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Patient Transformers

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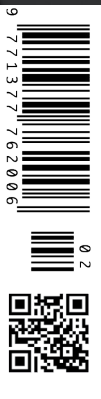
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The Transformative Power of the Patient Voice

◆ Author: [Fabian Bolin](#) | Keynote speaker | Co-founder of WarOnCancer | Stockholm | Sweden

How to amplify the voice of cancer patients worldwide in order to accelerate comprehensive care and improve the mental health of everyone affected by cancer.



Key Points

- The active patient is a novelty and the underlying assumption is that the patient will remain passive during their treatment.
- The War On Cancer app is a social cancer support tool for people in and after treatment, and their loved ones.
- The War On Cancer app aims to improve the mental health of those affected by cancer by developing a product that places the wellbeing of its members in focus, always.
- Healthcare has failed to recognise or sufficiently address the mental health effects that cancer creates.
- The healthcare sector will have to transform from a production-oriented approach to a service-oriented type of business, where customer happiness becomes the goal.

The Origins of Our Understanding of Cancer Patients

For many, the word “patient” conjures up a vision of quiet suffering, of someone lying patiently in a bed waiting for the doctor to come by and execute their expertise. There is an unequal relationship between the user of healthcare services and the provider. The user is described simply as suffering, while the healthcare professional has a title, be it nurse, doctor, physiotherapist, or phlebotomist.

Patient comes from the Latin word “patiens,” from “patior,” meaning to suffer or to bear. The patient, in this language, is truly passive—bearing whatever suffering is necessary and tolerating patiently the interventions of the outside expert.

Therefore, the active patient is an obvious contradiction in terms, and it is this underlying assumption of passivity that becomes most dangerous because the user of healthcare services takes a backseat in treatment and care that drastically impacts their health and wellbeing. The healthcare professional assumes full control and the patient abides, doing what s/he is told, and then patiently waits to recover. The healthcare professional is the healer, while the recipient of healthcare services is the healed who takes little or no part in any decision and cannot actively take part in weighing alternative options. This kind of uninvolved approach on behalf of the patient leads to feeling out of

control of their own health and wellbeing. It’s already proven that a cancer diagnosis affects mental health – feeling out of control and uninvolved in critical decisions exacerbate their mental health and wellbeing.

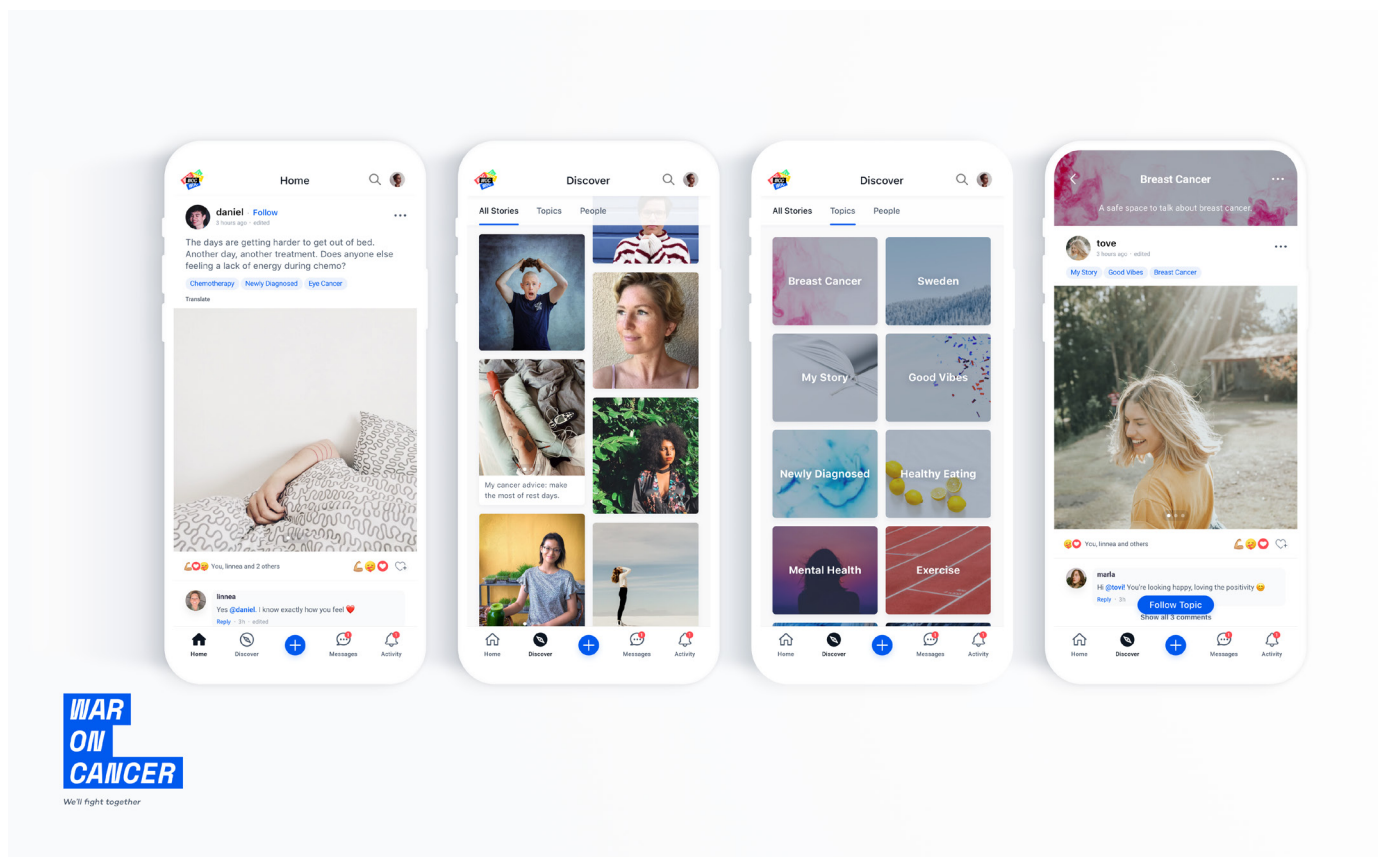
I can’t speak for all patients, but, as someone who has gone through cancer and am currently in remission following more than 900 days of chemotherapy for acute lymphoblastic leukaemia (ALL), an aggressive form of blood cancer, I refuse that this is the best option for patients.

After being diagnosed in 2015, at 28 years of age, I began documenting my cancer battle on a blog, which made me realise the true power of storytelling and how sharing my story helped me cope with my ‘cancer trauma’ and what it meant to be a patient in today’s healthcare system. Sharing my story helped me process what I was going through, emotionally and psychologically, but also gave me a sense of purpose that I had never felt before.

This, together with a strong urge to help others affected by cancer, became the foundation for the [War On Cancer](#) app – a digital support tool and network for people in and after treatment, and their loved ones.

The Correlation Between Mental Health and Cancer

Before we go into the way in which the War On Cancer app improves the mental health of everyone affected



by cancer, it's important to understand the way in which cancer affects mental health. To start with, each individual's mental health journey during cancer is, on some level, unique and there is no one-size-fits-all description or prescription. However, one experience that everyone affected by cancer can relate to is the experience of loss. Loss of career, or identity, the ability to have kids, financial stability, self-worth, or simply loss of control. Combine loss with periodically extreme levels of stress and you have a dangerous combination which will inevitably take a toll on your mental health.

From consulting research and experts such as psychologists and counsellors within this field, it's clear that cancer can inflict trauma on someone going through cancer, which subsequently can result in either PTSD (post-traumatic stress disorder) and/or clinical depression.

Studies have varied in the assessment of patients for the full syndrome of PTSD (i.e., all DSM criteria met) or only some of the PTSD-related symptoms. Because of this, incidence rates vary accordingly. Yet, research shows that the incidence of the full syndrome of PTSD ranges from 3% to 4% in patients recently diagnosed with early-stage disease to [35% in patients](#) evaluated after treatment. When the incidence of PTSD-like symptoms (not meeting all diagnostic criteria) are measured, rates are higher, ranging from 20% in patients with early-stage cancer to 80% in those with recurrent cancer.

Clinical depression affects approximately [15% to 25%](#) of cancer patients, and is believed to affect men and women with cancer equally. Individuals and families who face a diagnosis of cancer will experience varying levels of stress and emotional upset. Depression in people with cancer doesn't "only" affect the person going through cancer, but also has a major negative impact on their families.

So, depending on the overlap (which is yet to be determined), it's pretty safe to say that most people who experience cancer are in need of mental health support.

Leveraging Technology to Improve Mental Health and Amplify the Patient's Experience

As a person who's experienced cancer and a patient in the healthcare system, I was made acutely aware of the need for mental health support that isn't currently adequately addressed or fulfilled by healthcare. That was the idea that founded the War On Cancer app, and today, we aim to radically improve the mental health of those affected by cancer by developing a product that places the whole wellbeing of its members in focus, always. The functionality of the app is directly connected to trauma-coping mechanisms such as journaling, connecting with others who can relate, and finding answers to important, day-to-day questions from people who know what it means to go through cancer, and are currently not addressed by

medical staff. What makes War On Cancer unique is that we're not only creating a web of support for everyone affected by cancer, but amplifying their voices through "Health Studies" – a function in the War On Cancer app that allows members to provide insights about their experience with cancer through targeted surveys that contribute directly to cancer research. These insights, such as quality of life assessments or perceived quality of care, have the potential to improve healthcare across the globe and truly leverage the voice of the patient in cancer research.

How do Health Studies improve the wellbeing of members on the War On Cancer app? It turns out, [helping others](#) is an effective coping mechanism for trauma, PTSD and depression. By making it easy to directly contribute to cancer research, War On Cancer members are empowered to leverage their experience to improve the wellbeing of future cancer patients, but are also in control of what studies they wish to partake in. For every study conducted in the app, the member understands 1) which institution is behind the study and 2) the purpose of the study. Through personal storytelling and direct contribution to research all in one place, members of the app are empowered to help others and impact the future of cancer, which helps them feel a larger sense of belonging and purpose during and after their struggle with cancer.

Healthcare's Narrow Approach to the Wellbeing of Cancer Patients

The problem healthcare currently faces is the failure to recognise or sufficiently address the mental health effects that cancer creates. Most oncology departments focus solely on the main goal – survival. This is, naturally, top priority, especially since not long ago, cancer was a virtual death sentence and surviving was a miracle. But, thanks to the advancements in cancer research, [two out of three](#) survive cancer today. Tomorrow, it's going to be three out of four, and at some point in a not too distant future, survival will be the norm, though many may have to medicate for the rest of their lives. Cancer will become more of a chronic disease than a deadly one.

What does this mean for the healthcare institutions? Patients, for lack of a better word, will increasingly demand a comprehensive approach to treatment, rather than focusing solely on survival. Their physical and mental needs, which varies from patient to patient, need to be addressed and prioritised. Thus, the healthcare sector must transform their production-oriented approach, where maximum survival is the only measure of success, to a service-oriented type of service, where customer happiness becomes the goal. In the world of healthcare, this means delivering on patients' expectations and perceived quality of care.

Understanding and Accelerating a More Informed, Healthier Future

In order to achieve this, we need to comprehensively look at the way we perceive healthcare and challenge the role it plays in the larger ecosystem of society.

Firstly, there needs to be a better understanding of, and develop, a definition of health, and determine what hospitals and other healthcare institutions' role is in delivering on the needs and health of its citizens. If we decide to keep the understanding of health focused on only physical health, such as survival and the ability to function, people struck by cancer will continue to struggle with mental health during and after cancer treatment. This will have a major impact on their quality of life, financial situation, family wellbeing, and more. Considering global cancer rates are expected to hit [22 million](#) new cases per year by 2030, if these people's mental health and wellbeing needs are not adequately addressed, this negative impact will shake the very fabric of society at large.

However, if we broaden our definition of health to include the whole person's health, we can significantly improve the mental health and quality of life of everyone affected by cancer. By incorporating support from psychologists, career advisors, personal trainers, spiritual leaders, financial advisors, relationship experts, physiotherapists, and encourage personal growth and self-actualisation into healthcare, we effectively listen to and deliver on the individual needs of those affected by cancer, during and after treatment. This is what many people, to some extent or another, need, and, it's clear that in most cases, hospitals are not currently equipped to provide this kind of comprehensive care.

Adopting this whole-being approach to health demands a shift in mindset from measuring success only by means of survival and physical needs, to guiding the patient through their entire health journey, customised around the individual. One of the biggest challenges to assessing patient needs is the lack of digitisation within the healthcare sector, as well as information overload. Physicians today are stretched to their limits in regards to administration, data processing, and research development. Currently, it is a real challenge for physicians to process and deliver on the multifaceted needs and insights of patients. Leveraging technology to change the way in which healthcare tackles the quality of life of cancer patients is essential to accelerate and effectivise a comprehensive approach to the health and wellbeing of those affected by cancer.

We also need to take a good, hard look at Patient Reported Outcome Measures (PROMs). Research suggests that collecting PROMs lead to better care delivery and increased mental health for patients. To

accelerate the adoption process, we should implement a system where PROM data is used to compare and reward hospital performance. This would be an effective driver in improving patient satisfaction, an obvious goal for healthcare, now and in the future.

This is where the War On Cancer app comes in. Our aim with War On Cancer is to amplify the voice of patients and collaborate with healthcare institutions to better understand and address patient needs. By leveraging technology, War On Cancer is building a platform where people can connect and share their experience with cancer, and at the same time make it easy for them to contribute to cancer research and improve healthcare through in-app surveys. On the flip side of that coin, we help researchers access and connect with thousands of real-world patients all in one place, in order to draw more informed conclusions and transform care to become more individualised and patient-centric. By building that bridge, we hope to connect and contribute critical data

and accelerate the understanding of what needs to be done to improve the overall quality of life of patients during and after cancer treatment.

In the same way that there is no single pill that can cure every disease, there is not one doctor, one hospital, one pharmaceutical company, or one research team that can deliver perfect, comprehensive care to every person going through cancer, to help them achieve a higher quality of life. This is only possible by boosting collaborating between all stakeholders, and we at War On Cancer are ready to do so.

By combining real-world patient big data insights and incorporating them in order to bring about a more comprehensive approach to the healthcare ecosystem, it is possible to transform the world for the better for everyone affected by cancer.

Conflict of Interest

None. ■



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