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Managing Continuity of Care for Continuing Care Services in Two Health Regions: Perspectives on Waitlists

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** Over the course of the study, other co-investigators ceased being involved in the project as a result of transfers, retirement, etc. New co-investigators joined the team during the study as representatives of their agencies and are listed here.

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KEY IMPLICATIONS FOR DECISION MAKERS

The purpose of this study was to determine factors that influence continuity of care for older adults requiring continuing care services. Findings from analyses of continuing care waitlist data and interviews with waitlisted clients/families have the following implications:

- Clients and their families often expressed confusion regarding how the waiting lists operate. Regions should supplement verbal methods of communication with written materials to decrease confusion and improve the waiting experience for clients/families. Written information needs to be widely available in different forms (for example, electronic, hard copies of printed materials) and should answer questions about how the waitlist functions, average times on waitlists, how placements are determined for each category, how to access services while waiting, whom to contact with questions while waiting, and how to prepare for the transition to full-time continuing care.
- Regions may also need to provide families with a clearly identified single contact source, be it a case co-ordinator or organization charts/flow charts to ensure continuity of care during the transition to full-time continuing care.
- Family members often continue being involved after waitlisted clients are admitted to continuing care centres. Information on working with staff caregivers may increase the likelihood of continued positive family involvement with individuals living in continuing care facilities.
- Continuity for continuing care would be facilitated by ensuring databases have more information on functional needs of waitlisted clients, including diagnosis information, to help assist with future planning of services, facilities and education programs.
- Location of continuing care centre was of primary importance to family caregivers and thus has implications for planning of future centres.
- Evidence-informed decision making and planning is necessary. Specific measures of continuity for continuing care need to be developed and used to assess the effectiveness of waitlist management strategies from client/family perspectives and to enhance the regions' quality assurance programs.

EXECUTIVE SUMMARY

CONTEXT

The purpose of this two-phase project was to investigate continuity of care for older adults waiting for admission for full-time, publicly funded continuing care centres. Continuity of care may be defined as a service or chain of services that remains consistent or uninterrupted throughout the process of seeking full-time care, from initial contact to the point of placement in a centre providing that care. The research objectives of this study were to better understand (a) the nature of waitlists for publicly funded full-time continuing care in Alberta's two most populous health regions (here labelled Region 1 and Region 2) and (b) the experience of individuals and their family members as they wait for care. Of interest were waitlists for full-time continuing care in long-term care facilities and designated assisted living facilities, including enhanced designated assisted living facilities (Region 1) and designated enhanced lodges (Region 2) (See Appendix A).

IMPLICATIONS

The quantitative and qualitative findings have implications for policy and decision makers within the study regions and across regions in Canada. These implications relate to communication, resource allocation and outcomes measurement. Communication with older adults and their families about continuing care services must take various forms to be effective in reducing confusion about waitlist operation and access to services. Resource allocation considerations include increasing the supply of designated assisted living facilities for individuals with special needs and increasing staff in regional offices to assume case co-ordination responsibilities for waitlist clients and families. Outcomes measurement, including defining and assessing the effects of strategies to improve continuity for continuing care, must be undertaken by regional health authorities.

APPROACH

Phase I involved a seven-year review of waitlists for continuing care centres in Region 1 and Region 2 (1999–2006). Data from the Home Care Information System (2004–05) were also analyzed to determine services used by clients while waiting. Phase II involved interviews with waitlisted clients and their families to explore their perspectives while waiting for full-time continuing care and after they had received an admission offer.

RESULTS – PHASE I.

The primary results related to full-time continuing care waitlists are as follows:

In both regions, waitlist clients were mostly female, approximately 80 years of age and were waiting for admission to long-term care centres. Limited information was available on medical diagnoses of waitlist clients.

- Region 1 – Wait times for long-term care admission were an average of 25 days; for designated assisted living facilities, 44 days. Most waitlist clients were initially assessed in acute care settings; these clients waited the least amount of time for admission to long-term care (mean = 20.8 days) and designated assisted living facilities (mean = 37 days) as compared to clients assessed in the community – living in their own homes – or other settings.
- Region 2 – Most clients waiting for long-term care admission were assessed in acute care and community (personal home) settings; most waiting for designated assisted living facilities were assessed in the community. Compared to clients waiting in other settings like the community, clients waiting in acute care and geriatric assessment and rehabilitation settings waited the least amount of time for long-term care (mean ~ 13 days); those in acute care waited the least amount of time for designated assisted living facilities (mean = 23.6 days).
- Average wait times for admission to long-term care facilities generally declined in both regions, with some variability, from 1999-2006.
- In Region 1, when risk for institutionalization was rated as very high at assessment, average waiting times were shorter for long-term care and designated assisted living facilities/enhanced designated assisted living facilities. In Region 2, those with the highest risk scores waited the least amount of time for long-term care and those with the lowest risk scores waited the least amount of time for designated assisted living facilities/designated enhanced lodges.
- Clients waiting for long-term care in Region 1 used more hours of homecare per month than those waiting for designated assisted living facilities; the opposite was true in Region 2. Most hours of homecare service were provided by health care aides.

RESULTS – PHASE II

In our sample of 40, the waitlisted clients were mostly female (n=34) waiting in the community (n=23) in a supportive living environment (n=12) or in acute care (n=2). All 40 clients and/or their family members were interviewed while waiting; 26/40 were interviewed after clients were offered admission to a full-time continuing care facility; 24/26 had accepted admission offers. Most were using homecare services while waiting. Primary findings were as follows: (1) circumstances surrounding the decision to wait for full-time continuing care were described as *difficult, evolving over time, and being the “next step” in the client’s care continuum*; (2) the waiting process was described as *marked by uncertainty*; (3) families said they received information on waitlists and continuing care services from *various sources*; (4) the primary factor in choosing a continuing care centre was *location to the family caregiver’s home or work*; (5) *formal and informal supports/services* were used – most common formal supports were *assistance with activities of daily living and medication management*; and (6) after admission family caregivers expressed *relief and attempts at continuing involvement* in their loved ones’ lives.