our preferred future, our Spiritual Care Team is considering moving to a quarterly remembrance ceremony to ritualize, celebrate, and remember our oncology patients more often. Twice a year seems too infrequent to come together. Our team also recognizes that we need to continue to seek out and volunteer additional self-care education. For example, along with an emergency room nurse, I attended a self-care seminar for first responders, firemen, and highway patrol, which brought my understanding of the importance of training in trauma debriefs to a new level.

Our Spiritual Care Team is actively promoting our underutilized Employee Assistance Program and considering the recruitment of an on-call counselor. We are also in the beginning stages of developing a hospital-wide initiative that brings a multidisciplinary support approach to the self-care of our caregivers. In the literature, it is informally called Code Lavender to communicate when hospital staff are being overloaded by stress and traumatic events; many hospitals have already successfully implemented a Code Lavender Program.