News and Perspectives

CancerPEP: Harnessing the Power of Knowledge and Connection in Cancer Survivorship Care

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Abstract

Lifestyle modifications and social connection make a difference in cancer outcomes, but many people with a cancer diagnosis don't have access to support. In this *News and Perspectives* article, JMIR Correspondent Candice Marie Sage reports on the Cancer Patient Empowerment Program, a low-cost intervention designed to guide patients through health-promoting behaviors.

Key Takeaways:

- Healthy lifestyle changes after cancer diagnosis can help reduce the risk of recurrence, but not all patients have access to the information and support needed to make these changes.
- CancerPEP, an online patient empowerment program, provides patients with cancer with community and accessible guidance to help build physical and emotional health and resilience through home-based health-promoting activities.

A cancer diagnosis often brings anxiety and fear about what lies ahead. The process often involves a lot of waiting, worrying, and wondering. Perhaps unsurprisingly, people facing a cancer diagnosis often experience significant distress, including symptoms of anxiety, depression, or adjustment disorder.

One online initiative, the Cancer Patient Empowerment Program (CancerPEP), helps participants move from feeling overwhelmed and powerless to taking practical steps that can support their health. It focuses on elements that people can control, like diet and exercise—which have been associated with reduced recurrence risk and/or lower mortality—to better their recovery and overall health. The program was developed by two experts from Nova Scotia, Canada, in different but complementary fields: Robert Rutledge, MD, FRCPC, a radiation oncologist, and Gabriela Ilie, PhD, a psychology professor-scientist. The approach is distinct and holistic: it gives people a meaningful role in their own care, alongside any cancer treatments they choose to receive.

I spoke with Lesley Hartman, MSc, a registered psychologist who has been providing clinical services in Nova Scotia since 1995. A cancer survivor herself, Hartman has been through two cancer journeys in the past year—first breast cancer, then endometrial cancer. When Rutledge, her radiation oncologist, offered the program to her, Lesley felt "immensely cared about and supported."

CancerPEP: Practical, Patient-Focused, Patient-Informed

CancerPEP provides tools and an online peer community. Over 26 weeks, participants receive a daily email and a short PEP video. They can access online videos on aerobic exercise and strength training, nutrition and cooking, relaxation and stress reduction, and ways to strengthen relationships. An online community meets monthly through videoconferences and a Facebook group for those interested. Daily, weekly, and monthly activities provide structure through check-ins, group sessions, individual conversations, and a buddy system. Interventions are designed to build physical and emotional resilience, encouraging home-based health-promoting activities.

The CancerPEP website describes the program as "the story of love and resilience, of personal empowerment, and translational science." The voices of patients, caregivers, families, and clinicians informed the research and development of the program, which sought to address the distress—and sometimes loneliness and despair—of people impacted by a cancer diagnosis.

In a documentary about the cancer journeys of individuals enrolled in the program, Rutledge notes that the research was designed to "bring the voice of the patient back into the medical system." He highlights the importance of incorporating patient consultations, how he "learned more about the effects of cancer in a person's life in these two hours than [he] did in all of medical school." He reveals that "the secret sauce" of the program is "human to human connection."

CancerPEP's Impact

The Prostate Cancer-Patient Empowerment Program (PC-PEP) clinical trial demonstrated that patients who engaged in 6 months of the program experienced significantly lower distress. The timing also mattered: those who participated in the program earlier after diagnosis reported less distress at the 1-year mark than patients who participated later. An earlier qualitative study of a 28-day version of the program found that, while some participants found the time commitment

demanding and challenges to work obligations were reported, overall, patients deemed the program "extremely useful" and endorsed integrating it into standard care from the very beginning of diagnosis.

While not actively part of the CancerPEP currently, Hartman has dipped her toes in by viewing several of the videos and says that she "is really impressed." She was "initially excited to join, but it was early in [her] recovery and [she felt that she] was too overwhelmed to benefit from it"—suggesting that, for providers, there may be more or less optimal moments to recommend the program for some patients. She was also in a fortunate position before being made aware of CancerPEP, with the means to seek support from health providers outside the public system.

Many survivors are not able to access such services. "The CancerPEP provides access to important information, typically only available to people with the means and awareness to seek it, on what cancer survivors can do to improve survival outcomes," Hartman explains. "They translate empirical research and good psychological principles into concrete, practical recommendations around diet, psychological well-being, stress management, and exercise."

Having access to this information is critical, she feels. "People deserve to know what the research says, especially since lifestyle changes can in some cases be just as or even more preventive of recurrence than standard treatments," she says. "For instance, adherence to a healthy diet after diagnosis is associated with a 22% lower all-cause mortality rate." The program debunks persistent myths—such as a link between soy and breast cancer—and distills years of research into an accessible format for survivors, Hartman says.

In doing so, CancerPEP overcomes an important limitation of traditional care. In her experience as a patient, Hartman says, physician specialists are often seen by patients as the gatekeepers to research findings and knowledge dissemination. Because they may be siloed in their particular area of expertise, they may not always be aware of the entire body of research on lifestyle changes to reduce cancer recurrence and improve recovery.

The PEP also provides a sense of community. Hartman notes that contact with others going through similar experiences creates an environment where people "can talk about procedures that may be coming up and get input for their decision-making. It provides an existential reference point."

Expansion and Access

Across locations, CancerPEP creates safe and caring communities where participants can encourage and support one another. The program has grown to include centers across Canada and in New Zealand. It has also been translated for use in Belgium, the Netherlands, the United Kingdom, Ireland, Australia, and Romania. Starting with prostate cancer, the program now covers many cancers, including breast, colorectal, lung, bladder, kidney, endometrial, and chronic myelogenous leukemia.

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>
> Lesley Hartman, MSc

The previous Prostate CancerPEP clinical trial is now closed, but further research is underway, and the program is available commercially. According to its website, people can enroll for the 6-month program for a 1-time fee of CAD $210 or CAD $35 per month. People who have completed the program can continue to subscribe at CAD $10 per month. Hartman emphasizes that "this inexpensive program can save costs to the health care system by reducing recurrence. It is a cheap intervention that can save lives. Public health systems should invest in this intervention for their citizenry. The program should be offered across health regions in Canada and remain publicly funded, free, and accessible."

Hartman hopes all oncology physician specialists and nurses will be made aware of the CancerPEP so they can inform their patients about it. After cancer recovery, when Hartman is ready to resume her psychotherapy practice, she intends to refer patients with cancer and survivors to the CancerPEP.

While further research is needed to determine its impact on health-related outcomes for patients, based on Hartman's experience and the existing research, CancerPEP seems to be an incredibly useful tool for patients, and integration into the standard of care from diagnosis may be warranted.

Keywords: cancer; digital intervention; health promotion; patient empowerment; cancer survivorship

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