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Improving Transitions in Care for People with Dementia: the CARED Tool

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Improving Transitions in Care for People with Dementia: the CARED Tool

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Introduction and Literature Review

Highview Residences and Dementia Care

Highview Residences (HR) is a privately-owned care home in London, ON that specializes in dementia care. It was founded on the theory that people with dementia thrive in a home-care setting (Highview Residences, 2017). Dementia is a chronic disease characterized by impairments in memory and communication severe enough to affect daily activities (World Health Organization, 2017). Currently, 564,000 Canadians live with dementia and this number is projected to double within the next 15 years (Alzheimer Society of Canada, 2017). Dementia poses a special challenge to the healthcare system as it becomes an increasing public health concern.

Background of the Problem: Transitions in Care

Transitions in care (TIC) are movements from one healthcare setting or home to another setting, such as care home to hospital transfer (American Geriatrics Society, 2003). Current literature highlights that TIC are challenging for older adults and often lead to adverse events, low satisfaction with care, and high re-hospitalization rates (Naylor, 2009). Donna Hinschberger, Director of Care at HR, recognized that TIC are particularly challenging for people with dementia. Indeed, older adults with dementia undergo more TIC than other populations of older adults (Callahan, 2015). Furthermore, TIC are challenging for people with dementia due to impairments in communication and disorientation from being in a foreign environment (Aaltonen, 2012).

In one incident, a HR resident was physically and chemically restrained by hospital staff when she became agitated at the hospital. HR staff believed this incident could have been avoided had the healthcare providers (HCP) known about the resident, especially on a personal level. While HR staff knew her personally as a gentle and kind person, HCPs only interacted with her while she was agitated. More knowledge about the patient could have facilitated better patient care and mitigated responsive behaviours that resulted in use of restraints.

Improving Transitions in Care for People with Dementia

The question this project investigated was: *How can transitions in care for people with dementia be optimized?* Currently, an abundance of research exists that outlines the role of communication between care home staff and hospital staff on TIC. Early hospital readmissions were attributed to miscommunication, lack of coordination, and mistrust between care home staff and hospital staff (Kirsebom *et al*, 2012). Issues of miscommunication could be resolved by hospitals establishing a transition care nurse, who would facilitate better communication, support, and an ongoing relationship with care homes (Tew, 2013).

Stanyon *et al* (2016) found that HCPs lack training on how to communicate with patients with dementia. Communication with individuals with dementia is challenging because communication is impaired even in the early stages of dementia (Dooley *et al*, 2015) Additionally, some individuals in late stages are nonverbal (Ellis & Astell, 2017). Thus, training that focuses on communication with people with dementia as well as understanding what individuals with dementia experience is crucial. Research has shown that individuals with dementia respond better to certain forms of communication than others. For example, individuals with dementia displayed more resistance to care when care home staff used elderspeak, a form of infantilization (Williams *et al*, 2009). Instead, individuals with dementia respond better to person-centered communication and relationship-centered care, which enables HCPs to provide ongoing individualized care (Downs & Collins, 2015).

National and International Best Practices

National best practices for dementia care include the passing of Bill C-233, which led to development of a National Dementia Strategy in July 2017. The Dementia Strategy aims to increase research funding and enhance training for healthcare professionals relating to dementia care (Vogel, 2017). Canada, however, still needs to improvement in dementia care. Although dementia training programs currently focus on person-centered care, training is non-comprehensive and not standardized on a national level. Canada can adopt international best practices, such as the Silviahemmet dementia training program in Sweden. This nationally-recognized program offers extensive training for healthcare professionals on dementia care, and was reported to increase cohesion between medical staff teams (Prahl *et al*, 2016). Furthermore, Sweden has a nationwide e-Health Database while Canada only has regional healthcare databases (Webster, 2014; Adami *et al*, 2015). A nation-wide electronic healthcare record can aid with issues such as medication management, which is especially complex for patients with dementia (Deeks *et al*, 2016).

Methods

To answer the project question, a literature review was conducted to determine current challenges for people with dementia in TIC and how these challenges can be minimized. The search strategy used to find relevant literature is detailed in Appendix B.

Qualitative descriptive information regarding TIC was collected through three personal interviews to gain a broader understanding of mechanisms of TIC in London, ON. The interviews aided in understanding challenges faced by each HCP involved in TIC when providing care for people with dementia. Lastly, the interviews also provided insight on potential

strategies for enhanced care and recommendations on tools that would be most useful and feasible in London. Potential interview candidates were selected based on the following inclusion criteria: be a key HCP involved in TIC (care home, paramedic services, hospital emergency department (ED)) and have experience providing care to people with dementia during TIC in London.

Three interviewees were selected:

1. Donna Hinschberger: Director of Care at HR
2. Jay Loosely: Superintendent of Education and Training at Middlesex-London Emergency Medical Services (ML-EMS)
3. Janine Clift: Geriatric Emergency Management (GEM) Nurse at University Hospital

Three sets of tailored interview questions were developed using support from literature (Appendix C, Tables 1 to 3). Interviewees were provided with questions in advance to the interview. During interviews, interviewees were given the opportunity to contribute additional thoughts regarding the question subject matter. Follow-up questions were posed throughout to acquire a more comprehensive understanding and facilitate a conversation-style interview. All interviews were videotaped and voice recorded.

After each interview, group members made notes of the interview recording. The notes were collectively reviewed and compiled into summaries outlining unique perspectives of each HCP (Appendix C). Overlapping views and differences in perspectives were also identified.

By incorporating recommendations from interviews and best practice concepts from the literature review, a tool was developed that benefits all HCPs and people with dementia during TIC. The final tool was created on Microsoft Word, converted into a PDF, and made into an electronic fillable form using Adobe Acrobat DC.

Results

Literature Review

The literature review revealed three main themes to address the challenges faced in TIC for people with dementia: dementia care is specialized, person-centered communication (PCC), and relationship centered-care (RCC). All three themes pertain to maintaining wellbeing of the person with dementia throughout TIC by recognizing that care for the individual is complex, valuing their personhood, and recognizing their role in the therapeutic relationship. Maintaining wellbeing should lead to decreased distress and disorientation during TIC. In this population of people who are facing inevitable functional and cognitive declines, maintaining wellbeing is an especially important intervention (Mitchell & Agnelli, 2015).

Differing Perspectives on Communication

During interviews with D. Hinschberger and J. Clift, both HCPs reported strong communication during TIC coming from their jurisdiction and a need for improvement from the opposite party. D. Hinschberger stated that oral communication is the most reliable method of communication as it provides opportunities to ask questions. Nonetheless, she recognized that this is not always possible due to hectic schedules of hospital nurses. D. Hinschberger noticed that hospital nurses were often pressured to discharge patients. In such experiences, D. Hinschberger experienced improper handoff of information, resulting in multiple phone calls to the hospital to retrieve missing information. Consequently, care for residents was delayed (D. Hinschberger, personal communication, October 16, 2017).

In contrast, J. Clift reported that hospital nurses effectively communicate discharge information via phone call and documentation sent to the care home. Although J. Clift acknowledged that phone calls may be necessary to seek clarification, she claimed that clear documentation was the most consistent way of communicating. J. Clift also reported delays in care resulted from improper or lack of emergency documentation provided by care homes upon admission (J. Clift, personal communication, October 20, 2017).

Shared Perspectives on Communication

D. Hinschberger and J. Clift both agreed that communication needs to be improved between care home and hospital. This will provide care home and hospital nurses with information necessary to provide the best possible care for patients. Furthermore, J. Clift and J. Loosely stressed that TIC could greatly improve for people with dementia if someone who is familiar with the individual was present. This could ease communication barriers and make HCPs aware of patient preferences (J. Clift, personal communication, October 20, 2017: J. Loosely, personal communication October 5, 2017).

Comparisons Between Patients with Dementia and Pediatric Patients

When asked to make a comparison between patients with dementia and pediatric patients, J. Loosely indicated that the two patient populations were not comparable. He stated that the healthcare system favours care for children, demonstrated through entire hospitals dedicated to pediatric care. While children are immediately identifiable, patients with dementia cannot be easily differentiated from the rest of the adult population (J. Loosely, personal communication, October 5, 2017). J. Clift shared a parallel view, explaining that children almost never present at the ED alone. There is most often a parent or some other family member present to answer questions and advocate on their behalf. Unfortunately, this is not the case for older adults with dementia (J. Clift, personal communication, October 20, 2017).

Communication and Recognition: Engaging with Dementia (CARED) Tool

The CARED tool (Appendix D) is comprised of two components: a purple wristband and a double-sided CARED form. The purple wristband acts as an universal indicator of dementia, purple being the official colour for dementia (Alzheimer's Association, 2016). It also signifies that a CARED form is present. The front side of the CARED form provides information on *baseline mental status; code status*; and contact information for the person with dementia's *power of attorney (POA), next of kin, home care provider, primary care provider,* and *pharmacy*. The back side of the CARED form provides personalized information on *communication methods, assistive devices, behaviours, triggers to behaviours, calming techniques*, and a *get to know me* section. The fillable PDF version of the tool can be accessed, filled, and printed by anyone. The CARED tool will be packaged in a purple envelope and kept in a readily accessible place for when a person with dementia requires transport to hospital. Other emergency documents will also be housed in this envelope to make the documentation handover simple and efficient. The purple wristband will be put on the resident just prior to transport.

The goal of the CARED tool is to promote cohesion and optimized care throughout TIC by providing relevant and personalized information about the individual with dementia to HCPs. The tool will be easily identifiable and speak for the patient in ways they cannot. The goal is to avoid misunderstandings, mistreatment, and minimize situations resulting in restraints for patients with dementia to optimize their TIC experience.

Discussion

Dementia Care is Specialized

The CARED tool promotes social inclusion of patients with dementia through recognizing that people with dementia have complex needs, thereby allowing dementia care to be specialized to cater to such needs. The tool also combats ageist attitudes through promoting patient autonomy. Understanding that dementia is caused by abnormal aging, which adversely affects communication, promotes greater understanding from HCPs when responsive behaviours arise (Fukuda *et al,* 2015). Rather than chemically and physically restraining patients, which often precedes rapid decline in health, HCPs can assist patients in managing behaviours to avoid negative outcomes (Williams *et al,* 2011; Miller, 2008).

The sections outlining *behaviours* and *calming techniques* (Appendix E) on the CARED form help HCPs manage responsive behaviours. Each section contains an *other* option to fill with items that are not listed because individuals with dementia may have additional responsive behaviours or calming techniques. (Fukuda et al. 2015; Miller, 2008; Williams et al. 2011).

Personhood and Person-Centered Communication

PCC is a concept that emphasizes that importance of personhood in care. Mitchell and Agnelli (2015) define personhood as a status that someone has based on whether or not another person respects, recognizes, and trusts them as a person. Diminished personhood correlates with overall decreased wellbeing (Mitchell & Agnelli, 2015). Savundranayagam (2014) states that PCC helps maintain personhood by including individual preferences, values, and unique life experiences into care. Thus, PCC focuses on the individual, not the disease. Four strategies for PCC were identified: *Recognition, Negotiation, Facilitation, and Validation.* Of the four, *Recognition* most closely targeted the challenge of maintaining personhood throughout TIC. *Recognition* is acknowledging an individual as a unique person and providing care in a manner accordingly (Savundranayagam, 2014). Broadly, the CARED form is a tool for recognition as it provides HCPs with personalized information about patients that facilitates individualized care. Specifically, the *nutritional preferences/considerations/difficulty swallowing, get to know me, favourite topics of conversation,* and *interests/hobbies/songs* sections provide HCPs with the knowledge to provide care that is preferred by the care receiver. This allows HCPs to communicate with the care receiver in a way that acknowledges them as a unique individual with preferences, unique life histories, and interests.

Relationship-Centered Care

RCC provides an augmentative framework to PCC. It values HCPs as professionals in their field while also valuing preferences of patients and their families (Nolan *et al*, 2004). RCC specifies both the patient and the HCP are individuals with unique values, experiences, and perspectives (Beach & Inui, 2006). RCC recognizes the importance of autonomy and personhood, a foundation of PCC. However, it also subscribes to a relational view that values social relationships within which persons are “deeply connected and interdependent” (Nolan *et al,* 2004).

Nolan et al (2004) explain that RCC emphasizes developing authentic relationships so that HCPs are able to empathize with patients and serve patient needs. It is through these relationships that one is able to develop interest and investment critical to providing the best possible care. Building authentic relationships enhance quality of relationships, which mitigate severity of social isolation (Nolan *et al*, 2004). The *get to know me* and *favourite conversation topics* section on the CARED form will provide the HCP with personalized information about the patient that highlights individual preferences, experiences, and values. This information can be used to improve the quality of communication, through facilitating meaningful conversations, and therefore lead to more authentic HCP-patient relationships.

Interview Integration

The interview with J. Loosely proposed an insightful juxtaposition between care for children and older adults with dementia (J. Loosely, personal communication, October 5, 2017). The wristband portion of the CARED tool addresses this deficit by identifying patients as people with dementia. Furthermore J. Clift and J. Loosely stressed the benefit of having someone who was familiar with the individual present (J. Clift, personal communication, October 20, 2017: J. Loosely, personal communication, October 5, 2017). As it is not always realistic to have a family member present, the information in the CARED form replaces the need for a person to be present. The CARED form could easily be shared and applied by all HCPs.

Timeline of Implementation Activities

Appendix F outlines the timeline of expansion of the CARED tool from the HR-based pilot project to integration on the national level with the National Dementia Strategy.

Costs and Feasibility of Implementation

A detailed cost analysis of the CARED tool can be found in Appendix G. Each resident who utilizes the CARED tool will require one identifying purple wristband and one purple envelope. According to prices listed in Appendix G, each use of the CARED tool would cost $0.87. Cost of the CARED form is negligible, as it is printed on a single sheet of A4 paper.

The addition of the CARED form in TIC is feasible as it requires no additional time or work at the time of emergency compared to current practice. The CARED form will replace HR's current resident information sheet and be handed off in one envelope along with other required emergency documents. The envelope ensures efficient information translation during TIC. Putting the wristband on the resident is the only new step which may require some additional time, however, the wristband is a simple adhesive hospital wristband that is easy to put on.

Limitations

Limitations currently include mode of delivery, as the CARED tool exists in a physical form. HCPs, including care home staff and paramedics, must ensure that the form is physically handed over to HCPs. Continuity between care providers could be guaranteed with the existence of a nation-wide electronic health database. The CARED tool can be easily integrated into an online database as it already exists as a fillable PDF. Another limitation that arose while conducting research was the confidentiality of persons with dementia, which prohibited interviews with HR residents. Therefore, information was not gathered directly from the target population. Although the CARED tool is a step in the right direction, it does not solve the bigger problem. Policy reform that mandates dementia-specific training for HCPs interacting with this population is imperative as population of older adults with dementia is rapidly increasing.

Conclusion

Summary of Findings

Communication barriers need to be addressed in order to improve care during TIC for patients with dementia. Three main findings were found to combat these communication barriers: recognizing that care for people with dementia is different than care of cognitively healthy people, using PCC, and implementation of RCC values. The CARED tool provides a solution to these challenges by applying the three combative principles. Addressing the challenges faced in TIC for people with dementia is especially important for the future of care for older adults as the prevalence of dementia continues to rise rapidly, and with it, an increase in need for HCPs with the resources and knowledge to provide the complex care required to treat people with dementia.

Group Reflection

Through the process of trying to tackle the challenges faced in TIC involving people with dementia, we learned a lot as a team. First, we gained greater insight into the nuances of communication between places of care. Every healthcare setting seems to experience and perceive different challenges in communication and care for people with dementia. Interviews with D. Hinschberger and J. Clift revealed a difference in self-perceived effective communication by care home and hospital nurses. Despite this difference, both parties believe patient care would see positive benefits from increased and more effective communication (D. Hinschberger, personal communication, October 16, 2017; J. Clift, personal communication, October 20, 2017). We realized just how needed a coordinated care system is and just how much vulnerable populations like people with dementia would benefit from this. Second, our knowledge of dementia and the impact it has on the individual's and their family's wellbeing was substantially increased. We have developed great empathy for older adults who are living with the frightening and progressive disease, dementia. It is this empathy that lit a fire in us to put forth our very best efforts to make TIC less of a traumatic, disorienting, and stressful situation for people with dementia to be in. Although their functional cognitive decline is inevitable, we learned that through the dedicated, compassionate care style of our community partner D. Hinschberger that it is worthwhile and necessary to make an effort to maintain the wellbeing of people with dementia. As a team, we learned the importance of quality care and communication. We learned that even as students, it is possible to make a difference in the lives of older adults with dementia as long as you are willing to put yourself in situations that challenge and propel you forward.

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Appendices

Appendix A: Abbreviations

Highview Residences (HR)

Transitions in care (TIC)

Healthcare Providers (HCP)

Emergency Department (ED)

Middlesex-London Emergency Medical Services (EL-EMS)

Geriatric Emergency Management (GEM)

Person Centered Communication (PCC)

Relationship Centered Care (RCC)

Communication and Recognition: Engaging with Dementia (CARED)

Power of Attorney (POA)

Appendix B: Literature Review Search Strategy Keywords

<u>Introduction/Background Information</u>

Transitions in Care

Dementia OR Alzheimer's Disease

Elderly OR Senior OR Older Adult

Communication

Long-Term Care OR Nursing Home OR Care Home

Hospital OR Emergency Department OR ED

Nurse OR Registered Nurse OR RN OR Hospital nurse OR Care home nurse

Paramedic OR Emergency Medical Services OR EMS

<u>CARED Form Development</u>

Person Centered Care

Person Centered Communication

Recognition

Relationship Centered Care

Dementia OR Alzheimer's Disease

Elderly OR Senior OR Older Adult

Communication

Behaviours OR Responsive Behaviours

Calming Techniques

Triggers

Appendix C: Interview Results

Table 1. Interview questions and abbreviated answers from the interview with Donna Hinschberger, Director of Care at Highview Residences.

Question	Answer
1. Can you tell us about your career and what you do?	• Director of care at Highview Residences • Registered Nurse for 27 years • Previously a manager and ED pediatric nurse • Been working at HR in dementia care for 6 years
2. Could you tell us about the issue in transport of residents with dementia?	Protocol: Call 911, ambulance picks them up, go to the hospital with EMS staff, may be hours before POA or family member is able to come Concern: That they are alone, they are confused, they don't understand what is going on, and they aren't able to communicate effectively about their feelings
3. Please describe the instance (with a specific resident) that made you realize that transitions in care for people with dementia are an issue.	Specific experience: • Resident became lightheaded, wasn't responding normally, pale and clammy, history of cardiac issues, blood pressure was very low, called 911. Taken by EMS to the hospital. • Found out that her POA was not able to be there so she was alone. Became very combative, confused and agitated. Had to chemically and physically retrain her Q: do you feel she was mistreated? • I think her treatment could have been different if they knew her and/or how to communicate with her • She was a very kind person- if their approach was gentle and understanding and maybe knew something about her (that she was from Germany, that she liked to knit) they may have been able to establish some sort of relationship with her and they would have been able to avoid

	either chemically or physically restraining her, or both. I think that would have been a better solution.
4. What factors play into why and when a patient is sent to the hospital?	• Depends on what is going on with them • We have nurses that can provide medication and oxygen • If they require more advanced care or require diagnostics or blood work, we will send them to the hospital
5. What are your perceptions on the role that the retirement and care homes play in coordination and communication of older patients' transport, admittance, and discharge from the hospital?	• Admit patient by calling 911 • Go to ER, may not be admitted to the floor if they can stabilize them in the ER • If they do get admitted, we call daily to get an update • If something is changing (had a stroke or cerebrovascular accident) they may require a higher level of care when they come back • In that case, we would communicate with the team there (hospital) to determine what needs they needed (physical therapy, occupational therapy, different meds, equipment) • So there is constant communication between the nurses at Highview and the nursing staff and care coordinators at the hospital while someone is admitted
6. Are there any gaps in communication between retirement and care homes, first responders, and the hospital that you are aware of? Please speak to that.	• Sometimes difficult to get hold of the hospital nurse as they are very busy • there have been times where the Highview nurse will call and they are unable to get information • Hospital nurses are pressured to get the resident or patient out of the hospital quickly. • Trying to facilitate a quick transfer back, resulting in improper hand-off

	• They should be communicating with us about any changes in their care. • There have been times when that has not happened, and they have been sent back • We have had to call back to the hospital and get some information that was missing Q: Did that contribute to hospital readmission? • No, but it did contribute to delayed care • Not able to order new meds and pick them up from a pharmacy or get specific equipment delivered
7. What do you think is the best form of communication that should be used between the hospital and retirement and care homes?	• Phone call because it gives the opportunity to ask questions • First Highview will call the ED to see if they have been admitted. • If they had been transferred to a room, we would ask for the nurses station number for that floor then ask for the nurse who is caring for that resident. • If they are already set up for discharge, then Highview would speak to the discharge planner
8. What is being done well for transitions in care for residents with dementia that hospital nurses should continue to practice?	• When we have the opportunity to speak with the nursing staff and explain what we need and why we need it they have been very supportive and compliant with us which is helpful
9. Who is responsible for bringing residents with dementia back to Highview after discharge from the hospital?	• POA or family member • If not available then van (Voyageur)
10. What are some things that anyone interacting with	• Be kind and very patient - takes time for them to communicate their needs

patients with dementia should know?	• Best way to establish a relationship is to show your genuine concern and interest in helping them
11. Is Highview Residences a typical dementia care home?	• Above and beyond. High standards of care. We are a home not a facility or institution. • Like to think everyone provides the best care possible but you always hear horror stories that suggests otherwise - unfortunate truth about health care

Unique Perspectives from HR. D. Hinschberger described the specific incident experienced by a HR resident that made her realized that current transitions in care was an issue for people with dementia. On one occasion, a resident's blood pressure had dropped very low and was not responding normally. D. Hinschberger called 9-1-1 for transportation to hospital because of the resident's history of cardiac issues. Despite the resident's POA not able to attend, the resident still needed to be taken to the hospital. D. Hinschberger reported that this is often the case for residents of HR. The transition from care home to hospital is stressful and scary because the resident is alone, confused, does not understand what is going on and are unable to effectively communicate their feelings. D. Hinschberger later discovered that the resident was very combative during her transition due to confusion and agitation. As a result, the resident was chemically and physically restrained. Knowing that the resident was a very kind person, D. Hinschberger felt that the resident had been mistreated and treatment could have been different had the HCP known how to communicate effectively with the resident. A gentle and understanding approach in combination with establishing some sort of relationship with the resident have led to a more positive outcome. D. Hinschberger advises that people interacting with people with dementia must be very patient as it takes time for needs to be communication. Additionally, the best way to establish a relationship is to show genuine concern and interest in helping.

When asked what factors are considered by care home nurses when a patient is sent to the hospital, D. Hinschberger replied that it is completely dependent on the resident. Aside from acute medical emergencies, transport to the hospital is decided on a case by case basis. Although HR is staffed by a registered nurse who is able to provide medication and oxygen, the scope of care is limited. If a resident requires more advanced care, diagnostics or bloodwork, they will be transported to the hospital (personal communication, October 16, 2017).

Table 2. Interview questions and abbreviated answers from interview with Jay Loosely, Superintendent of education and training at Middlesex-London EMS

Question	Answer
1. Can you tell us about your career and what you do?	• Superintendent of education and training for ML-EMS since 2002 • Oversees training and education for all paramedics • Previously a registered nurse, primary care paramedic, advanced care paramedic, and teacher at Fanshawe College
2. Were you trained on how to deal with the older population?	• No, do not receive a lot of training on the elderly patients
3. Was there any specific training on working with patients with dementia?	• ML-EMS provided additional training for their paramedics a couple years ago regarding dementia • Training was offered by a nursing home in London • No training in Fanshawe's paramedic program
4. Can you please give us an overview of the transport process from long term care homes to the ED?	• 9-1-1 call from care home • Care home staff will pull patient's chart and provide report (medical history, medications, allergies, etc.) and other paperwork to paramedics upon arrival • Paramedics transport patient to hospital and must relay information provided by care home nurse to hospital nurse • Like a broken telephone game, some information may be lost during the relay of information • Communication occurs through paperwork and oral communication; most important points will be vocalized
5. What kind of problems are you faced with when transporting a patient with	• When no escort or family member is present during transport to hospital (the case most of the time)

dementia?	• Paramedics are unaware of patient triggers because everyone is different • Patient may be confused about who you are and why they are there
6. What happens at the hospital when the patient with dementia arrives?	• Patient arrives on stretcher in hallway • Paramedic must stay with patient until handover of information to hospital nursing staff occurs • Wait time can range from 30min-4hours before patient is moved to hospital bed • Information may be lost during exchange • Nurse may or may not be aware of the patient's dementia • Nurse does not know the patient either
7. How does the experience of patients with dementia compare with the experience had by pediatric patients coming into the ED?	• Not comparable • Pediatric patients usually get seen much quicker • Much narrower scope • Every peds nurse is aware of challenges present in communicating with kids, all know how to talk to kids • Family members usually present for kids • Specialized hospitals for kids • Older adults with dementia do not receive special treatment, they are pooled together with all other adults in the ED where scope is much broader
8. Can you please tell us about a specific time that you transported a patient with dementia? What challenges did this pose? How did you work through them?	• Been a couple years since last transport • Challenges are the same no matter who is performing the transition • Must get a good patient history to determine triggers, what calms them down and makes them feel comfortable
9. Are there any specific strategies or tools you use	• Paramedic training very useful, received positive feedback

when working with patients with dementia?	• Conditions are often times non-critical, therefore care homes should try to contact family first to see if anyone can accompany patient during transitions (even if it means waiting an hour before calling for transport) • "Cool-aid form" is an information sheet created by individuals (usually for older adults) with medication conditions that is kept on the fridge in the case of emergency, paramedics will go straight to fridge to check for presence of form
10. What would be helpful in working with patients with dementia?	• Education and knowledge • The more you know about dementia that better prepared you will be to engage with patients with dementia • Provide understanding of why patients are acting out
11. Do you know anyone we can talk to in ED that could help us gain a better understanding of this problem?	• Emergency nurse • Triage nurse

Unique Perspectives from ML-EMS. The interview with J. Loosely revealed that current paramedic education programs, such as the primary care paramedic program at Fanshawe College does not prepare graduating paramedics to interact with older adults, let alone older adults with dementia. ML-EMS is a special case because they recognized the challenges associated with transitions in care for individuals with dementia and provided additional dementia training for all Middlesex-London paramedics. J. Loosely indicated that education on the topic of dementia is key for paramedics to understand why patients with dementia express responsive behaviours. Paramedics responded very positively to the dementia training as it provided the knowledge base and preparation necessary for engaging with patients with dementia during stressful times like transitions in care.

Prior to transport, paramedics try to gather as much information regarding patient responsive behaviour and calming techniques as they can. J. Loosely reported that it is the

paramedic's responsibility to hand-off the documentation provided by the care home to the hospital nursing staff. A combination of oral communication and paper documentation is used to relay patient information during transitions in care. While information can generally be found in the paperwork, the most important pieces of information are emphasized vocally between care providers. This is when he compared transitions to care to a game of broken telephone because information is inevitably lost at each hand-off. Once paramedics arrives at the hospital with the patient, they can be subject to wait times ranging from 30 minutes to 4 hours before the information handoff occurs. This poses an issue because important information can be forgotten and subsequently not communicated properly to hospital nurses (personal communication, October 5, 2017).

Table 3. Interview questions and abbreviated answers from the interview with Janine Clift, geriatric emergency management nurse at University Hospital.

Question	Answer
1. Can you tell us about your career and what you do?	• GEM nurse: 2004 pilot project introduced by LHIN to reduce hospital readmissions of seniors • Resource to increase capacity within nursing department for older adult care • Provides link to community services • In University Hospital ED • Mostly sees frail community-dwelling older adults but will see those from long-term care as well if there are issues
2. Can you please share some experiences of coordination and communication when patients with dementia are transferred from long-term care homes to hospital? Are there any shortcomings of this process?	• Most long term care homes have computer generated care plans and send them with residents when they come to ED • Looking for baseline function and cognitive function • Vulnerable, don't have another adult with them • Children would never come in by themselves • Encourage someone who knows the patient or resident comes with them to advocate

	• If this isn't possible the documentation about who is the contact person, what medications are they taking, how do they take the medications (i.e. difficulty swallowing)
	• Also need advanced directive
	    ○ What level of care are they requesting
	• Specific experience:
	    ○ Patient came in by themselves, no list of medications or other documentation, no POA
	    ○ Patient could not speak for themselves
	    ○ Led to a lot of phone calls back and forth
	    ○ Still information wasn't readily available
	    ○ Important for patient safety to provide documentation

3. Can you please share some experiences of coordination and communication when patients with dementia are discharged from hospital to nursing home? Are there any shortcomings of this process?	• Discharge: ○ Takes longer to create a care plan for older adults: complex care, comorbidities, polypharmacy, less social support • ED only responsible for addressing problem presented, i.e. investigate injury and cause of injury • Although it is not the role of the ED to address underlying conditions or all problems, often times hospital nurses tend to provide additional care • There are differences in expectations from care facilities
4. What determines if a patient is ready for discharge?	• Compare patient to baseline function and cognitive function as described by initial

	documentation provided from care home • Medically stable, clear, back to usual functional/medical baseline • Get patient back to their home as soon as we can because it is safer
5. What are your perceptions on the role that hospital nurses play in coordination and communication of older patients' admittance and discharge into the hospital?	• Admittance: o Hospital nurses have information on what usual baseline is, medications, advanced directives • Discharge: o Photocopy of emergency record (one page with laboratory results and radiology results) o There is some lag time with lab results but want to get that information back to care homes o Form has been developed for communicating back to care homes o Hospital nurses call the facility to notify that resident is ready for discharge, the findings, and what treatment was provided during the hospital stay
6. Are there any gaps in communication between long-term care and the hospital that you are aware of? Please speak to that.	• Communication is improving but still necessary to call care facilities to retrieve baseline information and why patient was sent in the first place
7. What do you think is the best form of communication that should be used between the hospital and long-term care facility?	• Clear documentation, most consistent way of communicating • There will be phone calls back and forth to seek clarity

8. What is being done well for transitions in care for patients with dementia that long-term care home nurses should continue to practice?	• Involved in project with Joey Carson "London Transfer Project" • Helps with communication between hospital and long term care facility • Makes documentation consistent • Improve understanding of role and expectations from both long term care homes and hospital • Any documentation from ED carries over to the inpatient department via electronic patient record that is linked between hospitals in London
9. Is there an electronic health record for each patient that is accessible by both nursing home staff and hospital staff?	• Electronic patient record is accessible within the hospital and between hospitals (University Hospital, St. Joseph's, Victoria) • Long term care homes are not linked to the electronic patient record; considered business not within the circle of care

Unique Perspectives from University Hospital ED. When a patient is admitted to the ED, nurses look to emergency documents provided by the care home to determine baseline motor and cognitive function, medication, allergies, advanced directives etc. J. Clift stressed the importance of complete emergency documents for patients with dementia because these patients cannot speak for themselves. The functional and medical baseline also serve as standards to determine if patients are ready for discharge.

Upon admission to the ED, nurses are only responsible for addressing the presenting issue. J. Clift acknowledged that may differences in the understanding of the ED's role in providing care. She would like care home staff to realize that it is not the role of the ED to address all problems or chronic conditions of the patient. ED Nurses may only be required to investigate injuries or presenting conditions and determine the cause. J. Clift expressed that ED nurses tend to provide additional care, but this is not required of them.

In organizing discharge from the hospital, J. Clift reported that the process is particularly time-consuming for older adults due to the comorbidities, polypharmacy and less social support that these patients generally have. Currently, electronic patient records are accessible within and

between hospitals, but not by long-term care homes and dementia care homes. Since these organizations are considered businesses, they are not members in the circle of care and there do not have access to the electronic patient record (J. Clift, personal communication, October 20, 2017).

Appendix D: CARED Form

CARED Form

Communication **A**nd **R**ecognition: **E**ngaging with **D**ementia

Name: ______________________ **Nickname**: ______________
Address: ____

Date of Birth: M: ___/D: ___/Y: _____ Age: ______ Sex: ( ) M ( ) F
Health Card#: _______________

Baseline Mental Status: ( ) Advanced Dementia ( ) Moderate Confusion
( ) General Anxiety and Confusion ( ) Short Term Memory Loss

Code Status: ( ) Full ( ) DNR ( ) Other: ______________________
**Attach: See Ministry of Ontario DNR form

Power of Attorney (POA): ______________________________
Home Phone #: ________________ Cell Phone #: ________________

Emergency Contacts
Name: ____________________ Home/Cell Phone #: ____________
Relation: ____________________ Work Phone #: ____________

Name: ____________________ Home/Cell Phone #: ____________
Relation: ____________________ Work Phone #: ____________

Home Care Provider: ______________ Phone #: ______________
Address/Practice: ______________________________________
____

Primary Care Provider: ______________ Phone #: ______________
Address/Practice: ______________________________________
____

Pharmacy: ____________________ Phone #: ______________
Address/Practice: ______________________________________
____

Figure 1. Front side of CARED Form

CARED Form

Communication **A**nd **R**ecognition: **E**ngaging with **D**ementia

Communication: (check all areas that apply) Primary Language: ____________

( ) Non-Verbal ( ) Sign Language ( ) Blind ( ) Deaf ( ) Hearing Impaired ( ) Vision Impaired

Other:____________

Assistive Devices: (check all areas that apply)

( ) Hearing aids ( ) Dentures ( ) Glasses ( ) Walker ( ) Cane ( ) Wheelchair ( ) Hoyer Lift

Other: ____________

Behaviours: (check all that exist)

( ) Biting ( ) Hitting ( ) Scratching ( ) Spitting ( ) Screaming/Swearing ( ) Complaining

( ) Argumentative ( ) Repetitive vocalizations ( ) Exit seeking/Wandering ( ) Shadowing

( ) Pacing ( ) Intentional falling ( ) Resisting Care ( ) Harmful to Self ( )Wanting to go home

( ) Active Hands/Taking Things ( ) Undressing ( ) Uninhibited Sexuality ( ) Anxiety ( ) Paranoia

( ) Hallucinations ( ) Delusions ( ) Sun-downing ( ) Sleeplessness ( ) Restlessness

Other: ____________

Triggers to Behaviours: ____________

____

Calming Techniques: (check all that apply)

( ) Music genre ____________ ( ) Singing ( ) Stuffed Animal ( ) Baby Doll ( ) Housework

( ) Picture books ( ) Photos/Reminiscing ( ) Arts/Crafts ( ) Walking ( ) Holding hands

( )Other:____________

Nutritional Preferences/Considerations/Difficulty Swallowing: ____________

____

Get to Know Me:

Place of Birth: ____________ Previous Occupation: ____________

Marital Status: ____________ Religion:____________

Spouse/Children:____________

____

Favorite Conversations Topics: ____________

Interests/Hobbies/Songs: ____________

Figure 2. Back side of CARED Form

Figure 3. CARED Logo

Appendix E: Responsive Behaviours and Calming Techniques

Table 4. Responsive Behaviours

Alterations In Activity	Alterations in Perceptions	Aggressive Behaviours
· Repetitive questioning · Restlessness · Shadowing · Wandering/exit seeking · Waking up at night · Uninhibited sexuality · Pacing · Intentional falling · Active hands/taking things · Undressing · Sleeplessness	· Hallucinations · Delusions · Depression · Anxiety · Euphoria · Nightmares	· Resisting care · Self Harm · Screaming · Hitting · Biting · Spitting · Scratching · Swearing · Complaining · Argumentative · Agitation · Irritability

Chalmers, 2000; Gitlin, Winter, Dennis, Hodgson & Hauck, 2010; Miller, 2008.

Table 5. Calming Techniques

Calming Techniques
· Singing · Stuffed animal · Baby doll · Music Genre · Housework · Picture books · Photos/reminiscing · Arts/crafts · Walking · Holding hands · Breathing exercises · Outdoors

Chalmers, 2000; Gitlin, Winter, Dennis, Hodgson & Hauck, 2010; Miller, 2008.

Appendix F: Timeline of Implementation Activities

Table 6. Timeline for expansion of CARED Tool

January 2018	• Incorporation of accessible CARED Form on websites of care homes around London and the Alzheimer Society of Canada website
February 2018	• **Pilot project (Phase I)**: implementation of CARED Tool during transitions in care for Highview Residences, ML-EMS, and University Hospital • Collaborative Training session for care home staff, paramedic staff, and hospital staff on how to use the CARED Tool
March 2018	• Conduct qualitative analysis of transitions in care through interviewing Highview staff, paramedic staff, and University Hospital staff to evaluate tool efficacy • Work with all staff involved to optimize tool
May 2018	• **Phase II**: expansion to care homes and hospitals throughout London, ON • **Goal**: implement CARED Tool across the LHIN
June 2018	• Conduct qualitative analysis of transitions in care through interviewing LIHN staff who participated in phase II to evaluate tool efficacy • Work with all staff involved to optimize tool
July 2018	• **Phase III:** Speak with the Minister of Health to research implementing CARED Tool electronically and inquire how to integrate CARED Tool into Canada's Dementia Strategy • **Goal:** implement tool nationally; provide regular training for all staff involved

Appendix G: Cost Analysis of CARED Tool

Table 7. Costs of wristbands and envelopes for CARED tool

Wristbands	**Envelopes**
From Wristband Giant Canada (https://www.wristbandgiant.ca/)	From Staples (https://www.staples.ca/)
1. Straight soft comfort solid colour in purple without customization: $88.07 for 500 pieces 2. Straight soft comfort solid custom in purple with CARED logo and text: $133.07 for 500 pieces	JAM paper® 9" x 12" violet purple envelops: $149.49 for 250 pieces

Appendix H: Video/Photo Consent and Release Form

Video/Photo Consent and Release Form

Lost in Transition: A Community Service Learning Project

By signing this form,

I provide my consent to be video/audio recorded by students who are part of the HS4711 Gerontology in Practice course at Western University.

I give approval for the future use of this video recorded interview in any reports, presentations, or videos made by this team of students related to a joint project with Highview Residences in London Ontario.

I further give approval that my name(s), likeness/voice, and information relevant to this project may be used in any reports, presentations, or videos made by this team of students.

I have been given information regarding the nature of this project and agree to participate in video/audio-recorded interview.

Name (Print)

____

Signature

____

Date

____

Figure 4. Video/Photo Consent and Release Form used for interviews