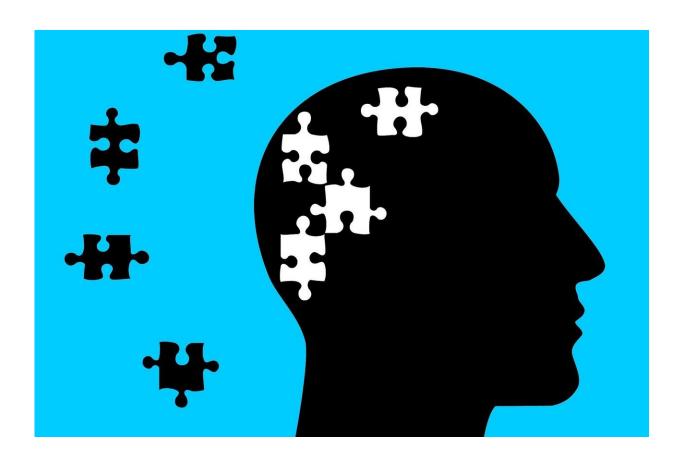


Research examines living well while dying

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A UBC professor has determined that people diagnosed with terminal cancer—who have hope, positivity and family support—are able to live well during the advanced stage of the disease.

Carole Robinson, professor emeritus with UBC Okanagan School of



Nursing, recently published a paper explaining the process of living well with an awareness of dying.

"While there is a growing body of research focused on select aspects of people's experiences with advanced cancer, there is little research examining the process of living with advanced cancer across the trajectory towards death," says Robinson. "Even patients whose prognosis is limited are living longer and want to live well, making this issue a global concern."

Robinson notes that globally there are 14.1 million new cancer cases diagnosed each year, 8.2 million cancer deaths, and 32.6 million people living with cancer. Historically, researchers have studied the concept of living well with a <u>chronic illness</u>, but not specifically cancer. Robinson says those studies convey the idea it may be possible to live well with advanced cancer, but little is known about how it is done or how to support it.

The study analyzed 22 interviews with Spanish residents involved in previous research that explored their experience of living with advanced cancer. The researchers found the <u>participants</u> engaged in a five-phase iterative process: struggling, accepting, living with advanced cancer, sharing the <u>illness</u> experience and reconstructing life. This process revolved around participants' awareness of dying, which differed from people living with chronic illness and was a unique aspect of this newresearch.

Each phase was revisited, and as the disease advanced living well got more challenging. Participants talked about strategies for living with advanced cancer, including making life adjustments, maintaining a positive attitude, normalizing and hoping.

Over time, participants realized struggling against the disease created



additional difficulties. In fact, they understood it was counterproductive so they made a conscious choice to let go of struggling. Some referred to it as being the only choice they could make while living with the uncertainty of advanced cancer. This enabled accepting their life circumstances at some level and learning to live alongside their illness.

Robinson says that the importance of family love and support cannot be underestimated. For all the participants, she adds, awareness of dying led them to focus on living well. Sharing the experience with loved ones softened suffering remarkably. They were aware they did not have time to lose.

"Although it might happen in moments, participants were able to put advanced cancer behind them and live life rather than living their illness," she notes. "Living in the moment enabled deep appreciation of everyday things such as the beauty of a flower garden."

Robinson says the key takeaways to living well encompass a balance between dependence and independence, being able to see the positive and maintaining hope even in the end stages of the disease.

"The participants in this study worked hard to live a life rather than live an illness," says Robinson. "The implication here is to support the positive. It has been found in previous research that hoping for a cure when <u>cancer</u> is advanced is not lack of awareness—it can be a choice in focusing simply on positive possibilities."

More information: Maria Arantzamendi et al, People With Advanced Cancer: The Process of Living Well With Awareness of Dying, *Qualitative Health Research* (2018). DOI: 10.1177/1049732318816298



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