CONFERENCE ABSTRACT

Measuring Integrated Care’s Reliance on Caregiver Support: A Caregiver Experience Survey

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Introduction: In 2015, an integrated care and payment initiative (ICPI)—launched as the “Integrated Funding Model”—aimed at integrating care and payment across hospitals and homes to improve quality and decrease cost of care was piloted in Ontario. One of the main sources of cost containment for ICPIs is the shortened acute length of hospital stay due to early discharge. Unpaid care provided by friends and relatives is instrumental to success of such interventions. Increased reliance on informal caregivers, however, might contribute to known adverse health and financial consequences of caregiving making caregivers’ contributions to ICPIs unsustainable in the long run. Despite this, caregivers are often underrepresented in ICPI designs and evaluations. The purpose of this study was to develop an instrument (Caregiver Experience Survey [CES]) that measures the consequences of ICPI on caregivers.

Methods: A multiphase study design was used to develop CES:

1) Development of a questionnaire pool: Guided by a modified “Triple Aim” framework, grey and scoping literature reviews focusing on quantitative articles were conducted to identify common instruments used to measure caregivers’ health, experience, and costs. Findings were shared with key stakeholders (caregivers, patients, researchers, and policy makers) to gain first-hand knowledge on what should be measured from caregivers’ perspectives. A series of literature reviews were then conducted focusing on psychometric properties of identified instruments.

2) Development of CES: Specific items or questionnaires were chosen in consultation with the research team; CES was then developed and revised in consultation with caregivers.

3) Pilot sample and psychometric properties: To test the validity and reliability of CES, it is being administrated among a sample of ICPI caregivers.

Results: CES has 58 items and 3 main domains (health, experience, and costs). EQ-5D-5L is used to measure caregivers’ health. The 4-item version of the Zarit Burden Interview is used to measure caregiving burden. Eighteen questions were adopted from a variety of questionnaires to measure caregivers’ experiences in and before leaving the hospital, and in the community. The cost section contains 21 items to measure the economic value of informal
care, productivity loss, opportunity costs, and uses of healthcare and social services. Additionally, sociodemographic information is gathered (10 items).

Discussion: CES is a generic survey that captures the entirety of a caregiver’s experience with ICPI allowing for a thorough investigation of its unintended impacts on caregivers. When the effects of ICPI are known, measures can be taken to provide caregivers with adequate support ensuring the sustainability of their contribution.

Conclusion, Lessons Learned, Suggestions for Future Research: This study provides evidence that contributes to the design and evaluation of ICPIs. Lessons learned from stakeholder engagement resulted in identification of three main areas that require further investigation: caregivers’ healthcare utilization costs, changes in patients’ care utilization due to presence of caregivers, and the dyadic pattern of care for patients/caregivers.

Limitations: Reviews were limited to electronic health sciences databases and quantitative studies; additionally, the scoping review was limited to Alzheimer/Dementia caregiving. Consequently, landmark instruments might have been missed in development of the questionnaire pool.

Keywords: integrated care; integrated funding model; informal care; caregiver experience survey