

Recovering a Life in Dementia: Exploring the Lived Experiences of People Living with
Dementia and Their Caregivers

by

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A Dissertation by Portfolio Submitted
to the College of Interdisciplinary Studies
in Partial Fulfilment of the Requirements for the Degree of

DOCTOR OF SOCIAL SCIENCES

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April, 2021



Komal Bhasin, 2021

COMMITTEE APPROVAL

The members of Komal Bhasin's Dissertation Committee certify that they have read and reviewed the dissertation titled *Recovering a Life in Dementia: Exploring the Lived Experiences of People Living with Dementia and Their Caregivers* and recommend that it be accepted as fulfilling the dissertation by portfolio requirements for the Degree of Doctor of Social Sciences:

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Abstract

Although dementia is formally classified as a mental illness in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), the specific and unique nature, characteristics and care needs of people living with dementia are rarely included in broader mental health discourses. As the global focus on mental health rightfully gains momentum, so too has the application of a more progressive and holistic approach to mental health, known as a recovery orientation. While a recovery orientation is increasingly seen as a leading approach to mental health care, its application in the context of dementia remains largely unexplored. The focus of my doctoral research is to understand how people living with dementia and their loved ones “recover a life in dementia” in terms of their hopes and vision for a meaningful and optimal life, in spite of and because of their dementia. In accordance with Royal Roads University Doctor of Social Sciences program requirements, this synthesis paper includes: a brief summary of my qualitative research study, the rationale for my approved dissertation format (i.e., dissertation by portfolio), and a description of my three approved portfolio elements (i.e., a traditional manuscript, a commentary article, and a manuscript for a public talk), which are provided in the appendices.

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Acknowledgements

At the heart of my research is the desire to understand how people make meaning of their lives and circumstances in spite of the challenges they face. For me, this process has been an act of meaning-making in and of itself, and I am grateful to have had the opportunity to learn and grow in grace. My mother and father are the inspiration for my research. Mom, thank you for teaching me that there is always light. If we look for it, we can find the light in everything, every moment, every person. I am grateful for your light, Mom. Dad, thank you for the strength, courage and resolve you show every day as a caregiver to Mom. I am in awe of you and I thank you for modelling how to live well, both in spite of, and because of this dementia journey we are on together.

I have been fortunate to have had the support of three wonderful women academics throughout my research. To my supervisor, Dr. Vicky Stergiopoulos, thank you for your unwavering sponsorship and guidance every single step of the way. Dr. Sophie Soklaridis, I will forever be grateful for the kindness, generosity and humility with which you share your remarkable expertise. Dr. Brigitte Harris, thank you for your thoughtfulness, thoroughness and precision which helped me to refine and elevate my work. I could not have asked for a more supportive and cohesive committee, and I am grateful to each of you for all you have contributed to my growth as an academic.

My research was supported by an advisory group whose participation added tremendous value throughout the research process. To Larry Singer, Kari Quinn-Humpherys, Gail Bellissimo, and Dr. Tarek Rajji, I am incredibly grateful for your expertise, insights and advice. To the geriatric psychiatry team at the Centre for Addiction and Mental Health and the social work team at the Alzheimer's Society of Toronto, thank you for sharing your time and resources at key points during my study. I would also like to thank Niloofar Shanmohammadi and Marie-Claire Conlin for their administrative support along the way.

Finally, to my beloved Sumit, to my rock Ritu, and to my wonderful family and friends, thank you for being you and for letting me be me. I love you.

Introduction and Research Rationale

I come to my doctoral studies at a poignant time in human history. According to the World Health Organization, mental illness is the leading cause of disability worldwide, impacting 350 million people across the globe (2016). At the same time, the world's population includes more seniors than ever before, and more elderly people than children for the first time in human history. In this context, the impact of dementia, a relatively newly-explored neurodegenerative mental illness that overwhelmingly affects people later in life, is increasingly coming into societal focus. With an estimated 50 million people in the world living with dementia today, the profound health, social, cultural and economic impact cannot be ignored (Alzheimer's Disease International, n.d.).

Because dementia is classified as a mental illness in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), it is often conflated with broader discourses on mental health policy, services and care, where the specific and unique nature, characteristics and care needs of people living with dementia are often unexplored. This presents a missed opportunity as mental health has, over the past decade, received unprecedented global attention, and as newer more critical approaches to understanding and treating mental illness, including a recovery orientation, emerge in policy and practice.

In the field of mental health, "recovery" refers to the deeply personal process of shifting one's attitudes, values, feelings, goals, skills and/or roles in the face of illness. It is an approach to living a satisfying, hopeful and contributing life, even with the limitations caused by illness or decline. At the heart of a recovery approach is the deep knowing that people can develop new meaning and purpose in their lives beyond their diagnosis, and that aspects of their lives that they

personally deem to be important can be recovered, reframed and recreated into a meaningful and purposeful life (Anthony, 1993; Slade & Longren, 2015).

While it is increasingly being adopted as a leading approach in mental health care around the world, the application of a recovery approach in the context of dementia remains largely unexplored. The language of “recovery” being applied to dementia can be uncomfortable and challenging because people living with the disease do not recover for the disease. My research explores how a recovery-in-dementia approach offers an alternative, more progressive paradigm that goes beyond traditional biomedical and person-centred care approaches, in favour of new ways of understanding, caring for and supporting people living with dementia.

Research Methodology

The aim of my qualitative research study was to bring together critical interdisciplinary knowledges across health and social science disciplines to explore alternative perspectives on meaning, identity, and the concept of an optimal life for those living with dementia and their caregivers. As an alternative to positivist, reductionist, and biomedical approaches to understanding and treating dementia, I attempted to uncover and amplify perspectives that look beyond the loss of dementia to uncover new ways of understanding, connecting with, and supporting people living with dementia and their loved ones.

In terms of my personal epistemology, I lean heavily towards hermeneutic phenomenology as an a priori methodology because it aligns well with my research interests insofar as it privileges the understanding “lived experience”, the integrated human psycho-social-biological nature, the deep meaning of “being in the world”, and the self-reflexivity of the researcher (Savin-Baden & Howell Major, 2013). Phenomenology involves treating the

“consciousness” of subjects as the primary source of ‘data’, which can be profound when conducting research with people in the early to mid-stages of dementia, as their memories, life stories, and identity may be evolving and changing. In this way, phenomenological research can give voice to people with dementia who have been the subject of academic debates around their identity, personhood, and consciousness (Eustache et al, 2013). Phenomenology has been used across a wide range of studies involving people living with dementia, and has been shown to be effective in gleaning important insights on topics such as hope, meaning, spirituality, identity, and “meeting the illness” (Caddell & Clare, 2011; Clare, 2002; Clare, Roth & Pratt, 2005; Clare, Rowlands, Bruce, Surr & Downs, 2008; Dalby et al., 2011; Dalby, Sperlinger & Boddington, 2012; Sabat & Harre, 1992; Gilles & Johnston, 2004; Westius, Kallenberg & Norberg, 2010; Wolverson et al., 2010).

Study Design and Findings

My research study was conducted in the Memory Clinic at the Centre for Addiction and Mental Health (CAMH) in Toronto, Canada. People over the age of 65 with a diagnosis of mild cognitive impairment (MCI) or early to mid-stage dementia, and their caregivers, were interviewed. Additional caregivers whose loved ones were current or former patients of the clinic were also sought in order to ensure that the perspectives of those supporting people in the mid to late stages of dementia were included.

Semi-structured interviews were conducted with 18 participants (five people living with dementia and 13 caregivers) between April 2019 and September 2019. Topics that were explored included: the social and relational lives of people with dementia, hope, acceptance, agency, identity, spirituality, coping and meaning-making in the context of dementia. Interviews were

analyzed using the hermeneutic phenomenology data analysis approach developed by leading phenomenologist, van Manen (2014).

All participants shared accounts of their lived experiences of dementia, or of supporting those living with dementia, during which four major themes: being present, acceptance and gratitude, resilience, and retaining agency. Participants shared the ways in which they live in the moment, accept their condition, retain abilities and agency, adapt to change, rely on the support of loved ones who carry them in personhood, and create meaningful experiences. Only one sub-theme was unique to caregivers, which related to caregivers setting their own personal goals and boundaries in order to experience a life beyond providing care and support for their loved one. Findings highlight the importance of going beyond current deficit-based models of care, and offer support for adoption of a recovery-orientation in dementia care. Importantly, the study affirm the findings of the small number of existing studies on recovery in dementia, thereby contributing to an emerging knowledge base (Daley et al., 2013; Jha et al., 2012). The study also highlights the importance of further research in this developing area. Study details are described in my traditional manuscript (see Dissertation by Portfolio: Three Components section below, and Appendix A for full manuscript).

Setting the Context for a Dissertation by Portfolio

My research is based on the notion that there is no singular way to understand the scope and impact of dementia on individuals and their caregivers or the meaning they give to the presence of the disease in their lives. Because dementia “shows up” not only physically, but also mentally, psychologically, behaviourally and socially, it raises important questions about citizenship, personhood, the nature of consciousness, and the social construction of a wide

variety of related topics such as memory, identity, communication, ability and aging. Within this context, scholars and applied researchers who are interested in exploring the totality of the lived experience will find themselves looking strongly towards interdisciplinary applied research as a way of uncovering new ways of understanding dementia. Those concerned with making real-life, timely social change in the understanding and treatment of dementia will also consider broad and relevant approaches to producing, disseminating, and translating knowledge.

I chose a dissertation by portfolio format because it conceptually aligns best to the critical, interdisciplinary, and applied approach that I brought to my research. As I have stated, my hope for my research is to learn about the experiences of people with lived experience of dementia and their loved ones in terms of their hopes and vision for a meaningful and optimal life in spite of, and because of, their diagnosis. My aim was to uncover common experiences that can offer an alternative voice, and influence how we understand, connect with, and care for people with the lived experience of dementia. Critical social theories ask that the researcher privilege approaches that support real life impact that can be made through creative, pragmatic, diverse and applied approaches (Aboelela et al, 2007; Green, 2010; Nissani, 1997; Newell, 2013).

My approach to my doctoral studies has been heavily influenced by world-renowned psychiatrist, Victor Frankl, who was himself informed by a range of health and social science disciplines. Frankl's work on logotherapy ("logos" as Latin for "meaning"), which focuses on the lived experience of finding meaning in the face of suffering, strongly challenges the role of scientific specialization and reductionism in creating limited, fragmented and ultimately "sub-human" constructions of man. Frankl suggests that the dominance of positivism and specialization has caused researchers to no longer see "the forest of truth for the tree of facts".

He asserts that the challenge we now face is “how to attain, how to maintain, and how to restore a unified concept of man in the face scattered data, facts, and findings supplied by a compartmentalized science of man” (Frankl, 2014; p.7).

While the field of science has delivered amazing revelations to humanity, an era of longstanding, positivistic, hyper-focused science, has, in many ways, oversimplified the whole and complete nature of being. Conceiving of the human experience in physical, or mental, or spiritual layers, implies that our “somatic, psychic and noetic modes of being” can be disentangled from one another, and that the constructed meaning given to an experience of suffering must somehow also reside within the same domain. I believe that this limited view of the human experience is what has shaped our understanding of dementia to date. As Frankl says, within this context of reductionism “scientists aren’t specializing, specialists are generalizing”, ignoring the multidimensionality and humanness of phenomena.

In applying a critical lens to my research, I tasked myself to think beyond traditional, academic, and positivistic approaches to generating knowledge, and to imagine more relevant and meaningful ways to connect with the “end-users” or beneficiaries of my research. For me this means influencing discourses on how people talk about dementia, contributing to new constructions, reimagining living well in spite of and because of dementia, and challenging how we, as providers, caregivers, and as social beings, relate and connect with people with dementia. In my view, achieving this aim requires taking a non-traditional approach to my studies, which has been an opportunity afforded to me through the dissertation by portfolio option. Instead of producing a dissertation by traditional monograph, I produced three distinct yet conceptually-linked elements to form a portfolio. As described in the next section, each component has been

selected with a specific aim and desired impact in mind. I provide a detailed overview of my 3 proposed portfolio components below.

Dissertation by Portfolio: Three Components

1. **Journal Article Manuscript:** This is a required portfolio component in which I, as a single author, have produced a manuscript that is ready for submission to a peer-reviewed academic journal. My manuscript is based on the research study described in this paper, and consists of previously unpublished work which will contribute to a knowledge base on recovery and dementia. See Appendix A for the complete manuscript. Per program requirements, the manuscript must be accompanied by a link to the academic journal where the article will be submitted for publication and a copy of or link to the journal's submission guidelines. The journal I intend to submit to is *Aging and Society*. I selected the journal because of its focus on interdisciplinary and critical approaches to understanding issues related to aging, and has published studies that are similar to mine. The journal allows for substantial length (30 pages), making it ideal for the submission of qualitative research manuscripts which include a substantial number of participant quotes. A link to the journal is provided here: <https://www.cambridge.org/core/journals/ageing-and-society>. Submission guidelines can be found here: <https://www.cambridge.org/core/journals/ageing-and-society/information/instructions-contributors>
2. **Commentary Article:** For this portfolio component, I have produced a commentary exploring the application of a recovery-in-dementia approach. The article makes the case for advancing a recovery orientation in dementia care, and provides practical and applied steps that can be taken by providers who are interested in exploring this approach. See Appendix B

for the complete commentary. I will be submitting this article for publication to the journal *Community Mental Health Journal* which focuses on applied practice and has a new section exploring innovative practices in clinical care. A link to the journal is provided here:

<https://www.springer.com/journal/10597>. A link to the journal's submission guidelines can be found here: <https://www.springer.com/journal/10597/updates/17901918>

- 3. Public Presentation (Manuscript):** For this component, I created a professional presentation (in manuscript form) that resembles the content typically used in the production of a keynote address or TedTalk. The manuscript may also be adapted for traditional print publications (e.g., a newspaper or magazine article which are options I am also exploring). The intent behind this component is to provide an accessible, widely-available account of my research findings, with a discussion on broader public implications, in a way that resonates with people living with dementia, caregivers, providers, and/or interested members of the public. This component leveraged my communications experience and was developed using a more narrative, creative story-telling format. See Appendix C for the full manuscript of the talk. In the version provided, the talk has been adapted for an audience of interdisciplinary healthcare providers and academics who will be attending the 11TH Biennial International Meaning Conference 2021, which will be held in August 2021. I have applied to give a symposia presentation at the conference. Conference link:

<https://www.meaning.ca/conferences-and-events/meaning-conference-2021/>

Conclusion

The 3 portfolio components I have selected reflect the need to use multiple formats and interventions to produce change. Recent research suggests that passive dissemination of research

(e.g. peer reviewed journal publications) is unlikely on its own to produce significant social impact, and that service providers and communities have an important role to play in influencing policy and practice (Shuksmith, 2016). Effective knowledge dissemination involves going beyond traditional vehicles such as journal publications and academic literatures to include a genuine focus on extracting the key messages of the research and engaging in processes and development of strategies to ensure that information is delivered to key audiences in the most effective way so that the research can be adopted into policy and practice (Levin, 2008). Each of the 3 components presented above aims to address the needs of various audiences: academics (journal manuscript); service providers (commentary article); and people living with dementia, caregivers, and broader audiences (public presentation). My hope is that this interdisciplinary, multi-pronged approach will help to advance alternative perspectives on meaning, identity, and the concept of an optimal life *in* and *with* dementia.

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