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A Pilot Study to Develop a Cognitive Intervention to Support Dementia Caregivers: A Focus Group of Caregivers Caring for Persons with Dementia as Informants

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PROJECT TITLE: “A pilot study to develop a Cognitive intervention to support Dementia Caregivers: A Focus Group of Caregivers Caring for Persons with Dementia as Informants”

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INTRODUCTION

The incidence and prevalence of dementia are on the rise. The most common form of dementia, Alzheimer’s disease, is currently estimated to affect 1 out of 9 adults aged 65 and older in the US.¹ Eighty percent of the care provided for persons with dementia is provided by unpaid caregivers.¹ Previous research have shown that caring for persons with dementia can be very costly to caregivers’ physical and psychological health². Yet some caregivers of persons with dementia report that caregiving resulted in an enhanced sense of meaning in life and feelings of joy which resulted in decreased stress and positive mental health among dementia caregivers³. Dementia caregivers would benefit from cognitive-behavioral intervention that helps them to rise above their challenges and to be resilient. However, before delivering the intervention, there is a compelling need to identify Barriers and facilitating forces related to resilience from the dementia caregivers’ perspectives. Resilience is a dynamic process including positive adaptation within the context of significant adversity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors⁴. Resilience will enable caregivers not only to survive the day to day burden associated with caregiving but to grow into a healthier and stronger person.

SIGNIFICANCE

Previous research have shown a positive outcomes for dementia caregivers who are resilient including coping effectiveness and health related quality of life^{2,3,5}. However, the factors that enhance and or hinder resilience are lacking in the literature. Barriers and facilitating forces related to resilience need to be identified from the caregivers’ perspectives before an effective cognitive intervention can be developed to promote resilience among dementia caregivers. The intent of this pilot study is to use a focus group of dementia caregivers as informants to identify factors that prevent and or facilitate resiliency. The aim of this study is to gather information from dementia caregivers that will be used to develop a full protocol for the cognitive behavior intervention that enhance resilience taking into consideration factors that prevent or facilitate resilience. The ultimate goal of this study is develop further studies that will serve to decrease the caregivers’ burden and to enhance their psychological well-being.

FORWARD THINKING/INNOVATION

This study is innovative because it recognizes the challenges that dementia caregivers are facing that hinder and or facilitate their resiliency. Learning from caregivers’ experiences will be helpful in building an intervention that has fidelity and can be tested in a prospective study. Dr. Bekhet plans to extend this study to test the cognitive intervention using the Positive Thinking Skills Scale that she developed recently during her Sabbatical Semester and was published in Western Journal of Nursing Research as a direct measure of intervention fidelity. IRB approval will be obtained once the proposal gets funded. Karie will use the information gained from this study to build on her PhD study as she is interested in music and resilience in dementia caregivers. Karie is currently a full time PhD student at Marquette. This study will facilitate further research of the student and faculty.

STUDENT INVOLVEMENT

Karie will take the lead on this project with the support of and collaboration with Dr. Bekhet. Ms. kobiske will recruit the focus group participants (n=10), develop the focus group questions, and lead the 2 hour focus group that will be tape recorded, transcribed and analyzed. Dr. Bekhet and Ms. kobiske will systematically code the data and analyze the themes, coming to mutual agreement in the process. Karie R. kobiske plans to study dementia caregivers and resilience for her dissertation. This study will open avenues and thoughts for her dissertation in terms of understanding the resilience concept and its barriers and facilitators. The information gained from this study will help her to develop a proposal that integrates some of the resilience enhancing factors and use them as intervening variables to help caregivers rise above their challenges and become resilient.

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