

EDITORIAL

Family caregivers: Important but often poorly understood

Internationally, there are growing numbers of unpaid caregivers, with increasing numbers leaving paid work to provide care (National Academies of Sciences & Medicine 2016). Nomenclature for this role includes family, informal and unpaid caregivers as well as terms such as medical visit companion. This terminology in itself fails to encompass the importance of the role given the critical contribution to health care. Emerging data suggest that while the majority of individuals find caregiving to be a rewarding experience it can also result in hefty physical, emotional and financial strains (SCAN 2018). As the population ages, the burden of chronic illness rises and the emphasis on community-based care grows, it is timely that there is an increasing recognition of the role of unpaid or informal caregivers (Wolff et al., 2017). Moreover, in many countries ravaged by epidemics such as HIV and tuberculosis, caregiving reaches across multiple generations (Ogden, Esim, & Grown, 2006). Caregiving spans not only the family unit but also has broader societal implications, particularly in workforce participation.

Many stereotypes, misconceptions and monocultural viewpoints persist in the understanding of family caregivers (Deek et al., 2017). Data also demonstrate that caregiving can be an isolating and marginalizing experience (Pindus et al., 2018). The increasing importance of family caregivers to healthcare outcomes requires us to intensify our focus on this pivotal role in policy, practice, education and research. Although recognised as key partners in the healthcare enterprise, the caregiver role is commonly undervalued and viewed homogenously. Unmet needs that have been identified include increased stress, financial strain and social isolation, however, interventions to address these needs of caregivers have had mixed results (Pinquart & Sørensen, 2004). Commonly caregiving has been termed a roller coaster, a mixture of benefits and burdens (Davidson & DiGiacomo, 2015). In a nationally representative sample of 1,081 family caregivers of older adults in the United States found that 54% of caregivers reported feeling and unexpected joy in caregiving, attributed to satisfaction as well as increased understanding of their loved one (Skufca, 2017).

Many clinical practice guidelines advocate for the engagement of caregivers in care plans but methods to assess their readiness, skills, and competence are rarely applied. Commonly, family caregiving is attributed to spousal caregivers, failing to recognise that caregiving occurs across the life span and children are frequently engaged in caregiving roles (Evans, 2014). In older adults, individuals often co-exist in a delicate balance of assisting each other in living with decreasing functional capacity and chronic illness (Laver, Milte, Dyer, & Crotty, 2017). The mutual and reciprocal benefit of this relationship may impact on a range of activities of daily living, emotional support and collaborative coping,

yet is poorly understood, documented and underappreciated. Just as social determinants of health apply to individual's health and well-being, these factors also moderate the capacity of family caregivers to undertake the role without compromising their own social, emotional and physical health.

Caregiver research is dominated by a focus on educating the caregiver on managing the patient's illness including medication adherence, lifestyle changes and even personal care. An important factor that is rarely delineated is the differentiation between social and instrumental support for caregivers (Davidson, Abernethy, Newton, Clark, & Currow, 2013). Caregiver health and well-being is often not supported by "caregiver interventions." Many caregivers feel that need assistance, particularly in being able to support physical care and respite from responsibilities. We propose the following areas of influence for nurses to lead a deeper level of caregiver engagement, activation and support.

1 | POLICY

A positive and enabling policy context is critical to supporting family caregivers. The policy remit is broad and multifaceted across multiple jurisdictions and ranges from promoting dialogue and discussion of the role and impact of family caregiving to legislation providing benefits and entitlements for both patients and caregivers. Using a "Caregiver Policy Lens" is important to ensure that the perspectives of caregivers are included in strategy and legislation and that caregivers' well-being is recognised and negative effects and unintended consequences are considered (MacCourt & Krawczyk, 2012). Providing resources, financial support and respite for family caregivers is a critical consideration and yet we know that even when these are available many individuals do not take advantage of these resources (Davidson & DiGiacomo, 2015; Dunn, Zwicker, & Submitter, 2018). This underscores the need for providing information and support for access to services, particularly among those with low health literacy and from culturally and linguistically diverse populations. We also need to support caregivers to make use of these resources as often they feel guilty in the perception that they are abrogating their responsibilities (SCAN 2018).

2 | PRACTICE

Recognising the caregiver as an integral contributor to successful self-care in chronic illness, health professionals should engage

caregivers to support and extend service interventions (Fiest, McIntosh, Demianschuk, Leigh, & Stelfox, 2018). However, as caregivers are often recruited out of necessity, they may come to the role ill-equipped, with limited skills and knowledge and feeling under-prepared to participate in caregiving. Nurses are ideally placed to be an interface and buffer between caregivers and health services, to evaluate caregiver readiness for the caregiver role and to identify and address specific education and training needs to reduce adverse consequences of caregiving (Lutz et al., 2017; Schumacher, Stewart, & Archbold, 2007). Caregivers who report a high level of readiness for caregiving experience lower levels of caregiver strain (Schumacher et al., 2007, 2008). Readiness is also known to be a malleable state, it being possible to move caregivers from low to higher readiness in the presence of positive therapeutic engagement and perceived treatment benefits (Gitlin & Rose, 2014). Communications skills among nurses should be actively developed to foster positive partnerships (Belanger 2016) (Bélanger, Bourbonnais, Bernier, & Benoit, 2017). An appreciation of the construct of readiness among caregivers and an understanding factors associated with caregiver readiness will provide a framework for potential interventions. Engagement with caregivers should be undertaken with consideration of both commitment and capacity, should be structured through identifying gaps in caregiver and patient needs and strategies to improve caregiver readiness. Caregiver preparation should include activating resources, readying the home environment, providing information and skill training (Lutz et al., 2017). Consideration should also be given to contextual factors such as pre-established relationship patterns and an understanding of dyadic care typology (Buck, Kitko, & Hupcey, 2013). The patient carer dyad is complex and conflict and tensions may be evident. Caregivers can be supported by having a stronger voice through respectful engagement and effective communication.

3 | EDUCATION

Nursing curricula should recognise the diversity and heterogeneity of caregiving and the fact that the process is dynamic and influenced by the social determinants of health. Traditionally, nursing students have learned that including the family is important, but have been provided with very few skills to master inclusion of caregivers and family in healthcare delivery. Examples are often limited to incapacitated patients. However, disciplines such as pediatrics, palliative care and those who work with stroke and dementia patients provide critical insight into a family-centred model of care in which the caregiver is recognised as an essential team member. Inviting these specialists into the classroom to share clinical experiences of caregiver engagement is both a multi-disciplinary approach to education and will provide meaningful examples of caregiver involvement in care. Further, these disciplines should be invited to collaborate in developing simulation experiences which have been demonstrated to help students feel more confident in engaging caregivers. Additionally, introducing shared decision-making strategies in pre-licensure education will

ensure a workforce that is equipped for engaging all key stakeholders with patients as they make healthcare decisions. Nurses can also develop skills in helping patients and caregivers navigate shared decision-making aids which support more informed treatment and care decisions (Alegria et al., 2018).

4 | RESEARCH

Caregiving research is evolving in multiple ways. First, it is starting to include the complex dynamic of caregiving dyads, the circadian and condition-related rhythms of caregiving, and non-spousal models. Second, there is a growing recognition that all key stakeholders, including caregivers and those who receive care, should be integrally included in the development of research questions and the implementation of research about caregiving. Third, including people from different ethnicities, backgrounds and socioeconomic position in caregiver research is vitally important. Much of the evidence on caregiving is with white middle-class populations for whom caregiving may be the only strain. And finally, there is a need for a greater understanding of the contextual factors of family caregiving including social determinants of health such as physical, financial and emotional resources, as well as social support. Meaningful benefits to both the caregivers and patients are evident when supportive care interventions are provided to the family and caregiver (Ferrell & Wittenberg, 2017; Northouse, Williams, Given, & McCorkle, 2012). The role of the caregiver is often poorly negotiated between the patient and caregiver and rarely communicated to providers. However, a recent study among cognitively impaired patients and their medical visit companions/caregivers demonstrated that a simple intervention to help the patient and caregiver clarify the role of the caregiver and important topics to cover during the visit helped maintain a higher degree of patient-centred communication (Wolff et al., 2018).

5 | CONCLUSIONS

The role of family caregivers is important but not well understood and requires strategic emphasis in policy, practice, education and research. Recognising the prevalence and importance of family caregiving is just the first step. Collaboratively developing and evaluating interventions that are person-centred, tailored to individual circumstances and targeting those with the highest unmet needs is important in supporting this valuable dimension of healthcare delivery. Nurses who are intimately involved in the patient care experience are well placed to assess caregiver readiness and provide tailored and targeted interventions.

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