

Title: The Voices of Family Caregivers: A Window Into their Experiences

Abstract: Learning Objectives: Participants will gain an appreciation of (1) the experiences of family caregivers, and (2) spiritual resources that family caregivers utilize. **Background/Context:** Family caregivers are the backbone of the healthcare system. For some, caregiving comes easily, while for others it is a source of consternation and distress. Regardless, over time, caregiving takes a tremendous toll on the caregiver – personally, financially, emotionally, cognitively, socially, physically. This is particularly true for those who provide >21 hours of care per week, or who support those experiencing depression, moderate to severe cognitive decline, aggressive behaviours, or life-limiting conditions requiring complex care. Many caregivers juggle multiple roles, and experience time pressures, financial concerns and childcare issues. Some face deteriorating physical and mental health, social isolation, family conflict, and job loss. Changes in roles, relationships with one's self and the other, and a shifting sense of identity (of the caregiver and the person being cared for) complicate reality all the more. Caregivers often feel overwhelmed with the tasks before them, and have little energy or time to access resources. Their spiritual resources, coupled with experiences with the healthcare system, healthcare professionals and service agencies can either buoy them through challenging times, or contribute further to their distress. This project aimed to hear the voices of family caregivers – their challenges, struggles, joys and motivation for enduring perseveringly through hardship. **Design, Implementation, Evaluation:** As part of a pre-conference activity to a CIHR funded Supporting Family Caregivers of Seniors conference held in Edmonton on April 14th and 15th, 2014, three 2 hour long focus groups were held with family caregivers in Edmonton. Family caregivers were asked about supports they rely on, necessary knowledge and skills required for caregiving, resources that are lacking, barriers to accessing supports and services, where they access resources, and the rewards of caregiving. Focus groups were transcribed and a thematic analysis conducted. **Results/Outcome:** Caregivers related much, including their difficulties accessing resources, not identifying themselves as caregivers, a wide range of emotions, frustrations navigating the system, the need for time to take care of themselves, a need to have a voice in care, and both the enormous toll and gift associated with caregiving. They also clearly identified the spiritual resources upon which they rely.

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