Tailoring Websites to Survivors’ Needs: The INSPIRE Study

One of the biggest challenges for cancer survivors sounds like an odd one—too much information. With dozens of websites full of health tips, dietary plans, mental health warnings, and statistics, how does a long-term transplant survivor navigate the shoals of TMI? In the words of Dr. Jean Yi, co-author of the ongoing INSPIRE study, “There is a ton of stuff out there. We’re trying to give patients a road map,” a streamlined course custom designed for each individual patient, and that patient alone.

Enter the INSPIRE study, a multi-site clinical trial whose goal is to test whether personalized online content improves the health and well-being of transplant survivors. Many people reading this newsletter may have participated in this study. Participants first answer questions that evaluate their physical and mental health, exercise habits, energy levels, health care practices, and attitudes toward being a survivor.

The answers to these questions are used to create a customized website for each subject. The site features self-care tools, and links to online content specific to the needs of the survivor. There are also different modules for different challenges: mood, energy, heart health, stress reduction, strong bones, and secondary cancers.

There is an interactive component as well. Transplant survivors can choose to receive individualized texts and emails. They are invited to choose from a select list of motivating statements (or write their own). There are recommended apps to help with relaxation, exercise, and mood tracking, among other features. Survivors also have access to “Ask the Experts,” where they get answers to their questions from a panel of transplant and survivorship professionals.

An important part of the INSPIRE content is a personalized health action plan that gives specific guidelines on tests and exams that each survivor should be scheduling. This plan is designed to be taken to appointments, so that health care providers can utilize the information. In addition to all the online content, participants have the option to join a private Facebook page or Twitter account set up just for INSPIRE participants.

Those in the intervention group have full access to the website. If this were a medication trial, these are the subjects taking the new drug. The control group is given access to other existing websites with good information on healthy habits and attitudes for cancer survivors, but there are no customizations – no personalized content or text reminders, no social networking as part of their experience. However, they are not left out. After their last assessment at 12 months, people in the control group get full access to the INSPIRE site.

Participants answer online questionnaires to gauge levels of depression, emotional distress, and use of health care upon entry into the study, and again 3 and 12 months later. Similarities or differences within individual participants during this 12-month period will be analyzed once the study is over. While it may seem that the personalized website would be better for patients, it is more expensive and time consuming to create and maintain. Also, personalization may not be required or even appreciated by patients whose needs may change. That is the why the study is testing whether there is a benefit to having a website personalized just for transplant survivors.

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A secondary test of the website is its reach, or the spectrum of participants in the study. Other studies have highlighted the challenges in providing consistent internet access for people with lower incomes, those who live in rural areas, and minorities, as well as whether autologous and allogenic transplant survivors have the same needs for online resources. Cancer survivors under 40 are also less represented in most follow-up studies. The six study sites were chosen to engage a broader demographic by enrolling more people in underserved populations. There are future plans for a joint follow-up study with the Center for International Blood and Marrow Transplant Research (CIBMTR), a leading international research group, to broaden the reach even further.

The final analysis of the study is due out sometime in 2017. Once the results are out researchers will be contacting transplant survivors to see if they are interested in participating in the next phase of INSPIRE. Stay tuned to this newsletter for more details as they are available.

Dr. Yi’s background as a psychologist makes her an important part of this team. “Some patients want more info, some are struggling with all that is out there.” And some of what is out there is misinformation. She feels that the ultimate goal is to “help people live the best possible life after transplant.” What is sometimes seen as too much information may simply be the wrong content. A uniquely tailored website may slow the data stream down so that it can be used more effectively to aid in a healthy lifestyle.

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**HAIKUS**

*On the Chinese vase*

> flowers retain brightness
> --pouring out water

> --David McCroskey

*No sky*

> no earth – but still
> snowflakes fall

> --Hashin

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