

Dementia Caregivers' Engagement of Informal and Formal Supports and the Potential Role of Consumer Health Information Technology

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Introduction

- Every year, approximately 15 million informal caregivers spend 17.9 billion hours caring for people with Alzheimer's disease and related dementias (PwD) (1)
- Informal caregiving is associated with burden, burnout, high rates of depression, and mortality (2-6).
- **Formal support** refers to paid services, and **informal support** refers to unpaid services performed by family, friends, or neighbors.
- Technological advances have assisted caregivers in obtaining **formal support** for caregiving (e.g. adult day care, meal delivery, transportation)

Research Questions

- 1) How do informal caregivers of PwD currently engage formal and informal support?
- 2) What are some of the challenges associated with engaging formal and informal support?
- 3) What is the role of technology in facilitating access to support for caregivers of persons with dementia?

Methods

Participants. We interviewed 10 ($N=10$) informal caregivers of PwD. Caregivers identified as the primary informal caregiver of either their spouse ($N=7$) or parent ($N=3$) and ranged in age between 49-82.

Design. 60 minute semi-structured interviews pertaining to 1) the daily activities of informal caregivers; 2) the strategies developed by informal caregivers to manage caregiving responsibilities; 3) unmet needs in providing care; and 4) the context in which informal caregiving occurred. For example:

“Tell me about a particularly difficult day of caregiving. What went wrong? How did you manage it?”

Analysis. We first used Grounded Dimensional Analysis (GDA), a methodology intended to generate theory about how social understandings guide actions and to identify consequences associated with various actions (8). This was followed by Thematic Analysis, or structural coding of the passages identified in GDA, guided by the current research questions.

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Results

We identified three key themes related to informal caregivers' engagement (meaning *initiation* or *request*) of informal and formal supports:

- 1) Caregivers engage formal supports despite experiencing challenges
 - 1) Formal supports included **housecleaning** (e.g., P101, P105, P108); **Meals on Wheels** (e.g., P101, P110); **Senior Helpers** (e.g., P103); **senior move specialists** (e.g., P108); **transportation for seniors** (e.g., P108, P109); **homecare** (e.g., P107, P110); and various resources offered by the **senior center** (e.g. P106, P109, P101).
 - 2) Challenges included **high cost, inadequacy of the assistance, and distrust** of support providers.
- 2) Caregivers do not engage informal support despite its availability
 - 1) Informal support was rarely engaged by caregivers, even though it was frequently offered by **neighbors** (e.g. P109, P107, P103), **friends** (e.g. P105), and **children** (e.g. P102, P105, P106, P107, P108, P110)
 - 2) Reasons for failing to engage social support included barriers of self-perception and barriers of other-perception.
 - 1) Self: *“I don't want to share down times I'm having”* (P106); *“I'm a private person”* (P107)
 - 2) Other: *“[My children] have very, very busy schedules”* (P110); *“I didn't want to sound like I was complaining”* (P108)
- 3) Expectations of formal supports can be filled by informal supports.
 - 1) The challenges associated with engaging formal support could be reduced or eliminated by engaging informal support instead.
 - 2) Caregivers desired a type of support that could be provided by a family member or friend:
 - 1) *“Someone to help with grocery shopping”* (P105)
 - 2) *Someone you could “text,” “like your best friend is also taking care of your mother”* (P101)
 - 3) *Someone to talk to “in the same or similar situations”* (P103)

Discussion

Despite the high cost, low trust, and perceived inadequacy of formal support, caregivers were hesitant to discard it in favor of informal support.

Why?

Perceptions of self: participants viewed themselves as independent, private, and capable.

Perceptions of others: Participants viewed *others* as unable, unwilling, or too busy to help.

However, services entrusted to formal supports could easily be completed by family and friends.

The problem may not lie in the availability of resources, but in the availability of formats in which to comfortably ask for support.

Conclusions

Consumer Health Information Technology (CHIT) HIT must acknowledge not only how people interact with technology, but how people interact with each other and with themselves.

For caregivers of PwD, unwavering perceptions of self and others stand in the way of obtaining much-needed support.

CHIT should be aimed at reducing discomfort related to requesting informal support by working with and around these perceptions of self and others.

CHIT should acknowledge the truism: “to make a friend, ask someone for a favor.” People need help; people want to help; and people are connected by helping each other.

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Effective consumer HIT will

acknowledge the truism:

“to make a friend, ask someone for a favor.”

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