Caregiving at the nexus of the public and the private spheres

Anne Martin-Matthews, Joanie Sims-Gould & Catherine Craven

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Social Policy In An Aging Society: Multiple Challenges Of Demographic Change

- Session: “Who cares? Caregivers and population aging”
- Asked to:
  - Speak about research on home support workers “working at the nexus of the public and private spheres”.
  - Consider policy implications of research and any recommendations for reforms.
Outline

- Family Carers in Home Care
  - Sharing the Care
  - Filling the Gaps
  - Link with Labour Force Issues
- Policy Implications and Recommendations
- Challenging Assumptions about ‘Who Cares’
- Contextual/Complicating Factors:
  - Variability/Diversity in ‘Who Cares’ and ‘What For’
  - Where You Live – What You Get
  - The LONG View
Who cares?

- An estimated 2 million “informal” (unpaid) caregivers in Canada

- National survey of older adult home care clients:
  - 98% reported receiving some support from an informal caregiver
  - Spousal caregivers were at a higher risk for burnout and distress than other relatives and friends

(Source: CIHI, 2010 “Supporting Informal Caregivers- The Heart of Home Care”)
**Nexus- Focus of the Research**

- **Intersection of the *public and private spheres***:
  - Workers* negotiate private sphere(s) of clients’ homes and families, and public world of health services

- **Intersection of *professional and non-professional labour***:
  - Perceptions of roles, relationships with employers, co-workers, clients and caregivers

- **Intersection of *paid and unpaid labour***:
  - Emotional vs contractual nature of ‘care’
  - Worker unpaid time to meet client need
  - Family/friend unpaid labour: ‘sharing’ the care

*Home Support Worker, Personal Support Worker, Community Care Worker, ‘Homemaker’ – unregulated - *80% of Home Care
Nexus - Methodology

- **Pilot study (2006)**
  - Agency interviews (n=11)
  - HSW interviews (n=30)

- **Full BC study (2007 - 2008)**
  - Home Support Worker interviews (n=118)
  - Elderly Home Care Client interviews (n=82)
  - Family Member interviews (n=56)

- **Data collection in Ontario and Nova Scotia (2008)**
  - Ontario HSW interviews (n=28)
  - Nova Scotia HSW interviews (n=40)

- **Key Informant Follow-Up Interviews (July 2011) (n=7)**

- In-depth semi-structured interviews; Quantitative analyses; Qualitative team-based thematic analyses of transcripts
Conceptual Model: Nexus and Intersections
“Inside” Home Care

“*We Share the Care*”

Examples of ‘caring’ collaboration:

- Setting out medication for HSW to administer
- Performing lifts and transfers together
- Drawing bath so worker can bathe client
- Preparing meal, leave in fridge for worker to heat and serve later to client
- Writing out instructions or information to assist worker to:
  - know client preferences, capabilities, status
  - complete tasks efficiently
Family Carers Filling in the Gaps

- Limits of the ‘Care Plan’:
  - “What do you need? Is it on the list?”
  - Health Care/ Social Care/ “Hospitality”
- Time (the ‘50 minute hour’)
- Family as quality & care manager (often)
- ‘Revolving door’ of Home Care
  - Lack of continuity / constant (re) orientation
  - Importance of idiosyncratic knowledge
  - Challenges in dementia care
The Revolving Door

“Moving him from his wheelchair into the bed… [the new worker] didn’t know how to do that. He didn’t know how to operate the lift even. I showed him. Who am I to show him? [laughs]… these people, it’s like a revolving door. They come and they go…”

*Lara, 69, caring for husband, who has been receiving home support for 12 years.*
‘Why I became a HSW’: Previous Caregiving Experience
(Benjamin et al., *The Gerontologist*, 2008)
“I saw the caregivers and how they were treating my dad…there was some positive and negative experiences. Same with my mother… and I said, ‘This is what I’m going to do,’ because if I can make a difference then-- I can’t change the system but if I can make somebody’s life a little bit different then that’s going to make me feel better.”

Amber, 55 yrs, Canadian-born, HSW for 3 years

- Models of recruitment: Italy, USA (Unpaid → Paid);
- Some provinces (NS): labour force re-entry
Key Informant Perspectives: Policy Implications

- Supporting Caregivers:
  - Increase hours for respite
  - Improve the capacity, standardization & staffing of adult day care centres
  - Provide overnight care services
  - Recognize that non-medical home supports also support the caregiver
“If we don’t look at respite care, we are going to have two burned out people being placed into residential care.”

Alice, Home Support Manager, 18 years in the sector
Key Informant Perspectives: FPT Jurisdictional Issues

- Federal & Provincial support for family members who are caring for relatives with complex care needs:
  - Paid caregiver leave
  - E.I. supplements for caregivers

- Formal caregiver support should not be limited to “palliative” cases
Assumptions about…

.......Who Cares?
Home First: Reducing ALC and Achieving Better Outcomes for Seniors through Inter-organizational Collaboration

Leslie Stor-Hemsworth, Janet M. Farkas, and Susan Basilien

Abstract
Like many hospitals, those in the Mississauga Halton Local Health Integration Network (MH LHN) have used interprofessional collaboration to maximize system processes. Process improvements previously occurring in silos have started crossing hospital programs and systems within and beyond the hospital. The challenge is that few healthcare organizations consider, never mind implement, process improvements that traverse the LHN. This article discusses an innovation with a unique feature: concentration not only on interprofessional collaboration but on inter-organizational collaboration by professionals and providers throughout the LHN. The Home First approach exemplifies what is possible when culture is adapted to facilitate and enable inter- and inter-organizational collaboration and partnerships based on trust and respect. This approach has been spread and sustained successfully across the LHN, with alternative levels of care patients being reduced by 50% or greater.

Optimal patient flow is vital in hospitals to achieve operational effectiveness and efficiency. Over the past decade, it has been recognized worldwide that creating acute care capacity requires change through improvements that span the healthcare system. In February 2009, the Ontario Hospital Association (OHA) reported that 15,556 acute care beds (19% of acute care beds) staffed and in operation were occupied by alternative level of care (ALC) patients. (Alternative level of care is the term used by the healthcare system to describe patients waiting in one level of care but requiring another appropriate level of care.) Fifty-five percent of ALC patients were awaiting placement in long-term care (LTC). The
‘Home First’: The Front Page implies…

- There is a (suitable) home to go to

- Someone waiting at home, who is:
  - Vibrant, unencumbered
  - Able bodied
  - Female/ White/ Caucasian
  - Willing and delighted to care
    - apron, smiling, open arms

- Elderly client:
  - Faceless, genderless
  - Dull, frumpy grey clothing
  - Mobile with (only) single aid
  - Alone (most realistic?)

- Bottom Line:
  - Best outcome is going home
  - Caregiving ready to “kick in”
In reality: ‘Who Cares’…. 

- 70% of carers: age 45+; 25% age 65+
- 31% retired/homemakers (16%); 22% employed FT; 19% PT/SE
- 35% household incomes of $45,000+
- 15% first language other than English or French
- 8% care for two family members (usually, other parent)
- 70%: care work stressful (50% who handle responsibility very well)
- 70% need break from carework:
  - frequently (21%)
  - occasionally (47%)
- Stress:
  - significant (29%) or some (48%) emotional difficulties
  - finances (54%) and physical health (50%).
“I was going to the hospital and hiding...behind corners ... because they were trying to tell me I had to take her home. I had actually phoned this woman that had come, [asking], “What am I supposed to do?” ... that’s part of the problem with the way the health services are working right now. It’s, like, you can’t cope but they don’t want to just recognize that you can’t cope. They’re going, ‘You take her.’ You’re going, ‘I’m not taking her.’”

Libby, caring for her 88 year old mother
Contextual Issues/ Challenges:

- Canada: “Where one lives rather than what one needs determines what one gets” (Shapiro, 2001).
- Changing availability of family to provide care
- Changing profile of later life
  - Two generations over 65; growth of 80+
  - Ethno-cultural diversity (27% 65+ foreign-born)
- Expectations of aging in place
- Changes in Health Status:
  - “The Rising Tide” (Alzheimer Society of Canada, 2010)
- Health Care Workers: unmet need: recruitment and retention strategies
We can travel again!"

Now that mom has the help of a live-in certified Health Care Aide, we have peace of mind knowing that everything is just fine at home.

Thank You Drake Medox
Family Structure:
Availability of Surviving Adult Children

Proportion of females 65+ with no surviving children, among those living in the community, by age group, 2001-2051.

Taking the longer term view…

- David Foot’s 10 year planning window
- Boomers are turning 65, but real health care costs for people aged 80 – 85 and over
  - Keep focused on: at least two generations 65+
- Some aspects of aging and caregiving (a big bulge):
  - Huge and uncomfortable: Pig passing through a python
- Other aspects: life expectancy increasing (here to stay):
  - Common: 72 year olds with 98 year old mother
  - Wealthy nations: Gaining 5 hours life expectancy every day (T. Kirkwood, 2010. Why can’t we live forever. Scientific American, 303 (3): 42 – 49)
Per Person Average overall health care costs for continuing care patients in areas with/without cuts to social and preventive home care (Hollander 2001)

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Nexus Home Care Project

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Recent Manuscript Topics:
- Crises & safety in Home Care
- Ethno-cultural diversity in Home Care
- Perspectives of Elderly Clients
- Worker Recruitment / Retention
- Client & Family Member Satisfaction

website: http://nexushomecare.arts.ubc.ca

email: amm@exchange.ubc.ca