



Digital Oncology

Social networks for young patients with cancer: the time for system agility

In 1962, US physicist Thomas S Kuhn published *The Structure of Scientific Revolutions*, in which, in a pioneering view, he defined science as development by accumulation. Kuhn coined the term paradigm shift, which represents interruption of theoretical continuity in ordinary science by revolutionary science. Social digital media has become a game changer in the field of medicine, and even more in cancer care. It provides caregivers a mirror and a resource to study this patient population. Teenagers and young adult patients use digital media to maintain relationships with patients they meet through their cancer treatment, and some report that they established new and deeper connection with peers they met via this medium. Digital media can substitute long trips to cancer centres for peer and professional psychosocial interface. It has been shown that patients and their families stated this preference mainly for the possibility to maintain anonymity, constant availability of services, and convenience. The loose, non-formal nature of this peer support might feel less stigmatising and closer to what they consider as normal life. Young patients advocate and have a central role in the holistic decision making regarding their disease and treatment; therefore, social media can have a reciprocal approach of patient-caregiver interaction. Social networks can be a powerful tool for oncologists to learn from their patients about what truly matters to them. At the challenging point of transitioning to survivorship, social digital media can be a platform to buffer this transition.

A deeper view into the content of social digital media platforms revealed that they represent a broad stage for a multiperspective dialogue, beginning with discussion regarding social rights (as benefit or welfare payments), sharing clinical information on side-effects of treatments, and personal experience and questions, to a mentoring board of survivors who adopt newly diagnosed patients to support them through the new challenge of cancer treatment, unique initiatives such as web-based, back-to-work workshops, and even online dating engines for cancer survivors. Two leading platforms in terms of user numbers are the US Stupid Cancer, one of the largest web-based social media platforms, and the Israeli Stop Cancer, with more than 20 000 registered members of the 30 000 patients in this age group (20–45 years) in the country.

We used Stop Cancer as tool to further study trends in behaviour of young adults with cancer. We distributed a web-based survey via Stop Cancer for 5 days to characterise the user profile. 519 patients or survivors participated. The majority of participants had a non-metastatic disease (378 [73%] of 519). The most common diagnoses were

breast cancer (159 [31%] of 519), lymphoma (125 [24%]), leukaemia (52 [10%]), and colorectal cancer (42 [8%]). Most users (405 [75%] of 519) reported that they considered the platform for both medical and social resources, with a preference for tools that facilitate emotional coping of patients and their families. Notably, there was no difference in the nature of the results between participants with active disease compared with survivors, suggesting that transition into survivorship might be even more challenging that it appears to be. The majority of participants (323 [62%] of 519) had higher education and reported more satisfaction with the platform. Most patients stated that they would recommend other people to use the platform (487 [94%]).

The medical system should confront this paradigm shift and embrace the agility that is needed for the scientific community to be on the same page as the patients. We should strive to use the high potential of digital media tools to reach young adults with cancer and to bring the human dimension of this unique age group. Digital media represents an appealing tool for globalisation and facilitation of knowledge to the unique population of young patients with cancer. Exploiting the evolving digital platform as a high-potential tool to reach and understand young patients with cancer and to deliver adequate information is highly relevant. Young patients with cancer today will be the pioneers who will pave the way for widescale implementation of high-tech means into the health-care system. The challenge is for the scientific community, especially health-care providers, to gain the agility to harness these digital platforms to understand the needs of young patients with cancer.

Irit Ben-Aharon, Tal Goshen-Lago, Elisa Fontana, Elizabeth Smyth, Marianne Guren, Carmela Caballero, Florian Lordick

This online publication has been corrected. The corrected version first appeared at [thelancet.com/oncology](https://www.thelancet.com/oncology) on July 1, 2019.

European Organisation for Treatment and Research of Cancer, Gastrointestinal Tract Cancer Group, Brussels, Belgium (IB-A, EF, ES, MG, FL); Division of Oncology, Rambam Health Care Center, Haifa 3109601, Israel (IB-A, TG-L); Technion Integrated Cancer Center, Rappaport Faculty of Medicine, Technion-Israel Institute of Technology, Haifa 3109601, Israel (IB-A); The Institute of Cancer Research and The Royal Marsden Hospital, London, UK (EF); Department of Medical Oncology, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK (ES); Department of Oncology, Oslo University Hospital, Oslo, Norway (MG); Breast International Group, Brussels, Belgium (CC); and University Cancer Center Leipzig and University Medicine Leipzig, Leipzig, Germany (FL)
I.Benaharon@rambam.health.gov.il

We declare no competing interests

For more on **teenage and young adults with cancer experiences with digital media** see *J Clin Oncol* 2012; **30**: 1221–26 and *J Cancer Surviv* 2017; **11**: 670–82

For more on **social media for symptom monitoring during cancer treatment** see *JAMA* 2017; **318**: 197–98

For more on **Stupid Cancer** see <https://stupidcancer.org/> and for **Stop Cancer** see <https://www.stop-cancer.co.il/>

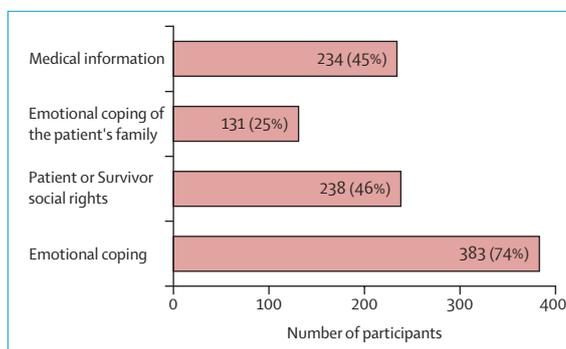


Figure: Motivations to use social network platforms among Stop Cancer users