The Compounding Nature of Transitions in Dementia: Nursing Implications to Promote Dignity

By Hannah Lawrie[1&2], RN, BN student nurse (hlawrie1@athabascau.ca) & Annette M. Lane, RN, PhD, Associate Professor
Faculty of Health Disciplines, Centre for Nursing and Health Studies
Athabasca University, Athabasca, Alberta, T9S 3A3, Canada

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[2] Corresponding Author: Hannah Lawrie (hlawrie1@athabascau.ca)

Abstract

Transitions in older age can be fraught with challenges for older adults and their families. In particular, a diagnosis of dementia – as a transition in and of itself – can lead to multiple transitions. Within this paper, we present a case study of a couple in which the wife is diagnosed with dementia, and the resultant transitions which follow for the wife, husband, and adult daughter. The case study provides a background of the tremendous difficulties that arise with a diagnosis of dementia, becoming a caregiver, and the precariousness of the caregiver role when health changes occur, resulting in a transition to a care facility. Psychosocial and existential responses in relation to a diagnosis of dementia, becoming a caregiver, and transitioning to a facility are discussed. Challenges in navigating the healthcare system are addressed that may diminish a sense of personhood for those with dementia, as well as nursing implications are presented. In particular, we discuss nursing implications of discourses in dementia care, as well as ethical issues of balancing the wishes of caregivers and individuals with dementia.

Key words: older adults, dementia, transitions, dignity, placement in a care facility.

Introduction

Transitions, "the passage or movement from one state, condition, or place to another (Chick & Meleis, 1986, p 237, as cited in Davies, 2005), can be difficult at any stage of life. However, they are particularly challenging in older age. Generally speaking, transitions are not looked upon as improvements, such as leaving home to study abroad or having children. Transitions in older age often involve changes in health of oneself or a family member, often leading to a move from the family home, and having enormous impacts upon the family (Lane & Reed, 2019).

Transitions resulting from dementia can be particularly challenging (Drummond et al., 2019). The transition of an illness (Meleis, 2010) such as dementia in one spouse leads to a transition for the other (caregiving), which ultimately may lead to placement of the person with dementia in a long-term care facility. Thus, we find a compounding of transitions, with one transition leading to another.

In this paper, we present a case study of a fictitious aging couple (a composite of couples we have worked with) in which the wife is diagnosed with dementia and the ensuing challenges. This provides the framework for discussing the compounding transitions that occur in persons with dementia (PWD) and their caregivers, as well as the potential responses of PWD and caregivers. Challenges for couples navigating the healthcare system, as well as nursing implications, are addressed.

Case Study

Marie and George met and fell in love at a dance hall in England where George had been deployed as a soldier during the Second World War. They married and moved back to Canada at the end of the war, settling in a small bungalow in a little prairie city. George eventually became a manager for the city power supplier, while Marie raised their five children and later worked part time in a nearby department store. After retiring 25 years ago, George and Marie enjoyed lawn bowling in the summer and travelling down to Arizona with several other couples in the winter months. This pattern continued until Marie became lost in an outdoor mall and was subsequently diagnosed with dementia. Since then, George and Marie experienced increasing social isolation as friends and neighbours moved or passed away, and as Marie's dementia progressed, friends felt uncomfortable to visit.

While still living together in their home, George spent most of his time trying to convince Marie to engage in basic care activities and redirecting her away from the doors as Marie had become an elopement risk (the police had brought Marie home on several occasions after she wandered off looking for her childhood home). George soon found being a caregiver overwhelming as he had to take over household responsibilities that Marie had always managed. Slowly George became familiar with operating the washer and dryer. George discovered that he could even make a passable roast for Sunday dinner, but longingly spoke of the meals and pies that Marie could make in her "younger years".

Their eldest daughter, Linda, lived nearby and stopped in several times a week. While she helped with running errands such as getting groceries and helping Marie bathe, Linda worked full-time and had a family of her own to care for. The rest of their children lived in other areas of the country. As Marie's care needs continued to grow, George's adult children chided him for not selling the old home and moving to an assisted living community where he wouldn't have so many responsibilities. However, George took pride in being able to care for Marie the way that she cared for their family for so many years, and still enjoyed helping Marie tend their well-established garden.

George's worst fear was realized one winter day when he slipped on their icy sidewalk and ended up in acute care with a fractured hip. When the physician entered the room to inform George and his eldest daughter that George would need surgery followed by at least six weeks of hospitalization for rehabilitation, both he and his daughter broke down in tears. Marie asked if she could go feed the ponies.

George and Marie had been married for over 60 years and had always promised each other that they would stay together until the end. When she was first diagnosed with dementia George promised Marie that he would never place her in a care facility, resolutely dismissing the occasional suggestion from family and friends to make contingency plans or look into available care options. George and his daughter Linda were then faced with having to find care for Marie as she could not safely remain in their home alone. As he heard his daughter ask if there was anyone who could help find suitable placement for Marie, George feared that, without Marie, their house would never really be "home" again.

When George had surgery and began rehabilitation, Linda took a leave of absence from work to care for Marie at home, where the Transition Services nurse met them to look at placement alternatives. Within a number of weeks, emergency placement was secured for Marie in a care facility. Both George and Marie were confused: George wondered how everything could go so badly with one fall; and Marie wondered where she was and where was George. Both George and Marie were frequently tearful while Linda struggled to help both of her parents deal with the compounding transitions.

Compounding Transitions

The case of George and Marie illustrates three interrelated major transitions that occurred over a relatively short period of years. First, Marie's dementia diagnosis (the initial transition) led to George transitioning to his wife's caregiver. The caregiver role led George to learn new skills, but also, to increasingly isolate himself from friends due to the demands of the new role. George's hip fracture led to a third transition as his ability to care for Marie was interrupted because of the surgery and subsequent rehabilitation, resulting in Marie's placement in a care

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facility. In this section we explore the transitions and the individual and family responses to each.

Dementia

Dementia, a progressive terminal neurological illness, results in the slow ongoing loss of cognitive functions such as memory, executive function, language, and the ability to perform activities of daily living (Sellars, Chung, Nolte, Tong, Pond,… & Detering, 2019; Travang, Petersen & Naden, 2015). PWD must increasingly rely on caregivers to fulfill daily care activities as their illness progresses, making it essential to include caregivers in discussing and formulating a care plan around dementia management (Kuluski, Im, & McGeown, 2017; Drummond, McCleary, Garcia, McGilton, Molnar, … & Freiheit, 2019). The progressive cognitive and functional losses experienced by PWD result in a gradual increasing burden of care for their caregivers (Fields, Xu & Miller, 2019; Ott, Kelber & Blaylock, 2010).

Following a dementia diagnosis, PWD are likely to experience fear, including fear of the loss of self (Birtwell & Dubrow-Marshall, 2018; Bryden, 2020), as well as loneliness due to diminished socialization with friends (Birtwell & Dubrow-Marshall, 2018). PWD may also fear becoming a burden to loved ones. Loved ones may experience uncertainty about the future of their PWD (Quinn, Jones, & Clare, 2017), depression (Bryden, 2020), as well as stigma from others (Weisman DeMamani, Weintraub, Maura, Martinez de Andino, & Brown, 2018). In the case study, George experienced isolation from friends who were not comfortable with Marie, as well as great uncertainty about his future when he learned that Marie would be placed in a care facility.

Existentially, both PWD and their caregivers may feel “Who am I” or “Who is my partner/parent?” in relation to the affected one with dementia. This may involve the loss of identity in the PWD (Birtwell & Dubrow-Marshall, 2018), while caregivers may feel that while their PWD looks the same, they do not psychologically resemble the person they once knew (termed ambiguous loss) (Boss,1999).

Caregiving

Within Canada, there are over half of a million people living with dementia (Alzheimer Society of Canada, 2018). The vast majority of PWD (initially) live at home with informal caregivers, who provide over 20 hours of physically and emotionally demanding unpaid care per week for an average of 5 years (Fields et al., 2019; Ott, Kelber & Blaylock, 2010; Smith, Schlauker, LeBranche, Reyes, & Lahtinen, 2019). The role of caregiver is most often assumed by either elderly spouses or adult children of PWD, 75% of whom are female, at a significant cost to the caregiver’s own physical, mental, social, vocational and financial health (Drummond et al., 2019; Kajiwara, Noto &Yamanaka, 2018; Smith et al., 2019). George and Marie had been living on their combined fixed retirement income. Marie’s placement into a care facility requires a large portion of their income to pay the costs associated with facility care, which in turn could

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compromise his ability to maintain their house or afford alternate housing for himself. Their daughter Linda was assisting in caregiving, and was stretched thin by her responsibilities of full-time work and providing care for her family.

Caregivers share the burden of the illness and often experience multiple reasons for grief throughout the disease progression (Noyes et al., 2010). Caregivers frequently grieve the loss of the relationship with PWD due to memory loss, admission of PWD to a care facility, and ultimately, the death of PWD (Kijiwara et.al., 2018; Ott et al., 2010). George felt grief that his home would never be the same without Marie; and we can surmise that he also felt considerable guilt for failing to keep his promise about keeping Marie out of a care facility.

Change of living environment

Of the three forms of transition mentioned above, placing PWD into facility care is viewed by many caregivers to be the most negative and difficult to face, characterized as the last resort (Drummond et.al., 2019; Merla, Wickson-Griffiths, Kaasalainen, Dal Bello-Haas, Banfield,...& Di Sante, 2018). Like George, the majority of caregivers strive to maintain PWD in the home, believing that they can provide the best care for their loved one, given their intimate knowledge of (and affection for) PWD; these caregivers strive to maintain an external memory rich with physical and emotional cues of personalized objects in the environment for the PWD and worry that PWD will be neglected or their personhood not recognized within a facility (Cairns, 2012; Lane, Hirst, Hawranik, Reed, & Rokhman, 2017). Caregivers may also grieve the loss of the caregiver role when PWD enter care facilities (Ott et al., 2010).

However, placement often occurs. There is a significant correlation between caregiver burden and risk of institutionalization, with caregiver burden attributed to be the greatest cause of facility placements (Dufournet, Dauphinot, Moutet, Verdurand, Dephin-Comb & Krolak-Salmon, 2019; Fields et al., 2019; Merla et al., 2018; Smith et al., 2019). Factors that contribute to caregiver burden include the level of cognitive and physical impairment of the PWD, the caregivers' own health-related issues, loss/grief and relational conflict between caregivers and PWD or others (Cairns, 2012; Dufournet et al., 2019; Fields et al., 2019). For George and Marie, the impetus for Marie's placement was George's fractured hip.

PWD themselves often view the transition to facility care as negative (Drummond et al., 2019). Areas of difficulty experienced in this transition include adjusting to a different living environment, preserving personal interests, accepting help, obtaining/understanding information and expressing concerns, meal-related expectations, loss of control, and having care needs recognized and met in a facility (Lane et al., 2017; Smith et. al., 2019). PWD may not be aware of their own developing deficits, resulting in anxiety which may be heightened by moving into a care facility (Cairns, 2012). PWD identify the relationship with their caregivers, specifically their ability to have confidence in their caregivers, as being crucial to their well-being (Tranvag et al., 2015). Being placed into a care facility without being able to understand why the transition is occurring could negatively impact the quality of this relationship, leading to isolation and the premature progression of illness (Kuluski et al., 2017). For Marie, if she forgot why George was hospitalized and why they were separated (both of might be expected), this could impact her response when George visits her in the care facility and heighten her feelings of being alone and isolated—and also exacerbate George's feelings of guilt and loss.

Challenges in Navigating the Healthcare System

Beyond navigating compounding transitions, PWD and their caregivers often experience difficulties in navigating the healthcare system throughout the disease process. The difficulties may begin when seeking a diagnosis, and throughout the disease progression, including placement into a care facility. Challenges may include interactions with healthcare professionals, the complexity of the healthcare system, as well as relocation to a care facility.

Conversations with healthcare professionals

For PWD and caregivers, engaging in knowledgeable and helpful discussions about dementia is important (Walker, Ratcliffe, White, & Visvanathan, 2018). The quality of interaction between PWD and others serves to preserve a sense of dignity and self (Lane et al., 2017; Tranvag et al., 2015). Preserving dignity in PWD and their caregivers also involves honest conversations about chronic, progressive illnesses, such as dementia, that ultimately lead to death. Unfortunately, healthcare professionals may feel ill equipped to have the hard conversations around the terminal nature of chronic progressive diseases (Sellars, Chung, Nolte, Tong, Pond,... & Detering, 2019). Literature supports the use of a disease specific palliative approach to dementia from diagnosis in order to support PWD living the best life possible for the full duration of the disease (Sellars et al., 2019; Tolson, Flemming, Hanson, Abrea, Crespo, Mcrae... Holmerova., 2016).

Complex healthcare system

The personhood of PWD and their caregivers can be diminished, not only through navigating a disease that robs individuals of a sense of their personhood (Cairns, 2012), but also in having to navigate a complex healthcare system that is often impoverished of resources and lacking intentional design to address the complex and perpetually changing care needs of PWD (Barnable, Welsh, Lundrigan, & Davis, 2015). As noted by Tolson and colleagues, "For people to experience a sense of living the best life possible with advanced dementia, there needs to be confidence in and quality of healthcare provision delivered within an integrated approach" (Tolson et al., 2016, p.6).

Relocation to a care facility

Transition to a care facility for PWD is seen as a last resort. However, the likelihood of this occurring increases as dementia progresses due to the increasing loss of physical functionality and the behaviours and psychiatric symptoms of dementia (BPSD), resulting in safety concerns and inadequate resources to meet the level of care required within the home (Dufournet et al., 2019; Fields et al., 2019; Merla et.al., 2018). In spite of this, caregivers and PWD, such as George and Marie, remain hesitant to proactively pursue placement due to negative perceptions of care facilities. Placement is viewed as similar to imprisonment and facilities as impersonal and dehumanizing (Merla et al., 2018). A major care deficit consistently identified by caregivers for PWD in care facilities is the lack of personalized care by prioritizing task over person (Drummond et al., 2019; Kuluski et al., 2017; Merla et al., 2018), and the lack of acknowledgement of the personhood of PWD in planning and providing care (Tranvag et al., 2015). Caregivers often must provide ongoing care despite their loved one residing in a facility, due to staff's failure to carry out seemingly small, yet essential, person-specific care tasks. For instance, anxiety-related vocalization may be prevented by putting two pairs of socks on an individual who suffers from cold feet at night, or saying grace at a mealtime, for an individual who never eats without saying grace first. PWD find that the mood and/or lack of attention from staff are demoralizing as they are not consulted or encouraged to be a part of their own care (Merla et al., 2018; Tranvag et al., 2015).

Nursing Implications

Nursing implications include provision of extra time (and quality of interactions) during assessments and transitions, as well as the importance of dementia-related education for nurses across various settings, such as home care, acute care, and facility care. Additionally, nurses need to address their thinking about dominant discourses in healthcare which impact their care of PWD. Finally, once placement into a facility occurs, PWD and their caregivers require care that recognizes their personhood and strengths, and promotes quality interactions.

Provision of time

PWD and their caregivers need extra time to complete nursing assessments throughout the experience of dementia, as well as extra time with admissions to care facilities (Drummond et al., 2019; Lane et al., 2017). For example, facility representatives who are knowledgeable in how to ease transitions may come to the home to meet PWD within their own environments and recommend strategies to reduce the stress of the move. In addition, PWD may be able to select their own room, select furniture, and help decorate it with important items from their current home. It also may be helpful if friends and/or family participate in the physical transfer. Caregivers should be assessed for their level of burden (facility representatives can also serve as neutral counselors in this assessment), as higher levels of burden may be associated with poorer transition experiences for caregivers (Drummond et al., 2019). In addition to the provision of extra time, the quality of interactions with PWD and caregivers cannot be overstressed (Lane, Reed, Hawranik, & Virk, 2019).

Education

Not only do nurses need up-to-date education about dementia and how to respond to

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symptoms/behaviours related to dementia, they need knowledge to effectively assist caregivers with PWD. Nurses need to be able to provide guidance to caregivers providing care within the home, on keeping the home safe, and responding to the challenges faced by those with dementia. Caregivers should also receive education on the importance of accessing emotional and instrumental support, such as support groups for themselves (Ott et al., 2010). Further, nurses need to be familiar with and provide information about resources such as day programs for PWD, which facilitate meaningful time for those with dementia while providing respite or time away from caregiving for caregivers (Alzheimer Society of Canada, 2017).

Caregivers also require support throughout the transition process and should be provided with education and access to community resources and supports to help them in the decision-making process (Fields et al., 2019; Merla et al., 2018; Ott et al., 2010). Families that are actively engaged in the process of planning for and selecting a facility for placement are significantly more satisfied with both the transition experience and subsequent care provision in their facility of choice (Drummond et al., 2019; Kuluski et al., 2017; Merla et al., 2018). Through transition planning, caregivers have found that they were better able to recognize the progressive nature of dementia and their eventual inability to meet the care needs of the PWD, and so viewed the transition of placement positively (Drummond et al, 2019; Kajiwara, Yoto, & Yamanaka, 2018).

Addressing dominant discourses in dementia

It is important for nurses to confront the dominant discourses about dementia in healthcare. A common position about dementia is that it involves the loss of self. Although dementia involves multiple devastating losses (Birtwell & Dubrow-Marshall, 2018), individuals still retain personhood (Bryden, 2020). As such, discourses of loss need to be balanced with discourses of strength and personhood. Bryden (2020), who suffers from dementia, notes that although she cannot find items that she is looking for, she can still experience meaning and a sense of self. She still writes articles – her autoethnography – about living with dementia. The importance of adopting such an approach helps nurses to look for the strengths in PWD and encourage them, and their caregivers, to engage in meaningful activities (Birtwell & Dubrow-Marshall, 2018; Bryden, 2020).

Another important conceptual shift would be to consider the “unit of care”; that is, considering PWD and their caregivers as indivisible units. This shift in thinking is important, given the dependence of PWD on caregivers and the significant burden of care managed by caregivers (Cairns, 2012; Ott et al., 2010; Smith et al., 2019), and affects how nurses work with PWD and caregivers. However, identifying the “unit of care” also may raise an ethical question: How are the wishes and emotional responses of the PWD balanced with those of caregivers?

For instance, when the transition to a care facility is being addressed, either due to sudden deterioration in the health of PWD or caregivers (Merla et al, 2018), the response of both the PWD and of their family should be considered. Caregivers faced with having to place a loved one in a care facility may experience a myriad of emotions such as ambivalence, apprehension, guilt, powerlessness, worry and loss or anger (Kuluski et al., 2017; Merla et al., 2018). Those having high levels of caregiver burden may find that placement magnifies their guilt (Fields et al., 2019). Similarly, PWD often react to placement into a care facility with confusion, grief, and depression (Mulkey, Everhart, & Hardin, 2019; Neufeld, Freeman, Joling, & Hirdes, 2014). The ethical dilemma lies within the wishes of caregivers (and often healthcare professionals) and PWD. Although caregivers wish that they did not have to place their loved ones in a facility, they may realize that they do not have a choice. Understandably, PWD do not want or choose placement, wishing only to stay at home (Drummond et al., 2019).

While it is vital to ensure the involvement of family caregivers as part of the unit of care, it is equally important to maintain the involvement and focus of care upon the PWD. Nurses should remember that, while families provide insights into the care needs of PWD, the perspective and concerns of PWD are separate, unique, and must be kept central when approaching nursing care in order to provide dignity to PWD (Haapala, Carr & Briggs, 2018; Tolson, et al., 2016). Maintaining this balance – listening to both caregivers and PWD - can at times result in an ethical struggle to accept caregivers' role as the proxy voices for the needs of PWD. This necessitates specialized education and professional supports for nurses providing care to PWD and their caregivers (Spenceley, Witcher, Hagen, Hall, & Kardolus-Wilson, 2017).

Care for PWD and caregivers within care facilities

When individuals transition to care facilities, caregivers and PWD may not receive the level of care needed from healthcare providers. Both PWD and caregivers should receive support in relation to their reactions to placement. This may occur by staff spending time verbally interacting with residents, rather than solely focusing on task-oriented care. Emotional support should extend beyond the transitional period, whereby interactions with residents about non-care issues are fostered and valued (Lane, Hawranik, Reed, & Virk, 2019). Engaging PWD in meaningful activities may also result in the preservation of functionality of these residents (Drummond et al., 2019). Care facilities should institute an intervention whereby caregivers specifically receive emotional support to address the emotions resulting from the transition (Lane, Hawranik, et al., 2019).

In relation to the physical care received by PWD in care facilities, caregivers can be an invaluable resource in providing helpful information for front-line staff in what works and does not work when providing care (Lane et al., 2017). Not only do family members appreciate when their expertise is accessed (Lane, Hawranik, et al., 2019), tailored care can be more effective. Front-line staff may not recognize the relationship between impaired cognition and deterioration of physical functioning. This may result in PWD not receiving the needed support to complete necessary care tasks, such as eating and toileting (Kuluski et al., 2017). If PWD are not able to recognize their own deficits, they are not going to be able to request assistance with meeting the subsequent care needs. Failure of nursing staff to recognize this may result in an inability to anticipate and provide for care deficits, leaving the client bereft of essential assistance. Physical

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and mental needs must be considered together when providing care planning for dementia-related cognitive deficits and their impact on the ability of PWD to effectively manage or even participate in care activities (Brown & Menec, 2019).

Conclusion

With the diagnosis of dementia, caregivers and PWD are faced with multiple transitions. These transitions can cause increased stress on their physical, mental and emotional resources. Eventually, placement in a care facility often occurs. Research has shown this transition to represent the most difficult and negative transition that PWD and caregivers face throughout their journey through dementia. Caregivers face difficult decision-making surrounding placement, requiring significant information, as well as emotional support. PWD require support in the transition to ensure that their dignity and sense of self remains supported in the new environment. This can be facilitated through personalized care planning and positive relational interactions between themselves, caregivers and healthcare professionals

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