



SUCCESS STORIES

Summit Quest Survivorship Resources

SUMMARY

The Northwest Georgia Regional Cancer Coalition conducted a focus group study to gather information from cancer survivors and their families in Northwest Georgia about their experiences and needs. The focus group study grew out of Georgia's recently-revised state cancer plan, which identifies improving the quality of life for cancer survivors as one of its priorities. The information gathered by the study was used to develop a resource list to be used throughout the community to help families and children affected by cancer and to assist the state in developing strategies to meet the needs that have been identified.

ACTION

The focus group sessions were held on September 12, 2013 and November 10, 2013. The adult focus group was comprised of 17 parents, caregivers, and volunteers who are either experiencing a cancer journey themselves or are involved in the care of a cancer patient. The child focused group was comprised of 22 children who are living with family members afflicted with a cancer. The research questions and content were developed in consultation with the Cancer Navigator's Survivor's Advisory Committee in order to assess the maximum impact Summit Quest and the NWGRCC could have on families in our region living with cancer. Summit Quest is a non-profit organization that reaches out to children of families dealing with cancer. The program provides outdoor activities, support groups, and basic care services for children and their loved ones as they face cancer together. Once the focus group sessions were completed, the information was analyzed and used to create a comprehensive resources list for cancer patients and survivors living in this area. The list was distributed throughout many non-profit organizations in our area so that at any entry point families could access the resources needed. The information gained from the focus groups has been shared with a healthcare providers and community groups throughout the region.

*Resource List Attached

CONCLUSIONS

- 1) Overwhelmingly, the participants felt like there were a variety of services offered in this area for patients/survivors but no one central place for accessing or learning about the services offered.
- 2) Participants felt like their practitioners were unclear about steps after treatment- or at least in communicating with the patients.
- 3) Participants want more time with providers during and after treatment- want to express concerns and receive feedback.
- 4) Participants expressed concern about being forgotten once treatment phase has ended.
- 5) Barriers identified: Knowledge and access, liability for volunteers.

178 families have been served by the resource list developed and the services provided as a result of referrals from local healthcare providers learning about the needs of cancer survivors and their families. Specifically 91 children have been supported through the efforts of Summit Quest. Work continues to educate regional providers about the needs of families affected by cancer but already we are seeing an increase in the number of direct referrals by healthcare providers .



SUCCESS STORIES

MyJourney Compass Tablet Project

SUMMARY

The Northwest Georgia Regional Cancer Coalition purchased, loaded, and distributed tablets to cancer patients in Bartow, Chattooga, Floyd, and Polk Counties in collaboration with the MyJourney Compass project. MyJourney Compass provides cancer patients with internet enabled tablet devices that integrate electronic health records, Georgia Direct Health Information Exchange, Microsoft Health Vault, and a combination of off the shelf and custom apps to provide a cancer survivorship tool to help patients manage their cancer journey. MyJourney Compass was designed to help patients organize and use health information technology in partnership with their healthcare providers. By utilizing secure DIRECT email messaging, they can share important health related information bi-directionally with physicians and care teams. MyJourney Compass allows patients focus on their cancer journey instead of the everyday hassles of managing their health care.

ACTION

The NWGRCC purchased, loaded, and distributed 52 tablets for cancer patients in the region. Each tablet was customized with education and resources unique to the patient's needs, including personalized contacts of healthcare providers and a unique Microsoft Health Vault account. The symptom tracker developed by the Rome cancer community was also installed on each tablet. A customized suite of applications was uploaded to each tablet for patient use. Patients are provided education on using the tablet and the resources. Patients are continually supported during the duration of their tablet use through one-on-one and group education.

CONCLUSIONS

MyJourney Compass is a collaboration between Floyd Medical Center, Harbin Clinic, Redmond Regional Medical Center, Cartersville Medical Center, the Northwest Georgia Regional Cancer Coalition, Cancer Navigators, Georgia Tech, and Cancer Patients. Healthcare providers in this community have been working together to create MyJourney Compass to enable patients to share their health records with whomever they like, whenever they like. The symptom tracker has allowed patients to share their daily symptom log with providers to ensure a faster, more responsive healthcare experience during their cancer journey. Patients report being more engaged and empowered by having access to all their records while visiting the variety of healthcare providers during their journey. Many have reported a sense of freedom in being able to travel with family without having to worry about access to records if needed—they have them at their fingertips! Patients have also expressed increased feelings of connection with other cancer survivors and spirituality through application use on the tablet.