

# Cancer Caregivers' Needs for Their Well-Being in Information Era

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- Dr Koo Ah-Choo is an Associate Professor at the *Faculty of Creative Multimedia (FCM), Multimedia University (MMU)*. Dr Koo received her B.Sc (Hons) from the *Technology University of Malaysia* and her PhD from *Multimedia University*. She is active in the research of media usage, interactive multimedia, creation and methods especially in the promotion of education, communication, collaboration and life-long learning.
- She was appointed as the deputy director of *MMU Digital Cities Research Institute* (2018-2019), Deputy Dean (2010 - 2013) for FCM and Dean (2014-2016) for the *Learning Institute for Empowerment*. Dr Koo is an alumna of the *International Deans' Course (IDC 2014 / 2015)*. She is a senate representative to Senate Committee of her university for the cluster of *Creative Multimedia and Cinematic Arts*. She is a *Tzu Chi Foundation* volunteer for charity and recycling at her local community.

# Research Interest and Workgroup

- **Research Interest:** Interactive multimedia, media contents & usage; creation & methods especially in the promotion of education, communication, collaboration and life-long learning.
- **Workgroup:** Currently she is the Chairperson for the Research Centre for Interactive Multimedia in the Faculty of Creative Multimedia (url: creative.mmu.edu.my) and the lead for the Research Programme of Green and Wellness at her university (www.mmu.edu.my). Dr Koo is keen to facilitate / work with any collaborative group under the research area(s) of Interactive Multimedia and Creative Multimedia.
- She published her research in the *Journal of Educational Technology and Society*, *International Journal of E-Health and Medical Communications*, *The Turkish Online Journal of Educational Technology*, and *Int. J. Innovation and Learning*.
- She is currently the project leader for a *Fundamental Research Grant Scheme* (FRGS) by the *Ministry of Higher Education*, entitled, “*eHealth Modality for Mental Wellness among Digital Talents*”. She also led research and creative projects funded by various agencies:- 1) *Affective Roles of Ubiquitous Learning in a 'Patient Centred Health Care Model'* for Malaysian Hospitals; 2) ProbMobile: An interactive mobile learning framework for Probability; 3) UNHCR’s Health Media Production project; 4) Members of many other research projects.
- Her CV: <https://mmuexpert.mmu.edu.my/ackoo>

*Position of the current research:*

## >> Background & Issue

- Caregivers face with competing sources (“infodemic”) => to identify accurate / trustworthy resources; required Internet and Information Literacy.
  - >> Mis- and disinformation can be harmful to people’s physical and mental health;
  - >> mHealth/eHealth services and applications are able to offer opportunities on health / cancer education
- Increasing cases of cancer rate; challenges of caregiving (Being informal caregivers)
- Caregivers - “someone who performs hands-on care and / or provides emotional support to patients, such as a partner, relative or friend”; caregivers can be partners and family caregivers, who are mostly informal
- Literature was conducted on the aspects of dealing with cancer, information access on caregiving and cancer caregivers’ need, one aspect of needs is Learning Needs too.

## >>Purpose

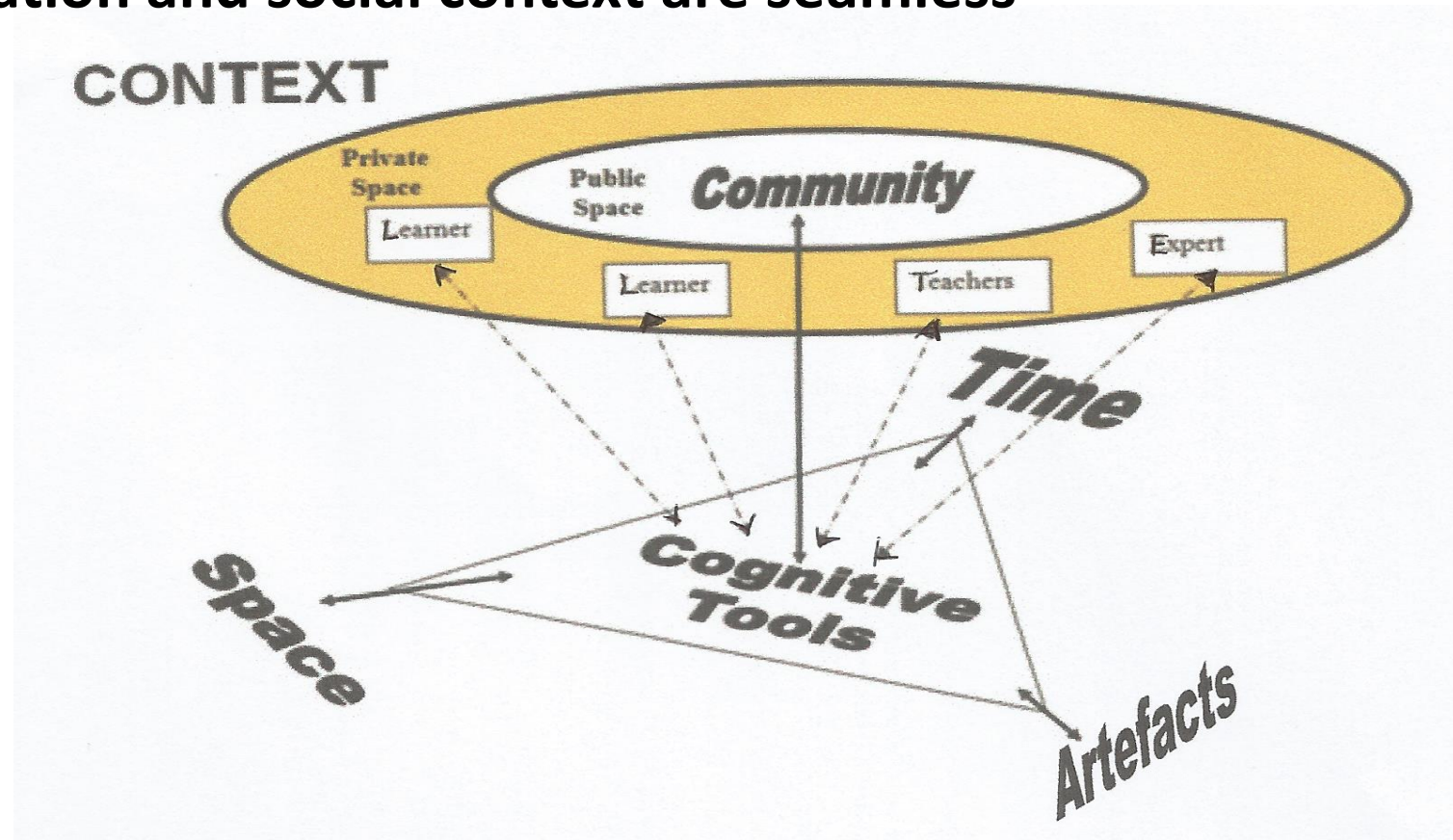
The study explored the four + one dimensions (of needs) faced by cancer caregivers, namely:

1. Healthcare service
2. Psychological & emotional
3. Work & social
4. Information + 5. Learning need

Girgis et al. (2011) suggested the four dimensions.

## Why Learning as another dimension?

>> Information and social context are seamless



A Seamless Learning Framework (Looi, et al. 2010.)



## >>Methods

- A survey was conducted at two private cancer clinics in a hospital; with support from an NGO.
- Number of survey respondents: 84 informal caregivers; mostly Malaysian Chinese.
- Instrument –adapted from Girgis et al. (2011).
- Factor analysis is employed in analyze the data with two main stages of analysis
  - Stage 1: Extracting factors      →      Stage 2: Factors rotation

## >> Findings

The six-factor of needs were identified in this study, they are elaborated based on research items:

- Factor 1: Communication Need** – Regular communication for better understanding and balance of needs between caregivers and person with cancer;
- Factor 2: Personal Well-Being Need** -- Especially on the control of emotion, communication and spiritual beliefs mainly on the quest of meaning of life and the faith in the healing process;
- Factor 3: Basic Health Need** – Healthcare need, counselling and service;
- Factor 4: Information Need** -- Access to Information related to cancer or patient care information and Services;
- Factor 5: Need for Coping with Change in Life** – Cope with the changes of life routine and perspective on life;
- Factor 6: Learning Need** – Learning through online information and connections with other people on caregiving / cancer care.



## >>Discussions, Conclusion and Future Work

- The known domain of needs emerged (as predicted):- Basic Healthcare Service, Psychological & Emotional (Personal Well-being Need), and Access to Information.
  - >> Additional needs identified in this study: Communication Need, Coping with Change (In life), Learning Need.
- Communication Need – being the moderate need by the caregivers (the higher need of all factors); learning need is low need. Other need-factors are between low to moderate need.
  - >> Communication Need for caregivers are multifaceted in nature: communication target, content, style, timing and preferences (Li et al., 2020; Yuen et al., 2014); it has influenced on Information Need; effective communications influence caregivers' well-being.

## >>Discussions, Conclusion and Future Work (continued...)

- Communication aspect and all other need-factors should be considered for any policy or training modules for caregivers.
- The study has sampling limitation; data from respondents may has some biases.
- Future directions >> Consider the different duties of caregivers and the level of quality of treatment received by patients; >> In depth study on specific well-being dimensions due to the reason that well-being is large construct.
- During pandemic time, caregivers' well-being should be safeguarded; research on Covid-19 caregivers is urgent, to study their unmet needs and also to compare their needs at different regions.
  - >> Future collaborative research on this area is welcome.