

Creating Web-Based Patient Education – An Oncology Nurse’s Experience

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Do you like to learn new things? Do you wish you could read more about the treatments that your patients receive? Do you wish you had time to read about the clinical trial results that provide the evidence for recommending and establishing these treatments as standards of care? And do you want to know more about how these treatments compare to other treatments, and more about the potential side effects? Part of my day-to-day job responsibilities involves just that; reviewing new medical literature and staying current as to changing standards within oncology care (someone is paying me to learn!). What a change from the hospital environment!

I loved my job working in a hospital. I was the Oncology Clinical Nurse Specialist at Northwest Hospital for more years than I want to admit. Each day brought new challenges as healthcare changes never ceased through the 80's and 90's. I especially enjoyed working for oncology nurses at the bedside by providing education, or creating system or process changes. But even if things are good, we sometimes need a change and there came a time for me to make a job change.

What did I want to do? There are so many opportunities within our nursing profession. My first decision was that I didn't want to give up my involvement in oncology nursing, followed by the decision that I did want to try something outside of the hospital setting. With excitement and a little trepidation I left my safety zone, the community hospital, hoping I could successfully stretch in new ways as an oncology nurse. That decision was 5 years ago.

In the spring of 2000 I joined NexCura, Inc., a small company of 30 in

Seattle. My job title was clinical specialist, but this role had few similarities to my previous job. NexCura's mission is to provide web-based healthcare education and information to patients, caregivers, and providers, individually tailored to a patient's specific situation.

In the first 15 months I was at NexCura, 20 different web-based cancer treatment decision support applications were developed for use by patients, family members, and their physicians. I worked on a team that included myself and 4 other clinical specialists along with several non-healthcare professionals. My learning curve was straight up! The goal of these tools is to help patients make informed decisions about treatment options with the focus on optimal outcomes. Using a patient's responses to questions about their clinical profile, including personal diagnosis and test results, the software matches patients to peer-reviewed clinical research studies and generates relevant treatment options, side effects descriptions and questions patients can discuss with their healthcare providers.

The behind the scenes algorithms that generate the individualized reports are developed by the clinical staff in collaboration with a medical editorial board made up of physicians and health care specialists from around the country who are recognized experts and leaders in their respective medical specialties. This opportunity to meet and work with oncology physician leaders has been especially rewarding at the same time that it is challenging. So many issues in oncology are "gray", not black & white as our patients would like. The clinical team works with the board members to identify consensus on controversial treatment issues based on medical evidence in the literature and then incorporates that into the tool.

The clinical staff at NexCura also develops the questionnaires, and the

many other components of the tools including treatment descriptions, side effects, questions to ask the doctor and the glossary. Needless to say, my writing skills have improved! While the numbers of fulltime clinical specialists are now fewer, we have several oncology nurse consultants from the Puget Sound area working with us whose job is to review the literature for a specific cancer and update the tools in collaboration with myself and the medical editorial board. I enjoy staying in touch with my oncology nursing colleagues, and through them, the clinical arena through their part-time work with NexCura.

We continually receive feedback via email from the patients and families that use the NexProfiler Treatment Options tools asking for additional information and support that we do our best to provide. Their stories are no different than the cancer patients you may see and touch; we are just reaching out in a different way to provide that individual support that we know each patient needs. We are often encouraging patients to go back to their doctors and nurses with the questions they pose to us, and often arm them with additional questions. I am still surprised at the trust individuals place in asking an unknown someone very personal questions specific to their medical condition.

Today we know that the number of Americans who turn to the Internet seeking information about an illness continues to grow. In 1998 the number of individuals seeking information on the internet was reported to be 54 million. It has more than doubled since that time. One survey found that 24% of respondents felt the Internet had provided "crucial" or "important" information during their own major illness. Those numbers tell us that consumers need nurse educators to be involved; involved in the development of informa-

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