Roles and Guiding Principles for Health System Navigator Programs Serving Older Adults and Caregivers

Lori E. Weeks, Gloria McInnis-Perry, Colleen MacQuarrie & Sanja Jovanovic

Our Future is Aging: Current Research on Knowledge, Practice and Policy, June 16, 2016
Mount Saint Vincent University
Definitions

**Transitional care** is a set of actions designed to ensure the coordination and continuity of healthcare as older adults transfer between different locations or different levels of care within the same location. Essentially, older adults and their caregivers are the common thread moving across types of healthcare, and transitional care supports them through this process.

Definitions

Health System Navigators (HSN) collaborate with colleagues across sites of care and endeavour to ensure that transitions are safe and effective. They provide many services including: care planning, home visits, patient education, assistance with medication management, fostering coordination and continuity across health settings and early identification and response to health changes.

Rationale

• Older adults navigate between health care settings
  • Acute care
  • Community-based care
  • Residential care

• How can we improve older adults’ experiences when changes in health status occur and transitional care is warranted?

• We need evidence-based recommendations to provide better transitions between these settings
There is a lack of consensus on the desired characteristics of the role of HSN. There is also a lack of knowledge about overarching principles to meet the needs of older adults with multiple chronic conditions and their unpaid caregivers.
Methods
Focus Groups with Older Adults and Caregivers

- 10 focus groups with 98 participants
- 78% women, Almost ½ 75+
- Cross section of educational levels
- 21% receive the GIS
- 60% live in rural places, 36% live alone
On-line survey of people working in the health system

• 52 usable surveys
• 84% women
• Type of position:
  • 46% provide direct services to clients
  • 31% health admin, policy, evaluation, research, planning
  • 15% managers
• Type of service:
  • 34% work in hospitals
  • 19% work in nursing homes
  • 15% in a physician office or health clinic
Questions Asked:

1. In your experience, what are the issues for older persons going through the transitions between acute, community-based and residential care?

2. What currently works well in these transitions on PEI?

3. What are the challenges, snags, gaps in these transitions?
4. What attitudes have you encountered by older persons, families, caregivers, professionals or others transitioning among acute, community-based and residential care?

5. What are your suggestions to improve the transitions among acute, community-based and residential care?

6. What are the priority questions for research on transitions among acute, community-based and residential care?
Results
Theme 1: Overall Guiding Principles for Health System Navigator Programs

1. Person-centred
2. Needs-based Eligibility Criteria
3. Easily Accessible
1) Person-centred

- “I think we have to be careful that when this movement is made that it is made with the needs of the person in mind and not about the cost, such as we can’t afford to keep this person at this level of care, so we will kick them out back to their home. Which is reactionary rather than a planned situation (FG2).”

- “This should be someone who only has a select number of clients they work with at a time as to build a trusting relationship and get to the core of what this person needs (OS28).”
2) Needs-based Eligibility Criteria

- HNS programs should be targeted at those who most need them:
  - people with insufficient financial resources
  - people with serious health conditions
  - people who lack support from unpaid caregivers
  - people who unpaid caregivers who require support
3) Easily Accessible

• “A one stop portal plus a physical person to answer the questions on all aspects of the process from knowing the options to advice on end of life processes. There is currently a wealth of individual knowledge but no independent central advice point (OS29).”

• A 1-800 number or similar for persons to call to ask questions of
Theme 2: Roles Identified for Health System Navigators

1. Information and education
2. Health assessment
3. Planning for future health needs
4. Supporting the acceptance of necessary care
5. Facilitating access to the right services at the right time
6. Facilitating communication between services
7. Facilitating the discharge planning process
8. Advocacy for older adults and caregivers
1) Information & Education

- In half of the focus groups, participants identified a lack of information about available programs and services.

- Supporting seniors with relevant information not only helps them prepare for transitions but also:
  - “supporting and providing meaningful information truly is useful to them in maintaining health status “ (OS57).”

- Comprehensibility of the information was problematic when using the internet:
  - “I looked up stuff on the internet, but none of it was really helpful because it was a mass of information (FG1).”
2) Assessment

• Individually or in cooperation with other service providers

• Conduct assessments at appropriate times:
  • “Do not complete assessments when seniors are in their most fragile state (OS59)”.

• HSN could potentially assess a broader range of issues than a professional working in one area.
  • “Assess the client according to their lifestyle (mental wellness, eating choices, activity status) family supports safety assessments in home, living arrangements, financial status (OS38)”.
3) Planning for Future Health Needs

• Most people are going to require a higher level of care as they get older and that’s not a surprise but the whole fragmented system we have treats all these transitions as surprises and it’s not systematic... I’ve seen is when this happens, it is a crisis to the families and it shouldn’t have to be a crisis. There should be a system connecting all these pieces together so that’s it’s coordinated. (FG2).

• HSNs could also be particularly useful in helping older adults and caregivers make decisions during an unanticipated event:
4) Supporting the Acceptance of Necessary Care

- Older adults may not want to accept care for various reasons including being in denial about needing help, not wanting to move, or not wanting assistance with personal care.
  - “Resistance by family and clients to move to community homes when it is very obvious that client and family no longer able to cope at home (OS83).”

- “It seems that caregivers need more support, respect and help. We should be listening to the stories of the caregivers not just the patients! The caregivers need help as well and seem to be forgotten (FG1).”
5) Facilitating Access to the Right Services at the Right Time

• “She went at least 4 times a week by ambulance for about a month and finally they put her in a nursing home. But if there were a nurse there on duty to come down and check her out and assure her she is fine then she would be fine without the ambulance. That’s just one example (FG7).”

• “I would like to see more areas or services/supports for the caregivers of the older persons. Often, you see these caregivers burnt out and do not know where to go for help or assistance (OS74).”
6) Facilitating Communication between Services

• “In the hospital there may be a team, in the nursing home there may be a team, but to get to one from to the other there is no team (FG2).”

• “Maybe we need some sort of generalist to act as a coordinator, and there would be problems with that because when you have silos you have people who are used to doing things their own way on their own terms and not communicating, not taking advice or giving it, but none the less without an overseeing structure we will continue to have the silos (FG2).”
7) Facilitating the Discharge Planning Process

• “I know some people have been discharged too early and sent home to look after themselves and ends up getting sicker or even dying, who looks after the discharging? Why is there no one to follow up with a patient after they are discharged to make sure they are getting along okay?”

• “I don’t know if there is someone who can sit down with the senior and family and say this is what you would need if you went back home, this is how you get it, what you get and how much it costs (FG3).”
8) Advocacy for Older Adults and Caregivers

- “We need an advocate and we need someone who sees the patient through until they are looked after ... Someone to look after you from start to finish to make sure you are taken care of (FG8).”

- “If the resident does not have an advocate in their corner fighting for certain needs then they can get lost in the system (OS28).”

- “Participants observed how: “seniors are a marginalized and too many assumptions are made about what they need without asking them (OS59).”
Implications: Policy, Practice & Research
• Incorporating HSN to support older adults and caregivers has the potential for transformative change within the health care system
  • greater focus on preventative and educational approaches,
  • Facilitating coordination and continuity of care

• Which healthcare professionals should fill this role? What is ideal HSN training, credentials, skills, experience?

• From a person-centred perspective, can support advocacy and empowerment of older adults and caregivers
• Supporting older adults to use necessary care
  • Why and how should this be done?

• Future research
  • Comparative research between health systems
  • Data collected from HSN
  • Data collected from older adults and caregivers using HSN services
  • Greater diversity of participants
Acknowledgements

Funder:
Canadian Institute for Health Research: Health Services and Systems for an Aging Population, Planning Grant

Investigators:
Janice Keefe, Mount Saint Vincent University
Elizabeth Townsend, UPEI
William Montelpare, UPEI

Research Staff:
Lorraine Begley
Emma Gillis
Kaylee Blackett
Questions & Comments
Contact Information

Lori Weeks, Ph.D.
Associate Professor
School of Nursing
Dalhousie University
Halifax, Nova Scotia
Canada  B3H 4R2

Phone: 902-494-7114
E-mail: lori.weeks@dal.ca