
Abstract

The Informal Caregiver Engagement Framework

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Abstract

Background: In the United States, there were 42.6 million adults age 65+ in 2014 and that figure is expected to double by year 2060 to 98 million. According to the AARP, 90% of older adults would prefer to age in their homes, creating an ever growing need for informal caregiver (ICG) support. About 34 million Americans provided care to a person 50+ years old with an average of 24.2 hours of care per week in 2015. Caregiving comes in many forms and levels, from providing a ride to a grocery store to administering medications and help with bathing and dressing. High levels of caregiving can cause high strain on caregivers. Therefore it is important to understand informal caregiver (ICG) needs as caregivers engage in providing care at different levels.

Objective: This work aims to map different ways informal caregivers engage in providing care to an elder care recipient (CR). We sought to define stages of an informal caregiver's engagement journey to uncover their needs in a progressive fashion.

Methods: Literature review, journey mapping and a commercial landscape of ICG solutions were conducted.

Results: Five stages of engagement in caregiving process were identified including Noticing Changes, Making Adjustments, Shifting Responsibilities, Actively Helping and Running the Show. Categories of needs (e.g. communication and information), as well as tasks they may complete at each stage of engagement (e.g. share and gather information about care recipient condition in the communication need of Stage 3), were also mapped. The first two stages are the lowest level of engagement and are often hard to differentiate. The main distinction is that in Making Adjustments, caregivers have acknowledged that changes in the care recipient's health and functional abilities require some level of engagement. The informal caregiver's health and functional limitations start to limit their independence in Stage 3. Caregivers take over more responsibilities from the care recipient, mainly instrumental activities of daily living like shopping, transportation, and housework. The ICG is more deeply engaged with providing care in Stage 4. The care recipient is likely still living independently; however, doing so safely is becoming increasingly more difficult. Informal caregivers in this stage start to need deeper engagement in self-care as caregiver burden is a concern. In the final stage, the care recipient has lost their independence, relying on the ICG for most needs. The care recipient may collocate with the caregiver or alternative living arrangements like transfer to a skilled nursing facility are made. Caregivers are very familiar with the care recipient's disease and treatment options and are instead in need of emotional and decision-making support.

Conclusions: As the number of people age 65 and older continues to grow, the need for informal caregiver support will increase. Consequently, informal caregivers themselves will also need support. This work focused on revealing different stages of engagement for informal caregivers and caregiver needs at each stage. This work shows the landscape of informal caregiver needs and engagement points for which solutions can be proposed. This will help academic, legislative, and commercial entities deliver the support informal caregivers need.

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KEYWORDS

caregivers; engagement; informal caregivers; needs; journey

Multimedia Appendix 1

Full poster.

[\[PDF File \(Adobe PDF File\), 4MB-Multimedia Appendix 1\]](#)

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