

Notice of the Final Oral Examination for the Degree of Doctor of Philosophy

of

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MSc (University of Victoria, 2012) BSc (University of Alberta, 2009)

"Advance Care Planning: A Qualitative Study with Families of Deceased Cognitively Impaired Older Adults"

Department of Psychology

Monday, July 9, 2018 10:00 A.M. Clearihue Building Room B007

Supervisory Committee:

Dr. Holly Tuokko, Department of Psychology, University of Victoria (Supervisor)
Dr. Mauricio Garcia-Barrera, Department of Psychology, UVic (Member)
Dr. Kelli Stajduhar, School of Nursing, UVic (Outside Member)

External Examiner:

Dr. Paulette Hunter, Department of Psychology, St. Thomas More College

Carol MacDonald, School of Nursing, LIV/in

Dr. Carol MacDonald, School of Nursing, UVic

Dr. Stephen Evans, Acting Dean, Faculty of Graduate Studies

<u>Abstract</u>

Older adults with dementia are at increased risk of becoming incapable of making their own decisions and may therefore benefit from planning for care at the end-of-life. Advance care planning (ACP) is a complex, multifaceted process by which people can express their wishes about care at the end-of-life in case they become incompetent to make decisions for themselves. However, we have little understanding of the ACP process among people with dementia and their families. This study addressed three questions: 1) when and how to cognitively impaired older adults and their families receive information about ACP; 2) in which aspects of the ACP process do families of cognitively impaired older adults engage, and why (and does this fit within the framework of the transtheoretical model of behaviour change [TTM]); and 3) how ACP relates to the way in which family members perceive the quality of death of their loved one. 22 family members of deceased older adults with dementia were interviewed and data was analyzed using interpretive description qualitative methods. Participants reported that information about ACP is provided in a haphazard and often incomplete manner, leading to difficulty engaging in the ACP process. Older adults were in various stages of readiness to engage in ACP behaviours, with most only engaging in a subset of ACP behaviours. Although ACP was viewed as beneficial by participants, several barriers were identified that prevented people with dementia from dying in a way that was aligned with previously-expressed wishes. Implications for the practice of clinical neuropsychology and implications for policy on ACP are discussed.