

Oncology Couples' Retreats: A Focus on Relationships Between Patients and Their Caregivers

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Abstract

A cancer diagnosis not only affects multiple aspects of a patient's life, but can also have a significant impact on the caregiver, who is often the spouse as well. Beginning in 2012, the Johns Hopkins Gastrointestinal Oncology group has organized a couples' retreat program to help address the concerns of oncology patients as well as their caregivers in a safe and closed environment. These retreats are disease-site specific and include 10 to 12 couples with metastatic or locally advanced pancreatic or colorectal cancer. The program includes a multidisciplinary approach over 3 days and includes meals, activities, and lodging. Couples are encouraged to engage with each other as well as other couples enduring a similar journey in an effort to help them relate and express concerns and questions they may have. Sessions include topics by medical professions such as treatments and symptom management as well as sessions by additional professionals to address other practical needs related to the diagnosis, such as finances and advance directives. These retreats have shown that both patients and caregivers appreciate the opportunity to discuss their feelings with others and subsequently feel less uncertainty about their future. They have also been beneficial to the health-care professionals participating to gain knowledge on which activities as a whole are important to these populations. Data are extremely limited for programs such as these, but we are hopeful they will continue to help support these populations of oncology patients and their caregivers through a very difficult portion of their lives.

In addition to the physical health concerns that a cancer diagnosis brings, a wide spectrum of psychosocial concerns also accompanies a diagnosis. These psychosocial concerns affect not only the patient, but also the family and caregiver, and often to a greater extent. Some oncology patients are able to enter into a surveillance regimen where they are considered free of disease, while others

live with locally advanced or metastatic disease. In these cases, the disease is more of a chronic condition and the goals of treatment, as well as life, are now very different.

When one becomes a caregiver of one's partner, how to continue to be a partner in addition to acting as a caregiver can be a gray area. The same can be true for patients; there is often a struggle with the dynamics of being a patient as well as continuing to be a partner. At this stage, the dynamics change within a family, and finding a good balance can often be emotionally straining to all parties involved.

A connotation of cancer often creates extensive psychosocial, physical, emotional, and financial stress that can affect intimacy and relationships among couples. Psychosocial care among patients and caregivers with cancer is often unrecognized or avoided due to lack of experience in addressing such topics. In addition to anticancer treatments, clinician aims should also include recognizing and addressing the effects of a cancer diagnosis and treatments on mental health, emotional wellbeing, and quality of life of patients, family members, and caregivers.

The Johns Hopkins Gastrointestinal (GI) Oncology group has created a program that aims to provide an elevated level of well-rounded support to patients and their partners through a couples' retreat for patients with locally advanced or metastatic colorectal cancer and pancreatic cancer. These retreats are also focused on educating other oncology groups at Johns Hopkins and those outside our facility about these types of programs in the hopes of extending implementation of such retreats. Retreats have been conducted through the Johns Hopkins Breast Center with metastatic breast cancer survivors since 2001, then incorporating couples in 2009, off of which the GI Oncology retreat was modeled (Johns Hopkins Medicine Breast Center, 2019; Shockney, 2011). There are a few other programs such as the Young Adult Cancer Canada Tapestry program, whose efforts to address the psychological sequelae of oncology patients appear to be well received (Angen, MacRae, Simpson, & Hundleby, 2002).

CAREGIVER BURDEN

Caregivers and partners are often forgotten during the psychosocial assessment of the oncology pa-

tient. The National Coalition for Cancer Survivorship (NCCS) mission statement includes the following: "An individual is considered a cancer survivor from the time of diagnosis and for the balance of life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore now included in this definition."

It is imperative that health-care providers take the family and caregivers into account when making treatment decisions. It has been noted that heavy caregiving burdens can harm the physical and mental health of primary caregivers and reduce patient care quality" (Wang, Chen, Chang, Wong, & Wang, 2011). This study by Wang and colleagues examined caregivers of terminally ill GI cancer patients and found that the burden was significantly higher for spousal caregivers. There are limited data on family members of oncology patients, but studies have suggested that reactions of the family are often along the lines of the patient during that time (Turner-Cobb, Bloor, Whittemore, West, & Spiegel, 2006). One study that interviewed family members on their loved one's cancer diagnosis reported emotions of shock, devastation, fear, unhappiness, and sadness (Petrin, Bowen, Alfano, & Bennett, 2009).

Deficits in emotional and social functioning, managing physical oncology side effects, and financial difficulties are the main factors hampering the quality of life among colorectal cancer patients and seem to affect predominantly younger patients (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004). Previous studies have shown that areas such as sexuality, interpersonal and family relationships, economic status, and the emotional state of patients affected by the disease and treatments provide a deep complexity in the study of the psychosocial adaptation process in patients with cancer (Alvarado-Aguilar, Guerra-Cruz, Cupil-Rodriguez, Calderillo-Ruiz, & Onate-Ocana, 2011). Recent reporting from Moffitt Cancer Center looked at communication between patients and their spouses at home, which revealed that some did not engage in discussing the diagnosis or relationship and seemed to be able to focus on more routine aspects of life (Reblin, Sutton, Vadapampil, Heyman, & Ellington, 2018).

Much of the focus of psychosocial support has been on patients who have completed active

treatment for their cancer diagnosis and are entering into surveillance-type care; however, few programs exist for patients and their caregivers with locally advanced or metastatic disease who are dealing with cancer as a more chronic process with many more uncertainties regarding their future and prognosis.

Data are limited on the impact of these types of retreats, but interest about them among the Johns Hopkins GI oncology patient population has been expressed. Johns Hopkins has now been hosting couples' retreats for metastatic/advanced pancreatic and colorectal cancer since 2012. These programs have provided patients and caregivers with various resources and an opportunity to express their feelings and concerns in a safe environment with other patients and caregivers going through similar experiences, which is a primary goal of these retreats. Furthermore, allowing patients to tell their stories can generate discussion and a sense of cohesiveness among the groups of metastatic/advanced cancer patients and their partners. It also gives couples a chance to learn how to be intimate in different ways while going through many physical and mental changes.

MATERIALS AND METHODS

These GI couples' retreats at Johns Hopkins began in 2012 and have been held annually. Retreats are scheduled to take place in 2019: one for pancreatic cancer and one for colorectal cancer. The goal for attendance is 10 to 12 couples. Names and contacts are established and a wait list is maintained once space is filled. Potential retreat attendees are referred by treating staff throughout our institution as well as from community facilities. Patients and caregivers do not need to be patients of Johns Hopkins nor do they need to live in the local area.

The retreats consist of 3 days and 2 nights and have been traditionally held at the Bon Secours Spirituality Center in Marriottsville, Maryland (Bon Secours Retreat & Conference Center, n.d.). The retreat includes meals and housing accommodations, as well as activities scheduled throughout the retreat as an all-inclusive package at no cost to couples. Because lodging and food are provided at the facility, patients can travel from afar and rest when necessary in the comfort of a private room. We have also established a relationship with the retreat cen-

ter and are able to create custom menus tailored to the particular group's needs. We have found it difficult to execute a successful retreat in fewer than 3 days given all the topics we aim to include.

There is a committee focus group, typically consisting of nurses and advanced practice providers, that continues to meet throughout the year to identify the needs of these patient populations and their partners for each particular retreat. Those involved in the planning and execution of the retreat include physicians, advanced practice providers, nurses, nutritionists, physical therapists, and social workers from multiple oncology disciplines.

The committee focus group works to establish program goals and create the agenda to include experts from various fields: nutrition, exercise/physical medicine and rehabilitation, spirituality, coping, caregiver support, clinical trials, palliative care, advance directives, intimacy/sexuality, medical oncology, radiation oncology, surgical oncology, interventional radiology, social work, legal, and financial. Time is also allotted for meditation, massage, Reiki, and relaxation. There has also been a component built in for more social activities, which in the past have included a photo booth, painting, meet-and-greet sessions, movie night, and a newlywed game. See Table 1 for a sample agenda.

Pre- and post-retreat surveys on quality of life and distress are completed by patients as well as their partners, which we aim to have validated in the future for improved data analysis (Tables 2 and 3). Results are continuously being reviewed to determine if patients and partners had more, less, or the same amount of distress after attending the retreat and what impact it may have made on their overall mental health. We have also implemented evaluations for feedback on individual activities within the retreat to help the focus group with decision-making and planning of future retreats. Over the years, the cost of these retreats has ranged from approximately \$10,000 to \$13,000 per 3-day event. These costs include the facility meeting rooms and AV equipment, on-site lodging and meals for all participants, speaker fees, gift bags, and other miscellaneous items such as snacks, bottled water, office supplies, and social event supplies. Funding for these retreats has varied from individual physician discretionary ac-

Table 1. Johns Hopkins Retreat for Patients Living With Metastatic Colorectal Cancer and Their Partners: Sample Agenda

Day/Time	Topic
<i>Friday</i>	
12:00–1:00 pm	Lunch
1:00–2:30 pm	Registration, Introductions, Retreat Overview, and Check-In
2:30–3:30 pm	Advance Directive and Healthcare Decision-Making
3:30–4:00 pm	Break
4:00–5:00 pm	Nutrition
5:00–6:00 pm	Mindful Meditation
6:00–7:00 pm	Dinner
7:30–? pm	Icebreaker/Social Gathering
<i>Saturday</i>	
8:00–9:00 am	Breakfast
9:00–10:00 am	Exercise/Energy Conservation
10:00–11:15 am	Maintaining Quality of Life
11:15 am–12:15 pm	Ask the Pharmacist
12:15–1:00 pm	Lunch
1:00–3:00 pm	Ask the Expert
3:00–4:30 pm	Caregiver Café
3:00–4:30 pm	Patient Pow-Wow
4:30–6:30 pm	Painting/Happy Hour
6:30–7:30 pm	Dinner
7:30–? pm	Social Gathering
10:00 am–6:00 pm	Concurrent Activities: Massage and Reiki Treatments With Integrative Medicine Therapists
<i>Sunday</i>	
8:00–9:30 am	Breakfast and Check-Out
9:30–11:30 am	Spirituality/Introduction to Labyrinth and Walk
11:30 am–12:00 pm	Surveys, Evaluation, and Group Photo
12:00–1:00 pm	Lunch and Final Goodbyes

counts, donor funding, and/or co-funding by the divisions of surgical oncology, medical oncology, and radiation oncology.

DISCUSSION

To date, we have held a total of six retreats for metastatic colorectal and pancreatic cancer patients and their partners, with a total of 48 couples. 46% of the couples resided locally in Maryland, and the remainder of the couples resided in Virginia (25%), Pennsylvania (12.5%), Washington, DC (4%), West Virginia, New Jersey, New York, New Hampshire, Ohio, and Iowa. Patients' ages ranged

from 32 to 77 years (mean, 61). Preliminary data of post-retreat evaluations have shown the benefit of connecting and networking with other patients and caregivers.

Past sessions have included an "Ask the Expert" panel nutrition, quality of life, meditation, advance directives, exercise and energy conservation, social gatherings, spirituality, massage/Reiki, and a labyrinth walk (Figure 1). Many couples have expressed appreciation for an opportunity to have difficult conversations with their partners that had not taken place previously. Specifically, the caregivers and partners felt like they had a

Table 2. Patient Pre- and Postretreat Survey

Please respond to the following statements by circling your answer.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I am uncertain about the future	1	2	3	4	5
2. I want to make the most of my time	1	2	3	4	5
3. I have fears about physical disability	1	2	3	4	5
4. I am worried that my cancer will spread	1	2	3	4	5
5. I want to feel in control of my situation	1	2	3	4	5
6. I am worried that results of treatment are beyond my control	1	2	3	4	5
7. I am concerned about my loved ones because they are worried about my cancer	1	2	3	4	5
8. I am worried about how my loved ones will cope with my cancer	1	2	3	4	5
9. I want to talk with other patients who have advanced pancreatic cancer	1	2	3	4	5
10. I want to learn how to cope with my cancer	1	2	3	4	5

Pre-Retreat Patient Questions

How are you feeling physically?

What are your greatest worries?

On a given day, how much do you think about cancer?

How have you been coping with your cancer treatment?

What are your expectations of attending a retreat with other couples dealing with advanced cancer?

Post-Retreat Patient Questions

How are you feeling physically?

What are your greatest worries today?

Have you thought about your cancer experience in a different way since attending the retreat this weekend?

Please explain.

What, if any, new strategies for coping with cancer have you learned from this retreat experience?

Have your expectations of attending a retreat with other patients with advanced cancer been met? Please explain and/or provide examples.

Please provide any suggestions you may have for any future retreats (e.g., sessions, topics, activities, etc.).

voice and were able to express their frustrations, thoughts, concerns, and fears in a safe place. We have seen a trend in patients of feelings of less uncertainty about their future in post-retreat surveys as well as a trend toward having a feeling of wanting more control of the disease situation. For the caregivers, we noticed a trend toward having more fear about their partner's physical disability and the feeling of wanting to talk more with other partners after the retreat.

Through these surveys, we have also been able to learn which sessions within the retreat were felt to be the most valuable and well received, as well as which were not favored. Patients and caregivers of all groups listed the "Ask the Expert"

session as the most valued, followed by the nutrition session for patients and the advance directives session for caregivers.

Although these results are only from a few sessions with small sample sizes, and surveys have varied slightly over the years making data analysis difficult, they have given us insight for planning future retreats and what is most beneficial to patients and caregivers. Based on the success of past retreats for advanced/metastatic cancer, not only have couples expressed benefit from this experience, but speaker attendees have also expressed a benefit by being able to engage with patients and their caregivers in a more informal setting outside the hospital (Figure 2).

Table 3. Partner Pre- and Postretreat Survey

Please respond to the following statements by circling your answer.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I am uncertain about our future	1	2	3	4	5
2. I want to make the most of our time	1	2	3	4	5
3. I have fears about my partner's physical disability	1	2	3	4	5
4. I am worried that the cancer will spread	1	2	3	4	5
5. I want to feel in control of our situation	1	2	3	4	5
6. I am worried that results of treatment are beyond our control	1	2	3	4	5
7. I am concerned about my immediate family because they are worried about the cancer	1	2	3	4	5
8. I am worried about how my immediate family will cope with the cancer	1	2	3	4	5
9. I want to talk with other partners who are coping with advanced pancreatic cancer	1	2	3	4	5
10. I want to learn how to cope with the cancer	1	2	3	4	5

Pre-Retreat Partner Questions

How are you feeling physically?

What are your greatest worries?

On a given day, how much do you think about your partner's cancer?

How have you been coping with your partner's cancer treatment?

What are your expectations of attending a retreat with other couples with advanced cancer?

Post-Retreat Partner Questions

How are you feeling physically?

What are your greatest worries?

After this retreat, do you think differently about your partner's cancer?

What, if any, new strategies for coping with your partner's cancer treatment have you learned from this retreat experience?

Have your expectations of attending a retreat with other partners coping with advanced cancer been met? Please explain and/or provide examples.

Please provide any suggestions you may have for any future retreats (e.g., sessions, topics, activities, etc.).

We aim to continue to provide a safe environment for discussion and sharing that will enhance the connections among the group and within their families. By attending the retreat, facilitators can also get a better and more intimate sense of this patient population's needs to help direct their health-care team. Interest in these programs has been increasingly expressed among other providers within our institution as well as other institutions after viewing the prior retreat videos that were so eloquently put together and are available for viewing on our facility website (Johns Hopkins Medicine Colorectal Cancer Center, n.d.; Johns Hopkins Medicine Skip Viragh Center for Pancreas Cancer, n.d.).

CONCLUSION

We hope that others both within Johns Hopkins as well as other facilities can gain knowledge from these retreats and implement these programs to help even larger patient populations in an effort to better support all of our cancer survivor groups and their families in an intimate, safe, and individualized manner. Many of the participants have even remained in contact with each other and provided support for one another long after the conclusion of the retreat. We are aware that not all sessions may be sensitive or accepted for all populations or individuals, and therefore we continue to have both patient and partner evaluations of individual activities as well as the retreat as a whole



Figure 1. Retreat and conference center at Bon Secours, Marriottsville, Maryland. (A) Facility grounds, (B) labyrinth, (C) meeting space, and (D) private dining hall.

to allow us to better direct appropriate activities in the future.

We are hopeful that we can validate our current surveys to facilitate a more standard data collection process not only for ourselves but also for other centers that may adapt these retreats. Data is limited on retreats such as these, but lack of interest does not seem to be the limiting factor. There has not been any difficulty in securing speakers to volunteer their time. Although the planning process does take considerable effort and time, the reward of spending the weekend engaging with these couples and learning from them continues to motivate us to continue planning future retreats.

At times, there has been some difficulty in recruiting couples, but mostly as a result from last-minute cancellations due to patients' health at the time of the retreat weekend. Spreading the word on these retreats outside of our facility has also been challenging at times, and much of the recruitment of couples is through word of mouth internally at our institution. We would like to broaden the invitation and start extending to more outside facilities, potentially through the use of social media. Although the retreats can be time-consuming and costly, with appropriate support and funding, we are hopeful they will continue to grow. We will continue to gather enough feedback for future data to support the positive effect of these programs. ●



Figure 2. Pancreatic cancer couples' retreat closing photograph, including patients, caregivers, and staff (2013).

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