The structural burden of system navigation on families of older adults

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An increasingly salient issue

- Insufficient outreach to help families connect to resources

- Persistent assumptions

- Ever-changing information/service context

- Caregivers increasingly feeling pulled between multiple responsibilities/demands?

- 'Policy-making by other means'? (Herd & Moynihan, 2019).

- *More* formal services/supports available and/or *erosion* of appropriate services? (e.g., 'navigation to nowhere': Anderson & Larke, 2009)

Emerging and Existing Concepts

- Access to Care, Patient Navigation, Cultural Brokering

- System Navigation (Manderson et al., 2012)/Service Navigation (Davidson et al., 2020)

- Candidacy Model (Dixon Woods et al., 2006, Koehn, 2009)

- Linkage Processes (Carpentier & Grenier, 2012)

- Health literacy, navigational capital (Shim, 2010; Yosso, 2005)

- Care management or orchestration (Rosenthal et al., 2007; Sims Gould & Martin-Matthews, 2010)

- Information Work (e.g., Dalmer 2020)

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Research on Families of Older Adults and System Navigation

- Core theme of contemporary family care work
- Potentially more emotionally difficult than direct care
- Spans across care continuum, esp. salient at transitions
- Hinges on carer abilities, learning
- *Stressful* - Important aspect of burden?
- Carers' frustration with problematic systems

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Research Manitoba Establishment Grant (2013-17)

- Component 1: explore how family/friend carers experience navigating through systems, organizations and bureaucracy
  - Multiple qualitative in-person interviews over time (6 mos apart)
- Component 2: how formal navigators help families navigate systems; perspectives on common challenges
  - Qualitative in-person interviews
- IRPP extension (2019): how can we best address navigational burden faced by family caregivers?

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Caregiver Participants
(T1 n=32; T2 n=29; T3 n=17)

- 27 female, 5 male

- Average age 57, range 25-90

- 50% were married/common-law

- 6 racialized persons

- Overall highly educated, middle-to-upper income

- Average of 8.45 years in carer role

- 72% caring for a parent; 53% co-resident

- 75% employed in paid labour

- 8 caring for a person living with dementia

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Carers as System Navigators: Exploring Sources, Processes and Outcomes of Structural Burden

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Abstract

Background and Objectives: Structural features of formal care systems influence the amount, difficulty, and complexity of what carers do as they interface with those systems. In this study, we explored how carers navigate health and social care systems, and their experiences of structural burden related to features such as complexity and fragmentation.

Research Design and Methods: This qualitative descriptive inquiry drew on data from in-person interviews with 32 carers of older adults, which were analyzed first using inductive thematic analysis and then using structural burden as a concep-

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Navigational Work

- Navigating the mystery: digging and hunting
  - Antecedents and consequences

- Navigating barriers: pushing through, working around
  - Antecedents and consequences

- Navigating fragmentation: pulling/piecing together (coordination, oversight)
  - Antecedents and consequences

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Summary of Key Findings

- Features of formal services shape need for, difficulty of navigation

- Navigation work does not stop after services are accessed

- Key pathways: a) time and energy required; b) emotions and emotion work. More indirect: c) shaping service pathways and outcomes of older adults

- Broaden our conceptualization of carer burden
  - Conceptualize structural burden (Taylor & Quesnel-Vallée, 2017) as long term process over caregiving careers, with potentially long-term implications

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The emotional landscape of accessing and navigating formal supports for older adults in one Western Canadian city

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Emotions may be pivotal to understanding how fragmented care systems for older adults can generate structural carer burden. Analysing 78 interviews with 32 carers who navigated formal services in a Western Canadian city, we explore and distinguish between emotional responses to navigation challenges and the emotion work that navigation entails. Emotional responses had a temporal dimension, and, at times, both positive and negative emotions coexisted simultaneously.

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Emotional Landscape

- Emotions infuse navigational work, impact carer burden.

a) emotional responses to navigation-related stressors

- Lost/confused; acute distress; worry/guilt; frustration; dismay
- Tied to sense of responsibility, perceptions of the system
- Over time, successes could generate pride/confidence yet this did not necessarily reduce resentment and frustration

b) the 'emotion work' (Hochschild, 1983) of navigation

- How navigational experiences intersect with generalized emotion work of caring
- Interacting with formal professionals requires emotion work

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How can we address system navigation challenges?

- Onus is currently on older adults/families to do this work, generating inequities and structural burden

- Recognize navigation as a public issue, not private trouble

- Better/improved information available about services/resources/supports?

- Formal system navigators?

- Carer/'patient/client' friendly systems? Integrated care…

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Research on 'Patient Navigators'

- Originally a formal program/intervention for cancer patients; eliminate barriers to accessing care

- Growing popularity/expansion (older adults – Manderson et al., 2012), yet still tends to be 'disease' or 'setting' specific.

- Conceptual/role diffusion/lost of focus, little guidance
  - Patient-centred and/or system-centred design

- Some interest in lay/volunteer programs

- Navigation support sometimes the formal/informal role of other professionals, privately paid case managers

Formal Navigator Participants (n=22)

- 11 Health authority employees (navigators, LTC, home care case coordinators, social workers, etc.)
- 8 Employees of local non-profit agencies serving older adults and/or carers
- 3 Private navigation consultants
- Average length of interviews ~ 1 hr.
- Interpretive and thematic analyses

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How formal navigators interpret their roles supporting families

Laura Funk and Wanda Hounslow

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Abstract

Purpose – The purpose of this paper is to examine how formal navigators interpret their roles supporting families of older adults.

Design/methodology/approach – This study was an interpretive inquiry informed by critical gerontology and discourse analytic methods. Interview data were collected and analyzed from 22 formal service providers who helped older adults and their families navigate health and social care resources in one Western Canadian city.

Findings – Although acknowledging structural barriers to service access, participants emphasized individual empowerment as their dominant strategy, interpreting their roles as providing information and education about services. In part, these interpretations may reflect the limited nature of their ability to help broker access or advocate; in part, they may also reflect the broader political and economic discourses surrounding care in Canada.

Research limitations/implications – When providers position navigation and access to care as individual problems, this can obscure structural burden as well as potential inequities among older adults. Future research should examine whether navigational role interpretations are similar or different to those of navigators in other regions. Navigators in other health and social care contexts may enact differing meanings

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Formal Navigators - Role Interpretations

- Targeting individual-level - knowledge, skills, dispositions.

- Providing support during key transitions or crises, or when asked

- *Cannot* address - insufficient resources

- Coaching families towards particular options

- Supporting organizational goals

- Less emphasis - active involvement, hands on, advocacy (except consultants).

- *Notable silence* – addressing structural inequities in access

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Formal Navigators – Key Findings

- Rare acknowledgment of systemic/structural issues

- Many emphasized their professional backgrounds, specialized experiences make them well suited to help

- Participants' interpretations/role definitions can be connected to limitations in job descriptions, time, workload constraints, and broader assumptions of individual/family responsibility

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Relieving the Burden of Navigating Health and Social Services for Older Adults and Caregivers

Laura M. Funk

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What we need to know more about

- Cross-sector knowledge transfer about navigation-related challenges, needs and solutions

- Tease out components of successful navigator supports and approaches – what works, why, in what contexts?

- Evaluate effects of navigational supports on care burden, equity, and patient/client outcomes

- How does complexity, intensity of navigation change over time for individuals/families?

- Have changes related to the COVID-19 pandemic shaped the nature of system navigation work performed by families?

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