

Caring for Caregivers: Balancing Formal and Informal Care in the Community for Frail Older Persons

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Acknowledgments

Thesis Committee

- Dr. Sheila Neysmith
- Dr. A. Paul Williams

Participating Members

- Central and Toronto Central Community Care Access Centers
- Participating Care Managers

Literature

Literature suggests:

- **Substitution**
 - Paying into more formal support to assist the 'unit of care' may result in having informal caregivers retract the amount of support they provide.
(Stabile, Laport, Coyte, 2006; Change-Ability Inc., 2009)
- **Multiplier**
 - Additional formal services provided to the 'unit of care' allows informal caregivers to do more while avoiding burnout.
(Stabile, et al., 2006; Dunér & Nordström, 2007)



Research Questions

- What formal services are individuals receiving and do these services change if an informal caregiver is present?
- How might ethno-cultural variations, location of caregiver and personal characteristics impact on the allocation of formal services?



Why Informal Caregivers?

- Currently 80% of all care provided in the home is provided by informal caregivers (unpaid family members, friends, or volunteers)
- A body of research suggests that limited caregiver support will result in heightened spending on formal services



(Barron & McMahon, 1998; Home Care Association, 2003; Canadian Caregiver Coalition)

Methodology

- This research used a mixed methods approach. The **qualitative** and **quantitative** data draws upon multiple data sources:
 - Central BoC simulations
 - In-depth follow-up interviews with case managers
 - Secondary data analysis from both Toronto Central and Central's RAI-HC



QUALITATIVE RESULTS



Five Common Themes

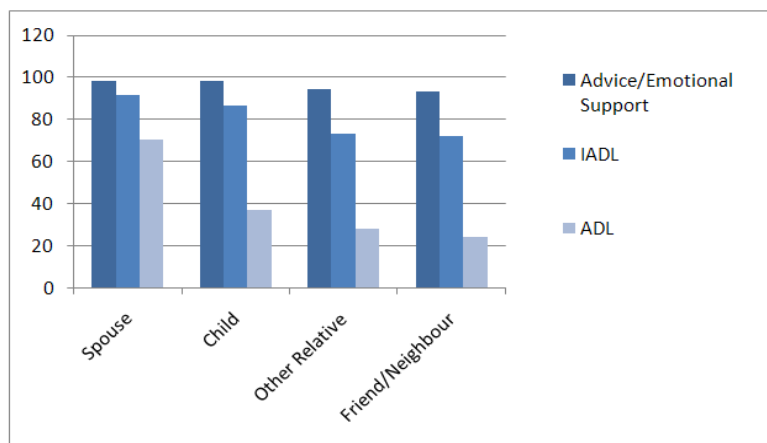
- **'Unit of Care'**
"A vital role. If it were not for the caregiver, they would be unable to return home [from the hospital]."
- **Personal characteristics of caregivers**
 - "I think a spouse or a daughter tends to provide more physical care and be more supportive and involved on a general basis."
- **Ethno-racial variations and considerations**
"*Filial piety may lead to caregiver's reluctance to accept services or they may not ask for assistance when they need it.*"
- **Caregiver availability**
"*Depending on if the person has flexibility to take time off, it varies on amount of time they can actually take part in their family member[s care]*"
- **Recommendations for the system**
"A lot of caregiver programs available...but some people find these exhausting-- to go to them. How do we bring those services to those caregivers?"



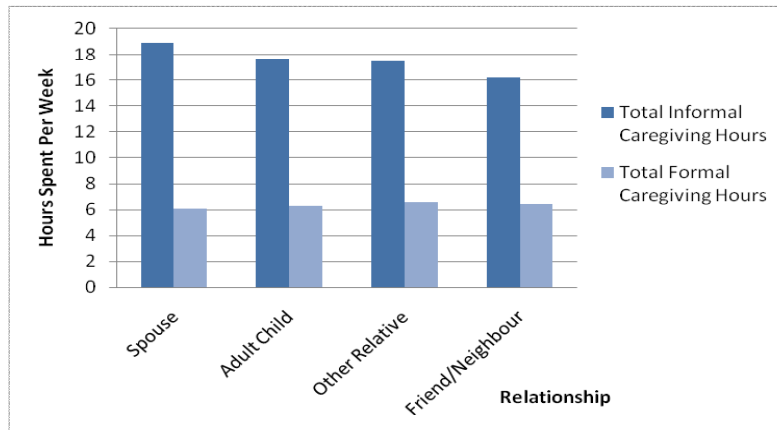
QUANTITATIVE RESULTS



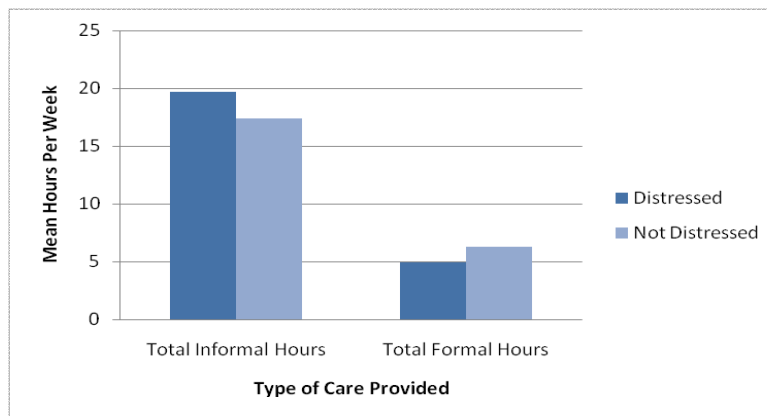
Who Provides What?



What do Caregivers Actually Receive?



Comparison of total hours spent by 'distressed' and 'not distressed' caregivers



Conclusion and Policy Implications

Conclusion:

- While there are differences with what caregivers provide there are minimal differences with what caregivers receive

Policy Implication:

- Future research- is this a function of our system or a reflection of the unwillingness of caregivers to accept services?



Conclusion and Policy Implications

Conclusion:

- Broad consensus about the importance of caring for caregivers

Policy Implication:

- Redefining the 'Unit of Care'
- We agree it is important to support the continued involvement of caregivers. Yet no clear pattern of resource allocation or consensus at the front line about what should be done.
- Case managers require the flexibility and resource capacity to provide services to meet the unique needs of caregivers



Future Research

- **Best Practices**
 - How is care provided
 - Barriers to service provision
 - What services might 'best' assist various and diverse 'units of care'



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