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Identification of Issues Faced by Cancer Survivors

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Introduction: Research describes that rates of perceived unmet needs among cancer survivors remain high over several years post treatment, and that survivors have a profound and ongoing desire for information about their cancer. The literature suggests that successful cancer survivor programs should include patients in the planning process, and that patient focus groups are an appropriate method to identify needs, as well as gaps in service.

Our goal was to identify needs of cancer survivors as well as gaps in services. We sought input on improving access to and participation in supportive activities designed for cancer survivors and their families.

Methods: 34 survivors, ranging in age from 32 to 69 years, with a variety of cancer diagnoses were recruited into a total of four focus groups. Breast cancer predominated (23/34). Participants were recruited from affiliated oncology practices and The Wellness Community. Four focus groups facilitated by a medical ethnographer, were audio-recorded and scribed. The Institute of Medicine film “From Cancer Patient to Cancer Survivor: Lost in Transition” was used as a discussion starter. Question topics included: reaction to the film; treatment summary/care plan; long term effects/supportive activities; and physician communication. Grounded theory methodology was used to identify themes across the groups and collated responses to the questionnaires.

Results: We found that respondents were reluctant to be followed by anyone other than the treating oncologist due to trust in the practitioner who knows them. No participants reported receiving a treatment summary or similar information. They also reported a desire to help other survivors and “give back”. Data is still being analyzed at the time of this abstract submission.

Conclusions: Survivorship providers must have credibility with the population in order to be trusted. Treatment summaries are not yet standard of care. Survivors can be utilized to assist with program planning and implementation.

Suggested Types of Support Groups

- “My type” of cancer
- Moms with cancer
- Survivors with similar belief systems
- Double mastectomies
- Under 40 survivors
- Significant others
- Children and Teens (whose family member has cancer)
- Navigating the future

Key Themes

TRUST is essential. Survivors trust their oncologists and are reluctant to entrust their care to anyone else. They need assurance that any other provider is knowledgeable, competent, and up to date, knows their case, and will communicate with their oncologist.

While the focus of our discussion was on post treatment survivorship, survivors “go back” to time of their diagnosis. It was difficult to “pull them back out” of that or redirect them.

Support groups are very important to survivors; they express a desire for groups specific to their experiences.

Treatment summaries and care plans are not the standard of care, although survivors believe they would be helpful.

Survivors express a desire to “give back” and help other survivors.

Treatment Summary/Care Plan

- After treatment is ended, you are turned out
- Didn’t have one, but would have liked one
- No information after treatment ended
- Written summary of treatment is helpful
- Standardized plan to follow would be helpful
- Communication regarding post treatment precautions among all providers

Survivor Clinic

- Concern with information—Will they have all of my information on file?
- Seems like a middle man—chance of miscommunication
- Adding another person you don’t know; just decreases money (more expense for the survivor)
- Not as a replacement of doctor
- Don’t want to lose relationship with oncologist
- May be okay after ten years out of treatment



Next Steps

- Survivor follow-up care pilot completed and clinic underway.
- Continue building collaborative relationship with local Cancer Support Community to assist with implementing activities identified by survivors.
- Explore opportunities for survivors to “give back” as part of survivorship programming.

Characteristics of Focus Group Participants

