

# PERCEIVED VALUE OF SUPPORT FOR OLDER ADULTS COPING WITH MULTIMORBIDITY: PATIENT, INFORMAL CARE-GIVER AND FAMILY PHYSICIAN PERSPECTIVES (PUBLICATION)



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## CONTEXT

In Ontario, Canada, Community Care Access Centres (CCACs) organize government-funded home-care services including professional care, home-making and personal support services. Over time, CCACs have increasingly provided more medicalized, post-acute care rather than chronic disease management due to budget constraints. Informal caregivers, in particular, are key to maintaining and supporting seniors in the community. However, little is understood about how, when and why older adults with multimorbidity make use of formal and informal home and community care supports. A better understanding of the perceived value of support services could inform the design and implementation of care that may better address patient needs.

## OBJECTIVES

The study aims to examine patients, informal caregivers and family physicians' perceptions of the value of various formal and informal supports for older adults with multimorbidity; and to identify non-financial barriers and facilitators of patient uptake of various health services.

## METHODS

Eligible participants were recruited by purposive sampling from a family health team within a tertiary academic health centre in Toronto, Ontario. All members of the patient-caregiver-physician triad had to agree to participate in order to be included in the study. Semi-structured interviews were conducted with 27 patients, their informal caregivers and family physicians. General Inductive Approach was used to identify key themes in the interview transcripts. Data collection and analysis was conducted simultaneously until theoretical saturation was reached.

## FINDINGS

Patient, informal caregiver and family physician narratives regarding support broadly focused on the importance of patient independence, concern regarding caregiver burden and burnout, the importance of social participation, and health and safety. Firstly, all participants had positive views of supports that facilitated patient independence, although patients expressed negative views of informal supports which were perceived as undermining their independence. Patients also often resisted additional formal supports, while caregivers and physicians viewed formal supports as facilitating patient independence. Secondly, the triad's perspectives were aligned with respect to supports that ease caregiver burden. Formal supports for home-making and transportation were reported to reduce caregiver burden. Thirdly, engaging in activities with social networks such as hobby groups and participation in alumni associations was highlighted as being important. Fourthly, support from informal caregivers, such as assistance with health planning, was viewed as important for patient health. Overall, convergent and divergent trends were also observed in the quantitative rating: all participant groups reported home care as 'not important'; and patients and caregivers rated family caregivers as being 'very important'. However, patients viewed community programs (formal supports) as 'not important' while physicians and caregivers viewed these as 'important' or 'very important'.

## CONCLUSIONS

The findings suggest that views of informal and formal support converge on supports that facilitate patient independence and ease caregiver burden. However, important differences emerged regarding how patient independence can be facilitated. A dichotomous perception of informal and formal support was also illuminated, suggesting that patients often overestimate caregiver capacity, which may reduce uptake of available formal supports such as personal support workers. The undervaluing of formal supports such as homecare services may be due to perceived necessity and/or the perceived lack of appropriateness of support provided.

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