

Author's declarative title: Living a life, not an illness: the process of living well with advanced cancer.

Commentary on: ¹Arantzamendi, M., Garcia-Rueda, N., Carvajal, A., Robinson, C.A. People With Advanced Cancer: The Process of Living Well With Awareness of Dying. *Qualitative Health Research* 2018. <https://doi.org/10.1177/1049732318816298>

Implications for practice and research

- The process of living well with advanced cancer revolves around an 'Awareness of Dying'. This leads to a focus on living a life rather than living an illness.
- To support development of the theory, future research should explore its applicability in both a family perspective and different cultural contexts.

Context

Little is known about the process of living well with advanced cancer or how to support it. The study addresses this by collating the experiences of people living with advanced cancer and comparing them with the 'Theory of Living Well with Chronic Illness'². The authors were familiar with the original theory and posed two questions: what is the process of living with advanced cancer and how might the theory be relevant given that this can be a prolonged and therefore chronic illness? The study also explores the perspective of the ill person as opposed to families in the original theory. Augmenting the understanding behind the process of living with advanced cancer may inform the support that patients can be given.

Methods

The study is a secondary analysis of qualitative data that explored the lived experiences of having advanced cancer³. Primary data were collected by interview with 22 adults who had been living with advanced cancer for at least three months. A vignette of each participant's characteristics and story was also provided. The data was then re-analysed with a new focus: what is the *process* of living with advanced cancer? Using the method of constant comparison coding, transcripts were coded to identify what happens in the process of living with advanced cancer and whether these codes fit the 'theory of living well', or if not, what is different about them. New core categories of the theory were subsequently identified that explained the process. Finally, the refined theory was confirmed by researchers from the primary study.

Findings

The study identified a new theory of living well with advanced cancer that describes a five-phase iterative process. The five phases are *struggling* (initiated with diagnosis and the possibility of dying), *accepting* (agreeing to the presence of advanced cancer to move forward with living), *living with advanced cancer* (focusing on what matters with limited time), *sharing the illness experience* (being supported yet protecting others from unnecessary suffering) and *reconstructing life* (to live a useful life not defined by illness). The process revolved around a core concept: awareness of dying (moving from the possibility of dying to the acceptance of dying).

Commentary

Previous research has explored people's experiences of living with advanced cancer such as what it means to cope well⁴. It was evident to the study authors however that the process of living with advanced cancer required further explanation. Using 'The Theory of Living Well with a Chronic Illness' helped to explain this process and added a new context to previous research findings.

The new theory of living well with advanced cancer identified an additional core concept: awareness of dying. This centred on the meaning participants gave to being sick with advanced cancer and an awareness that time was uncertain and limited. Consequently, this influenced the process of living such as letting go of 'struggling' as it was getting in the way of accepting the illness and living well with advanced cancer.

Within the period between living and dying, the ability to sustain and negotiate the tension between engagement with the world and preparing for death has been referred to as 'double awareness'⁵. The study authors found that 'double awareness' was also relevant to participants in their study and as a result, awareness of dying varied over time. Participants often returned to phases from which they had previously moved on from, e.g. struggling. This was especially true when challenging events happened such as treatment failure or difficult illness problems.

In this study, participants shifted their awareness of dying from it being a possibility to accepting the possibility of dying and subsequently 'I am dying'. The primary focus of participants however was to remain engaged with living. The authors therefore conclude that 'awareness of dying underpinned moving on toward living a life rather than living an illness'.

References

¹Arantzamendi M, et al. People With Advanced Cancer: The Process of Living Well With Awareness of Dying. *Qualitative Health Research* 2018. <https://doi.org/10.1177/1049732318816298>

²Robinson, C. A. Families living well with chronic illness: The healing process of moving on. *Qualitative Health Research* 2017;**27**:447-461.

³Garcia-Rueda, N. La experiencia de vivir con cáncer en fase avanzada: Una aproximación desde la fenomenología de la práctica. Spain:Universidad de Navarra; 2017

⁴Walshe C, et al. Coping well with advanced cancer: A serial qualitative interview study with patients and family carers. *PLoS ONE* 2017;**12**:Article e0169071.

⁵Colosimo K, et al. "Double awareness" in psychotherapy for patients living with advanced cancer. *Journal of Psychotherapy Integration* 2018;**28**:125-140.

Authors' Details:

Joanna Harrison

University of Central Lancashire – Faculty of Health and Wellbeing

Brook Building 425, UCLan, Preston, PR1 2HE

United Kingdom of Great Britain and Northern Ireland

T: 01772 895403

Email: jharrison12@uclan.ac.uk

Joan Devereux

Lancashire Teaching Hospitals NHS Foundation Trust -Palliative Care Department

Royal Preston Hospital, Sharoe Green Lane North, Fulwood, Preston, PR2 9HT

United Kingdom of Great Britain and Northern Ireland

T: 01772522055

Email: Joan.devereux@lthtr.nhs.uk

Acknowledgements

This commentary is supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care North West Coast (CLAHRC NWC). The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

Competing Interests:

None.