



OSRA Grant Cycle 5 Public Reports

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Living with Chronic Illness: The ABCs of Informal Caregiving

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Introduction

People living with chronic illnesses are often unable to perform activities of daily living, leading to care dependency (Fitzsimons et al., 2007; Janssen et al., 2011). As the world's population is aging, the burden of chronic illness is increasing, and people with debilitating chronic illnesses are living longer, the active involvement of informal caregivers becomes imperative. Caregivers are individuals voluntarily caring for a relative or a friend facing a disease, disability, or any condition requiring particular attention (Shulz & Sherwood, 2008). They provide around 90% of in-home long-term care needed by adults and play a key role in supporting the wellbeing and care of people living with chronic illnesses (Adelman et al., 2014). This responsibility and a lack of formal support for their role have increased the prevalence of caregiver burden.

While taking care of a loved family member could generate feelings of emotional fulfillment and a sense of accomplishment (Lopez et al., 2005), Caregivers often face health hurdles and emotional strains (Roth et al., 2009). Caregivers of people living with chronic illness report higher depression rates, lower overall life satisfaction, and poorer physical health than age- or gender-based population norms and non-caregiving control groups (Borg & Hallberg, 2006).

Objectives and Significance

The primary purpose of this study is to explore quality of life, family relationships, and health outcomes of patients living with chronic illnesses and their informal caregivers. Knowledge from this study will help place burnout tendencies at the core of caregiving processes. By preventing or addressing burnout, healthcare practitioners can enhance the positive outcomes of caregivers, control dyadic dependence, and maintain the patients' and their caregivers' psychological and physical well-being.

Justification

Studies on caregiver burden in caregivers of adult patients are limited by their emphasis on homogeneous diagnostic groups; this limits generalizability and identification of caregiving features that are common across diagnoses. This study intends to explore this phenomenon in patients with one of many chronic illnesses namely cardiovascular, pulmonary, and/or renal.

Moreso, research that recognizes the interdependence between patients and their caregivers and examines patients and caregivers within the context of the dyad is better positioned to inform practice and policy. This is especially true because the more dependent the patient is on the caregiver, the greater the caregiving burden and subsequent vulnerability of the caregiver to burnout. With the exception of one study (Pucciarelli et al., 2017), no other study addressed the interdependence of dyads and its effect on dyadic outcomes. This study examines the type of the dyad, which reflects the interdependence of the dyad.

Methodology

This was a sequential mixed methods study with the primary purpose of testing the association between family relationships, caregiving practices, dyadic coping, caregiver appraisal and burnout as well as the relationship between caregiver burnout and health outcomes [anxiety, depression, and quality of life] of dyads living with chronic illnesses. A secondary aim was to explore the lived experiences of dyads living with chronic illness in Lebanon.

Quantitative data was analyzed using descriptive statistics performed using IBM SPSS Statistics version 25.0 for Windows. The data was checked for distribution, skewness, and linearity. The level of significance for statistical tests was set at $p < 0.05$. Descriptive statistics will be used to summarize the characteristics of the study sample as well as characteristic of caregiving. Scores for caregiver burnout, measured using Maslach Burnout Inventory, were used as the main study outcome. Burnout scores were compared across demographic and caregiving characteristics using independent sample t test and analysis of variance tests or Pearson r as appropriate for the level of measurement of the variables. An analysis of potential baseline covariates identified in the literature will be conducted to identify a comprehensive set of covariates associated with caregiver burnout ($p < 0.05$) but without collinearity concerns.

Scores for patient and caregivers' quality of life, anxiety, and depression were then used as the main outcomes. Quality of life, anxiety, and depression scores were compared across demographic and caregiving characteristics using independent sample t test and analysis of variance tests or Pearson r as appropriate for the level of measurement of the variables.

A phenomenological approach was used to understand the lived experiences of patient-informal caregiver dyads living with chronic illness, with a focus on their main needs and challenges and the impact of the illness experience on their mental health and emotional wellbeing. In-depth interviews were conducted with 3 dyads so far. We have not yet reached data saturation and as such these interviews are being continued (Creswell, 2013). The interviews were guided by three main questions: (1) How do you describe your emotional experiences as they relate to the patient-informal caregiver dyad? (2) What context or factors have influenced your experiences in coping with your dyad relationship? And (3) How did this dyad relationship affect your health? (Høffding & Martiny, 2015).

Results/Findings

The mean age of patients in this sample was 73.43 ± 9.56 years while the younger sample of caregivers had a mean age of 54.43 ± 13.54 years. About 60% of the patients were males whereas 82.7% of the caregivers were women, highlighting the cultural and traditional role of women in informal caregiving in the MENA region. About 50% of the caregivers and 34.6% of the patients had a university degree with the majority making less than 1000 US dollars per household a month in income confirming the financial crisis Lebanon is facing. About half of the caregivers are employed, which makes caregiving an additional burden over their other financial burdens.

Patients and caregivers in this sample perceived their health status as good or very good. About half of this chronically ill patient population suffered from multimorbidity, 35.6% of them lived with a cardiac condition while 13.5% had a kidney disease. Patients lived with their chronic condition[s] for a mean of 13.82 ± 9.73 years and a median of 2 hospitalizations per year [range 0 to 13].

Caregivers in this sample were spouses [46.2%] or children [47.1%] of patients they cared for and more than three quarters of the caregiver patient dyads lived in the same household. Half of the sample of caregivers had other family obligations over and above their role as caregivers. Roughly 30% of the caregivers were the sole care providers of the patient they cared for. About 60% of the caregivers provided 41 hours or more of caregiving per week. About 70% of caregivers in this sample reported high care burden indicating that patients had high care dependency. The majority [94.2%] of caregivers reported having an often or always good relationship with the person they cared for. About 56% of the caregivers reported that the care was collaborative or complementary that is both members

of the dyad assumed care of the patient's health together or took care of different aspects of patient's health jointly. Only 4 dyads reported that the care is done purely by the patient. An alarming 40% of the dyads in this sample were considered discordant and did not agree on how and by whom [by patient, caregiver, or jointly] the care is being provided.

Caregiver appraisal which is based on a range of subjective appraisals of the nature of the stressors imposed by caregiving compared with the resources available and the perceived ability to cope was positive. Reported caregiver strain, which is the perceived role overload [extent to which caregivers perceive that they are physically or emotionally depleted by their caregiving activities] and average captivity [the extent to which caregivers feel trapped by their responsibilities and isolated], was low with a mean score of 2.40 ± 1.02 . Similarly, caregiver distress which addresses the negative emotional responses associated with caregiving was average. Positive Appraisal and Family Wellbeing which address issues of commitment, confidence, development of intimacy in the caregiver and patient, as well as satisfaction were reported to be high.

Our results confirm the presence of mild to moderate burnout in Lebanese informal caregivers. This is linked to poor quality of life particularly physical and psychological health, social relationships, and environmental in both patients and their caregivers. More than half of the caregivers reported spending more than 41 hours per week in direct caregiving with high reported care burden.

Determinants of caregiver burnout were Level of Burden, Care Typology (synchronous versus dyssynchronous), Hours of Caregiving, Caregiving Preparedness, and Dyadic Coping. This is the first Arab study to address caregiver burnout and as such results are expected to raise awareness about informal caregiving and dyad quality of life of patients. Knowledge from this study will help place burnout tendencies at the core of the caregiving processes. By preventing or addressing burnout, healthcare practitioners can enhance the positive outcomes of informal caregivers, control dyadic dependence, and maintain both the patients' and informal caregivers' psychological and physical well-being.

From the qualitative interviews, we were able ascertain the burden faced by informal caregivers due to the deteriorating economic situation in the country. *Uncertainty* and *fear* are prevailing and caregiving is seen as both *sorrowful* and *joyful*. "It was very painful to learn about her deteriorating heart condition. It's like my life is ending" mentioned one husband who felt the pressure of losing his partner. He then reports that when his wife was no longer acutely ill and they left home with her new device he started to feel it was "fun to take care of her wound and an opportunity for us to enjoy our time with some humor. Everyone in the family is joking about me being the expert doctor." Humor and taking things slowly seems like a way where dyads cope.

Recommendations

Being the first Arab study to address this issue, this study is expected to raise awareness about informal caregiving and dyad quality of life. Findings from this study will be presented in a national forum that is expected to provide grounds to inform clinical practice with recommendations for interventions that may potentially enhance dyad outcomes, prevent caregiver burnout, and maintain dyad well-being.

Informal caregiving is commonly practiced in Arab cultures where family members of an ill adult take on the responsibility of caring for their beloved one, many times ignoring their own well-being resulting in unwanted social and health consequences affecting the whole family. Our study specifically addresses the need for social policy that supports informal caregiving and the patient-

caregiver dyad for better health and well-being for both. These could include Paid Palliative Care Leave, Medical Assistance Leave, Training Programs for healthcare professionals on support for informal caregivers, and Education program for self-management skills for people living with chronic illnesses and their informal caregivers.

Impacts (Societal Impacts, and/or Legal Impacts and/or Policy Impacts)

Findings from this study will add to the available knowledge on quality of life, family relationships, and associated health outcomes of patients living with chronic illness and their informal caregivers. Our results revealed determinants of caregiver burnout [Level of Burden, Care Typology (synchronous versus dyssynchronous), Hours of Caregiving, Caregiving Preparedness, and Dyadic Coping] and the roles of dyadic coping on the caregiving process and dyadic outcomes like anxiety, depression, and quality of life.

Taken as a whole, these findings will provide the grounds to inform clinical practice with recommendations for interventions that may potentially enhance dyad outcomes, prevent caregiver burnout, and maintain dyad well-being. Suggested interventions include training programs for healthcare professionals on supporting for informal caregivers of patients living with chronic illnesses as well as planning an educational program for self-management skills for people living with chronic illnesses and their informal caregivers. In chronic illness, and because most of the care is provided at home, any further understanding and improvement in home care (in this case by informal caregivers) is expected to result in improved patient outcomes, and subsequently fewer readmissions to hospital, thus reducing the burden of acute illness exacerbations, associated health care resource utilization and cutting costs.

Benefits to Arab countries in terms of issues related to the Arab Family

Being the first Arab study to address this issue, our study findings will be used to raise awareness about informal caregiving and dyad quality of life, thus laying the ground to inform interventions to improve formal caregiving process and outcomes. Social and health policymakers are expected to benefit from the study's findings to create culturally sensitive policies that support the informal caregiving process in Lebanon and the MENA region. We plan, in collaboration with social and health policymakers and researchers, to use the findings to create a culturally sensitive policy that supports the informal caregiving process in Lebanon and the MENA region. We will be working with AUB's Faculty of Health Sciences and the University for Seniors to conduct an expert panel round table in October that will include patients and caregivers as well as expert researchers in the field of older adults and burnout to develop a policy brief [with emphasis on access to information and training] that addresses the needs of this *invisible workforce*.

Conclusion

The number of informal caregivers around the world is large, and research suggests that the number of people taking up the caregiver role will increase in the next years (Broese van Groenou & De Boer, 2016).

The informal caregiving process available in Lebanon fills the gap of the lack of availability of community nursing and or hospice and as such supports the already taxed Lebanese government and the scarce resources available. Results of this study confirm the presence of mild to moderate burnout in Lebanese informal caregivers. This is linked with poor quality of life particularly physical and psychological health, social relationships, and environmental in both patients and their caregivers.

Bibliography

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: a clinical review. *JAMA*, 311(10), 1052-1060. <https://doi.org/doi:10.1001/jama.2014.304>
- Borg, C., & Hallberg, I. R. (2006). Life satisfaction among informal caregivers in comparison with non-caregivers. *Scandinavian Journal of Caring Science*, 20, 427–438.
- Broese van Groenou, M. I., & De Boer, A. (2016). Providing informal care in a changing society. *Eur J Ageing*, 13, 271-279.
- Creswell, J. W. (2013). *Qualitative Inquiry & Research Design: Choosing Among the Five Approaches*. SAGE Publications.
- Fitzsimons, D., Mullan, D., Wilson, J. S., Conway, B., Corcoran, B., Dempster, M., Gamble, J., Stewart, C., Rafferty, S., McMahon, M., MacMahon, J., Mulholland, P., Stockdale, P., Chew, E., Hanna, L., Brown, J., Ferguson, G., & Fogarty, D. (2007). The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliat Med*, 21(4), 313-322. <https://doi.org/10.1177/0269216307077711>
- Høffding, S., & Martiny, K. (2015). Framing a phenomenological interview: what, why and how. *Phenomenology and the Cognitive Sciences*, 15(4), 539-564. <https://doi.org/https://doi.org/10.1007/s11097-015-9433-z>
- Janssen, D. J., Franssen, F. M., Wouters, E. F., Schols, J. M., & Spruit, M. A. (2011). Impaired health status and care dependency in patients with advanced COPD or chronic heart failure. *Qual Life Res*, 20(10), 1679-1688. <https://doi.org/10.1007/s11136-011-9892-9>
- Lopez, J., Lopez-Arrieta, J., & Crespo, M. (2005). Factors associated with the positive impact of caring for elderly and dependent relatives. *Archives of Gerontology and Geriatrics*, 41, 81-94.
- Pucciarelli, G., Vellone, E., Savini, S., Simeone, S., Ausili, D., Alvaro, R., & Lyons, K. S. (2017). Roles of Changing Physical Function and Caregiver Burden on Quality of Life in Stroke: A Longitudinal Dyadic Analysis. *Stroke*, 48, 733-739. <https://doi.org/doi:10.1161/STROKEAHA.116.014989>
- Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Quality of Life Research*, 18, 679–688.
- Shulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Am. J. Nurs.*, 108, 105–113. <https://doi.org/doi:10.1097/01.NAJ.0000336406.45248.4c>