ORIGINAL RESEARCH

Developing a Supplemental Assessment Tool for Younger Residents in Long-Term Care

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ABSTRACT

Background

It has been established that the needs of long-term care residents under 65 are distinct from those of older residents, and that these needs are not sufficiently met through the current model of LTC. Our goal was to create a supplemental assessment tool that can be used at the time of assessment to better represent the needs of this population.

Methods

Residents in the target age group (between 18 and 64), and staff who work with the target age group, were interviewed individually to identify important questions to be asked in the assessment tool. A preliminary tool was presented to the participants in a focus group, and feedback was used to make modifications to the tool.

Results

Questions developed from the study addressed several unique needs of this population, including the role of technology in their well-being, the need for time with visitors, and the need for supports as they transition in to LTC.

Conclusions

The needs of younger residents in LTC are unique, and through interviews with residents and staff we developed an assessment tool to better represent those needs at the time of admission.

Key words: long-term care, younger residents, assessment tool

INTRODUCTION

About 10% of residents in long-term care (LTC) are under the age of 65.(1) Younger residents in LTC often have complex physical needs associated with disabilities which have prevented them from living in their own home without considerable supports.(2) Many of them have little to no cognitive impairment, and those that do have cognitive impairment have different care needs than individuals with dementia. In contrast, older residents who live in LTC often have considerable cognitive decline, as well as physical needs.

The current LTC model is designed to best meet the needs of older residents, with social activities that are more appealing to the older generation and often little-to-no access to technology within the facility. Additionally, much of the research that exists about residents' experiences in LTC is focused around older adults,(3) which presents a challenge in assessing how effective the current care model is in meeting this population's needs. In the research that has been conducted, several areas have been identified for improvement of the experience of these residents. These include feeling as though they are not meeting the normal milestones for their age group,(3) a lack of engagement in the facility,(3) and struggling with the loss of independence.(4) Some of these issues exist because of the nature of LTC, in which a large population of older individuals are living with the younger generation. The older generation's interests are often inherently different from the younger generation's, such as in the music they enjoy or in the social activities of whichthey partake. Additionally, it can be difficult for younger residents to see their older co-residents decline as their dementia progresses. Ideally, younger individuals would be able to have their care provided in a private home.(4) However, due to financial barriers, lack of other housing and care options, and insufficient social support, this can be unattainable for this population.

There have been alternative methods of care delivery for this population developed, which include special housing programs where multidisciplinary teams provide care such as home care and physical therapy.(5) While these methods can improve the quality of life for this population, financial and geographical barriers can prevent these programs from being utilized.(5) Especially for people with disabilities living outside of urban areas, there can be difficulty accessing these programs, and they often require payment by those using the services.

The current study is a continuation of a previous study titled "From Surviving to Thriving." An objective of this study was to contribute new knowledge by developing a summary profile of younger adult residents from across Nova Scotia at the time of admission using variables from the interRAI home care assessment prior to nursing home admission.(6)

The sample included over 1,400 clients admitted to LTC, aged 19-64 at the time of assessment. Analysis was conducted on participant age, gender, income, reasons for admission, geographic location, and health status (i.e., diagnosis of disability, ADL, IADL). Results indicated that future research should focus on identifying processes at time of admission to gather more information on variables, such as prior employment, civic participation, and inclusion, to contribute to promoting meaningful participation and client-centered assessments before younger residents move into LTC. The purpose of the current study was to utilize findings of the prior research to create a supplemental assessment tool which could be used in the assessment of younger LTC residents (18–64) This is intended to be used in addition to the interRAI tool.

METHODS

The research was conducted at one LTC facility in Halifax, Nova Scotia. Compared to other facilities in the area, this facility has a high proportion of residents between the ages of 18 and 64, and the facility has an established interest in improving the experiences of these residents.

Currently the InterRAI home care assessment system is used to assess all residents, including younger residents. This is performed by home care to determine their needs and appropriateness for LTC before admission. This tool aims to understand the needs and preferences of individuals entering LTC, but does not ask in detail about needs unique to this population. For example, social functioning is one domain of the InterRAI tool, asking if an incoming resident likes to spend time with others, expresses conflict with family/friends, has recently experienced a change in their social involvement, or feels isolated. It does not ask about the types of activities a resident would like to participate in the facility, or about groups they are a part of outside of the facility and would like to continue to be a part of.

REB approval was obtained from Dalhousie University, and approval was obtained through the LTC facility's Research Advisory Council. Inclusion criteria were residents ages 18–64 or staff who worked with this population, who were willing and able to participate in the individual interviews and focus group. Those who did not fit these criteria were not eligible for the study. Posters were used to recruit residents at the facility, and a flyer was sent to staff describing the study and providing contact information for a member of the research team. Four residents and four staff members participated in the individual interviews.

Areas seen as important to this population in the previous "From Surviving to Thriving" research were used to create a questionnaire for the participants. For example, prior employment was an area of consideration unique to this group that was identified in previous research, and was thus an area of inquiry on the questionnaire in the current project. Information about the study's goals, methods, and inclusion/exclusion criteria was available electronically to participants prior to the individual interviews, and consent was obtained at the time of the interview by the interviewer. Participants were able to withdrawal their participation in the study before meeting in person with the interviewer, or before questions were asked in person during the interviews.

The interviews were conducted anywhere in the facility consented to by the participant, and the questionnaire was used as a script to structure the interviews, with the opportunity for participants to expand on points they felt were important but not directly asked about in the script. The responses were audio recorded, and after the individual interviews had concluded, recurrent themes identified were used to create a preliminary assessment tool. Any responses that were described by more than one participant were considered for inclusion in the preliminary assessment tool, with many questions being described as important by all eight participants. Feedback given in the interview portion of the study was compiled and used for the creation of an assessment tool to be used upon admission in to LTC. Key areas in which the needs of this population could be met more effectively were identified based on responses. These areas in which the admission process could be improved were incorporated into the assessment tool after Phase One of the study.

Four staff and two residents consented to participat in the focus group to give feedback on the tool, with the other two residents withdrawing from that portion of the study after individual interviews had concluded. The focus group was a two-hour session, during which guiding questions were used to elicit feedback about the tool. Each question on the preliminary assessment tool was evaluated by the group for its merit in understanding the unique needs of the study population and questions were changed, altered, or removed based on this feedback. After the focus groups, feedback provided was analyzed for key areas for improvement of the tool. This information was incorporated into the tool for final reporting.

RESULTS

Through individual interviews and the focus group, we created a supplemental assessment tool for younger residents entering LTC (Appendix A). The questionnaire encompasses several areas in which the current assessment tool does not adequately address the needs of this population. One area identified as important was visits from family, especially younger children and partners. Sharing a room with another resident, especially if the roommate is older with potential cognitive decline, can present a challenge if the younger resident needs uninterrupted time for visits, and participants felt that this was important to communicate during the assessment process.

Another important area was the need to ask about access to technology and internet access in the facility, as several residents identified the internet as an essential part of their well-being. Residents interviewed spoke to the importance of social media in keeping in touch with members of their community, as they often cannot see each other in person but find great value in communicating virtually. One resident reported that they used Facebook to communicate with fellow

advocates for the disabled community in Nova Scotia, and expressed how important internet access was to them for this reason. Technology was described by residents interviewed as one of the most important factors in increasing their sense of independence. The facility was trying out the use of smart technology to reduce the need of assistance from staff, and one resident interviewed was a part of that program. They described the use of smart technology as having a positive impact on their experience in LTC. While their physical limitations prevented them from being able to turn on the TV or raise the head of their bed, they were able to tell the smart technology to do these tasks for them. They found they needed much less help from staff at the facility, and found the technology allowed them to regain some independence.

A third area identified as important to include in the assessment tool were questions about supports as they transition into LTC. Residents in this age group may or may not have adequate social supports to assist them in this transition, and those interviewed believed asking about this could identify residents who may want more assistance from the facility when they move in. They also expressed that some younger residents have pre-existing relationships with mental health professionals, and that support in maintaining those relationships after entering LTC may be beneficial for some.

DISCUSSION

While there were many beneficial questions identified, there were also some limitations of a supplemental assessment tool identified during the study. The chief limitation was finances; although the facility can learn a lot about the needs of these residents using the tool, the facility works within a limited budget. Additionally, this population often lives within a fixed budget, which also limits what can be accomplished using this tool. It was emphasized that, if the tool were to be used, it should not be taken as an agreement between the resident and facility, but more as a starting point to understand what is important to the resident, and to determine how the facility can work with the resident to help meet their needs, where possible.

It has been established in the previous research that there are many challenges facing younger residents in LTC, including a feeling of not meeting the milestones expected of people their age,[3] a lack of engagement in the facility,[3] and struggling with the loss of independence.[4] While this assessment tool can aim to improve the lack of engagement in the facility, the loss of independence and normalcy are largely unavoidable when a younger person lives in a LTC environment. These feelings were echoed in this study, with residents noting the abnormal experience of living with people who were so much older than they were. They described the distress of seeing residents they had become close with experience cognitive decline as their dementia progressed, and found it difficult to see residents pass away. Participants also described frustration with the loss of independence, which was partially associated with the conditions under which they were living, and partially associated with the setting of LTC. The need for independence can be difficult to balance with the need for care. While addressing the unique needs of the younger population can help with some of the difficulties associated with living in LTC, some problems faced by this population, such as a loss of independence, cannot be overcome while living in LTC.

CONCLUSIONS

Younger residents in LTC have unique needs that are not sufficiently met through the model of LTC. Through individual interviews and a focus group, we aimed to better understand how LTC facilities can support younger residents entering their care, and provide a supplemental assessment tool to be used during the assessment process. We also hoped to add to the literature surrounding the experience of younger residents in LTC. We found several areas in which the current assessment process could be improved in order to better address the needs of this population, and acknowledge the limitations of a single assessment tool in improving the younger resident's experience. Next steps for this research are to run trials of the tool to determine its practicality in assessing this population.

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CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

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APPENDIX A. Supplemental Assessment Tool for Younger Residents Entering LTC

1. Are there any activities that take place in the external community that you participate in regularly and would like to continue to participate in?
    a. Are there any ways we can help you to participate? (example: help scheduling access-a-bus, etc.)
    b. Before moving into LTC, what types of activities did you enjoy participating in?
    c. If we were to run these activities, what time of day would you be most likely to participate in them?
2. Do you currently use mobility aids such as a wheelchair or walker?
    a. Are there any ways in which we could help you in meeting your mobility goals?
3. Do you have any family (including children), friends, or a partner who would visit regularly?
    a. Would you be in need of uninterrupted time for their visits?
    b. How could we best support you in receiving visitors?
4. Do you currently have access to a computer or other device to use the internet?
    a. What kinds of support could the facility provide to help you utilize this technology?
5. Would you be interested in pursuing further education after you moved in?
    a. If so, is there any way we could help you in participating in opportunities to further your education?
6. Are you interested in volunteer opportunities within the facility?
    a. What areas would you be interested in volunteering?
    b. How much time are you willing to commit to volunteering?
7. Do you currently volunteer or work in the community?
    a. Do you think you would like to, and are able to continue this after you move into the facility?
    b. If so, is there any way we could help you maintain this part of your routine?
8. If you practice a religious or spiritual belief, are there any ways in which we could help you to continue this belief once you move in?
    a. Do you currently attend religious/spiritual services in the community?
    b. Are there ways in which you think we can support you in continuing to do so?
9. Do you currently have supports who are able to help you during your transition in to LTC?
    a. Are there any ways in which we could help with this transition?
    b. Do you currently utilize the mental health system (ex. Seeing a therapist, psychiatrist, social worker)?
    c. If so, are there any ways in which we can support you in continuing to use the system while transitioning to LTC?
10. What do you see as your ideal living situation within the facility?
11. Are there any other concerns you have about LTC that you would like to address?
12. Is there any other information about the facility you would like to have before moving in?