

# Making Care Decisions in Home-Based Dementia Care: Why Context Matters\*

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## RÉSUMÉ

D'ici à 2038, le nombre d'heures de soins non rémunérées aux aînés offert par les membres de la famille devraient tripler. Les membres des familles sont souvent suppliés d'aider dans le processus parce que vivre avec la démence peut inhiber la capacité pour prendre une décision. Cette étude ethnographique a soumis les relations au sein de soins de la démence à domicile à un examen critique par le biais des entrevues face-à-face et les observations des participants des clients, des aidants naturels et des prestataires de soins à domicile. Les résultats ont révélé comment les décisions sont imposées dans le contexte du système de soins à domicile formels, et ont mis en évidence trois thèmes: (1) *L'accommodation de la compétence/incompétence, comme définie cliniquement*; (2) *La prise de décisions inopportunes*; et (3) *Le renforcement de l'exclusion des déments dans la prise de décision*. Ces thèmes illuminent la façon dont les valeurs culturelles (la compétence), les croyances (l'immutabilité du système) et les pratiques (le réglage des décisions) dans le système de soins à domicile sont finalement déterministes dans la prise de décisions pour les déments et leurs aidants. Afin d'optimiser la santé des déments qui se font soignés à domicile, il faut accorder d'attention supplémentaire aux pratiques collaboratives et inclusives des membres des familles.

## ABSTRACT

The hours of unpaid elder care by family members are projected to triple by 2038. Because living with dementia can inhibit decision-making abilities, family members are often besought to assist in this process. In this ethnographic study, relationships within home-based dementia care were critically examined through face-to-face interviews and participant observations with clients, family caregivers, and home care providers ( $n = 51$ ). The findings revealed how the formalized home care system contextually imposes decisions, and revealed three themes: (1) *accommodating clinically defined competence/incompetence*, (2) *making untimely decisions*, and (3) *reinforcing exclusion in decision making*. These themes shed light on how cultural values (competency), beliefs (immutability of the system), and practices (timing of decisions) of the home care system are ultimately deterministic in decision making for persons with dementia and caregivers. Additional attention to the collaborative and inclusive practices of all family members in dementia home care is imperative in order to optimize health.

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In Canada, more than half a million people live with Alzheimer's disease or a related dementia (ADRD) (Smetanin et al., 2009). The number of people living with ADRD is expected to more than double within the next 25 years, affecting over 1.1 million Canadians and their families (Smetanin et al., 2009). The cognitive deterioration associated with dementia simultaneously challenges the independence of those living with the illness and increases care needs. Half of those with dementia live at home (Canadian Study of Health and Aging Working Group, 2000), and this proportion is increasing (Cranswick & Thomas, 2005; Keating, Fast, Frederick, Cranswick, & Perrier, 1999). On average, people living with dementia require care for approximately 8.5 years (Keene, Hope, Fairburn, & Jacoby, 2001). With the increased need for care in the home over extended periods, families are often the ones to provide the bulk of this care (Ory, Yee, Tennstedt, & Shulz, 2000). Up to 90 per cent of in-home care is currently provided by family members and friends (Fast & Keating, 2001; Keating et al., 1999), and these hours of unpaid care are projected to more than triple, increasing from 231 million hours in 2008 to 756 million hours by 2038 (Smetanin et al., 2009).

The home care sector in Canada is complex. In recent years, government has pushed for client-centered care; a concept premised on choice and control for independent living, in which clients make choices about the services they receive (Feinberg & Whitlatch, 1998; 2002; Nolan, Davies, Brown, Keady, & Nolan, 2004). And yet, many government-funded home care agencies in Canada are mandated to determine the health care needs of community-dwelling older adults with dementia and the extent of the services they are eligible to receive. Indeed, most publicly funded services are allocated based on the ideals, values, and practices of the public sector, ultimately resulting in the question, who are the clients in home care and what service choices are available to them?

Because living with dementia can interfere with decision-making abilities, family members are often called upon to assist in this area (O'Connor & Purves, 2009). Previous research suggests that most adults, if they are incapable of deciding for themselves, would prefer a family member to make health care decisions on their behalf (Menne, Tucke, Whitlatch, & Feinberg, 2008). Relatives often make decisions either by themselves or in consultation with other family members, by acting as an advocate and/or by providing information to health care professionals (Livingston et al., 2010). However, family caregivers have reported experiencing distress and difficulty related to such decision making (Hirschman, Kapo, & Karlawish, 2006). Some obstacles to proxy decision making include a lack of emotional support from health care practitioners in

considering future care options with their relative during the onset of dementia (Davies & Nolan, 2003) and insufficient information about possible alternatives (Hirschman et al., 2006).

The medical and legal systems have had tremendous influence over how decision making is defined and operationalized in dementia home care. For example, the power of attorney concept – of ultimately giving legal primacy to one individual – is shaped by the values of medical and legal institutions. These institutions tend to value objectivity and autonomy, which in turn influence how decision-making ability is conceptualized. Although rhetoric towards family-centered in-home care is growing, many challenges to achieving the optimal decision-making process(es) exist. How decision making is enacted in the formalized home care system may not be congruent with the needs of family caregivers. For instance, the context of decision making has been described as “all-or-nothing” because decisions tend to be outcome driven and not easily retractable (Flegel & MacDonald, 2008). Such contextual circumstances ultimately fail to meet the needs of both older adults with dementia and of their family members.

Our ethnographic study (Ward-Griffin, McWilliam, Forbes, Klosek, & Bol, 2007) critically examined client, family caregiver, and health care provider relationships in home-based dementia care. The findings of that study yielded four relational care processes: (a) reifying care norms, (b) managing care resources, (c) evaluating care practices, and (d) making care decisions. This article focuses on the findings from the fourth process: making care decisions. Based on the study findings, this article illuminates how home care structures play a part in shaping decision making not only for persons living with dementia, but also for their family caregivers and health care providers. Specifically, this article exposes how decisions are contextually imposed by the formalized home care system, and makes recommendations for future home care policies in Canada related to decision making.

### *Review of the Literature*

The literature examines different types of care decisions; notable is a proliferation of studies related to end-of-life care decision making and health care preferences for persons living with dementia (Feinberg & Whitlatch, 2001; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Horton-Deutsh, Twigg, & Evans, 2007; McFall & Miller, 1992).

Several studies have revealed that both the severity of dementia and level of insight of the person living with dementia are determining factors for decision making (McFall & Miller, 1992; Moye & Marson, 2007;

Okonkwo et al., 2008). Yet, the severity of cognitive impairment and the level of insight are difficult factors to assess. Decision making in the post-positivist paradigm has been predominantly examined in relation to “competency” (Drane, 1984; Janofsky, McCarthy, & Folstein, 1992; Kuther, 2000; Lo, 1990; Loeb, 1996; Moye & Marson, 2007; Ochroch, 1990). While some authors have suggested that competency should be measured on a sliding scale (Kuther, 2000; Lo, 1990), most authors have considered competency as a dichotomous outcome variable (Janofsky et al., 1992; Ochroch, 1990). Competency has been vaguely defined in the literature, and one researcher has noted that it is difficult to evaluate because “the judgments that underlie decision making are covert and difficult to observe, operationalize and assess” (Kuther, 2000, p. 19). Kuther also described a recent shift towards competency’s being perceived as domain-specific (making financial decisions versus making medical decisions), and that a person can be deemed (in)competent in either domain.

Decisional capacity is ultimately a legal judgment; it is a process that requires an analysis of a person’s decision-making abilities according to a legal definition. However, in practice and particularly among seniors, the majority of such determinations are made outside of legal proceedings by clinicians, attorneys, and other professional groups (Moye & Marson, 2007). Because the conceptualization of competency is relative to who is evaluating competency and why, there is no standard method of assessing competency in decision making. A number of tools, however, are currently used in the evaluation of cognitive function, including the Wechsler Adult Intelligence Scale-Revised (WAISR-R, Wechsler, 1981). The WAISR-R has often been used to assess cognitive function. However, this scale has been criticized for being an inappropriate tool for seniors due to its psychometric properties oriented towards younger people, intergenerational differences, and a lack of accountability for heterogeneity among seniors (Anastasi & Urbina, 1997; Ochroch, 1990).

Another commonly used evaluation tool to clinically assess cognitive function is the Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). One shortcoming of this scale is that it does not indicate a cut-off point to determine capacity with the result that this determination is often left to the practitioner’s discretion. Furthermore, Lo (1990) has indicated that a person’s performance on the MMSE may not be related to decision-making abilities. Other tests include (a) The Cognitive Competency Test (Wang & Ennis, 1986); (b) Community Competency Scales (Loeb, 1996); (c) Cognitive Competency Test and Community Competence Scales (Moye, 1996); and (d) Hopkins Competency Assessment Test (Janofsky et al., 1992). Although these tests have merit in measuring a particular type of

competency, all have been critiqued for their accuracy, primarily due to the arbitrary nature of the concept *competency*. Skelton, Kunik, Regev, & Naik (2010) have also indicated that most interventions for determining capacity/competency are inefficient and highly variable, and that health care practitioners are rarely adequately trained to conduct these types of assessments (Skelton et al., 2010). Furthermore, although many of these tests claim to measure cognitive function as it relates to competency, none of the listed tools specifically assess decisional capacity. By its very nature, assessing decisional capacity is a complex, cross-disciplinary process (Moye & Marson, 2007). Additionally, nuances of decisional capacity are germane to professional bodies (Moye & Marson, 2007). Yet, many practitioners confuse evaluating for decisional capacity with scores generated from cognitive function assessment tools.

In contrast to a significant number of quantitative approaches that primarily focus on decision making as an *outcome*, some literature based on qualitative methods has examined decision making as a *process*. To date, a noteworthy portion of the interpretive research related to decision making in dementia care has favored a grounded-theory approach (e.g., see Caron, Ducharme, & Griffith, 2006; Caron, Griffith, & Arcand, 2005; Chang & Schneider, 2010). Authors have focused on the “process” of decision making characterized in several ways: (a) as “roles” and phases in relation to quality of life (in the context of end-of-life care); (b) by factors such as caregiver perceptions, evaluations, and interactions with health care professionals (in the context of institutionalization); and (c) in stages of decision making (in the context of nursing home placement) (Bryan & McIntosh, 1996; Forbes, Bern-Klug, & Gessert, 2000). While it is important to examine the process of decision making, few authors have examined how formalized home care has manifested as a consequence of the broader socio-political environment which in turn impacts decision making for persons living with dementia and their family caregivers. One exception is the work by Butcher, Holkup, Park, and Maas (2001), who discussed the need to examine the educational, social, and cultural background of family caregivers and how these shape the decision-making process, particularly in relation to access to information and services.

In reviewing existing literature, we found a need for additional research from a critical perspective. Although several authors have identified the decisions related to the institutionalization for persons living with dementia as among one of the most difficult experiences for family caregivers, the context in which decisions are made, such as inadequate planning for this decision, results in greater difficulty according to other authors (Bell, 1996; Gaugler, Leitsch, Zarit, & Pearlin, 2000;

Ryan & Scullion, 2000). According to Ryan and Scullion (2000), health practitioners rarely explicitly discuss how family caregivers could participate in decision making. Yet, according to the Health Care Consent Act in Ontario, Canada, health care practitioners have an obligation to obtain informed consent before providing care. Informed consent requires by law that a health care practitioner who is carrying out treatment discuss, with the substitute decision maker (SDM), the appropriate risks, benefits, side effects, alternative treatment, and what would happen if the recommended treatment were not delivered. A SDM is someone with legal authority to make decisions on behalf of a loved one or friend when they are not mentally able to make certain kinds of decisions. Furthermore, in addition to including the SDM in the decision-making process, case managers are also obligated to remind the SDM to consult with the family/friends of the person living with dementia as well as the person with dementia. A study by Caron et al. (2005) found that family caregivers are uncertain and ill-equipped for their role as substitute decision makers related to end-of-life care. Issues such as planning for long-term care and inclusion/exclusion in decision making extend beyond the individual caregiver experiences and require an examination of some of the systemic structures that shape care (Arksey & Glendinning, 2007).

Most of the studies in the literature have examined the decision for placement in long-term care (LTC), an important life event and decision for many people living with dementia (Caron et al., 2005; 2006; Chang & Schneider, 2010). A taken-for-granted assumption in most studies, however, was that persons with dementia (PWD) and their families had a choice in the relocation of a person from their customary living environment into LTC. Arksey and Glendinning (2007) argued that the choices for carers considering placement for their relatives are invisible because of wider organizational factors, such as wait lists. Although we recognize that institutionalization is often a reaction necessitated by the inadequacies of a failing home-based care strategy, it is important to consider whether decision making can actually occur in such a circumstance when there is a lack of choices.

More-recent studies have highlighted the importance of examining decision making beyond major care decisions, such as the institutionalization of a relative, and shedding light on those mundane, day-to-day decisions. Such studies have revealed that persons with even moderate cognitive impairment are able to determine their preferences for daily care (Butcher et al., 2001; Menne et al., 2008). Feinberg and Whitlach (2002) suggested that although it is important to consider major care decisions such as LTC, day-to-day decisions are omnipresent and can be the most difficult conflicts

for persons living with dementia and for their family caregivers. Everyday decisions, for example, include decisions related to driving, when to bathe, and whether to purchase additional support services (e.g., in-home care services such as housekeeping, or attending adult day programs).

Findings from our study suggest that as disease progresses, it can become increasingly difficult for PWD to communicate their preferences to their families. Therefore, it is important to recognize the wide variety of care decisions required on a day-to-day basis. Accordingly, this article focuses specifically on *making care decisions*, a process embedded within client-caregiver-provider relationships and contextualized by home care health services policy and programs. The article explores both major care decisions such as institutionalization as well as everyday decisions for families providing care to PWD.

### Methodology

To conduct this study, we employed critical ethnography as described by Thomas (1993). Underlying critical research are the basic assumptions that social inequities exist, and are often reproduced and reinforced by hegemonic discourses and taken-for-granted "truths". The goal of critical research is to shed light on and potentially change those historically situated structures that foster social inequities and exclusion, such as socioeconomic stratification and gendered norms. In keeping with these philosophical foundations, we used this methodology –grounded in the experience of the study participants – to examine the taken-for-granted cultural values, beliefs, and practices embedded within dementia home care. The following four research questions were examined: What are the relationship experiences of clients, families, and providers who engage in dementia care? What factors influence the negotiation of those relationships? What conditions support and strengthen the relationships between and among individuals with dementia, family caregivers, and home care providers? What changes are needed in health services policy and program delivery to enhance the quality of home-based dementia care?

*Recruitment.* Upon approval of the study by The University of Western Ontario Ethics Review Board, researchers met with the case managers of a local community agency and with other community collaborators to discuss the recruitment procedure. The interdisciplinary research team included four faculty members and four graduate students from the Faculty of Health Sciences. The community agency case managers and the provider agency's workers purposefully selected the prospective participants on the basis of eligibility criteria. Once the health care provider

identified potential research participants within its roster of clients, the provider's personnel approached clients receiving dementia care and/or their primary family caregiver to determine their interest in the study. For inclusion in this study, the clients were required to: (1) have a diagnosis of Alzheimer's disease or related dementia; (2) to be 60 years of age or older; (3) have at least one family member or close friend providing regular care (minimum of 4 hours of direct or indirect care/week); (4) have home care providers for a minimum of three home visits; and (5) speak and understand English. Once all network members (clients, family caregivers, and home care providers) consented to participate in the study, the research coordinator scheduled interviews.

*Sample.* In order to understand care *relationships* from multiple perspectives, the research team recruited "dementia care networks", meaning all persons involved in the care of an individual with dementia. In total, the sample comprised nine networks, which included nine older adults with dementia, 25 family caregivers, 10 formal health care providers, and seven community case managers. All 10 formal health care providers were personal support workers (PSWs). Although the eligibility criteria included those who provide paid or formalized care through a provider agency, which could extend to professionals such as nurses, occupational therapists, and/or physiotherapists, our sample consisted solely of PSWs, which may reflect who provides the bulk of home-based health care service. The nine PWD, four of whom were male, ranged in age from 75 to 91 (average: 83.7). All but one were married (one was a widow), three had post-secondary education, one had primary education only, and the remaining PWD had secondary education. Standardized Mini-Mental State Exam (SMMSE) scores ranged from 10/30 to 26/30, averaging 15.8 ( $n = 5$ ; four scores were not obtained due to participants' relocation, refusal, or confusion). All PWD and their families were white and of Anglo-Saxon descent. Of the 25 family members, five were spouses (three of whom were male), and the average age was 78.8. Among the 20 adult children (15 of whom were female), the average age was 50.1. All but three adult children worked full time.

Seven community agency managers also participated in the study. All were female and of Anglo-Saxon descent; their ages ranged from 45 to 57 (average: 50.9). The number of years they had worked as case managers varied from 4 to 20 (average: 9.4). Five of the seven community agency case managers handled caseloads that were largely urban (i.e., within a large city in southern Ontario); the other two case managers provide services for those living in the surrounding counties (i.e., small towns and rural settings).

*Data Collection.* In total, 52 in-depth, semi-structured interviews were conducted at multiple points in time: 37 initial interviews and 15 follow-up interviews were conducted approximately two to three months apart, shedding light on the oscillation of caregiving experiences that occurs over time. Of the 37 initial interviews, seven were conducted jointly with the person with dementia and their family member. Joint interviews were conducted at the request of the family member and/or the person with dementia. Attrition related to the follow-up interviews was largely attributable to the person with dementia entering LTC (and therefore no longer receiving home care services) or to the person's death. Furthermore, because the person with dementia was at the center of the dementia care network, follow-up interviews were not conducted when attrition was related to the person with dementia. All participants were asked open-ended questions about their relationships in the provision of home-based dementia care. Family members and PWD tended to elaborate more on the relational aspects of care while health care providers tended to focus more on the task-based elements of care. Member-checking in subsequent interviews (i.e., checking whether our interpretation had captured the perspectives of the study participants) was employed to give the participants the opportunity to share their thoughts related to the interpretation and applicability of the preliminary analysis. Furthermore, participants were asked to discuss how their relationship experiences had changed over time in follow-up interviews. Data collection extended over a period of 19 months.

In addition to interview transcripts, an additional source of data included field notes from participant observation. After each interview, researchers dictated full field notes about their observations, perceptions, insights, nuances of communication, nonverbal expressions, caregiving behaviours, and interactions between and among the interviewees.

*Data Analysis.* Following the guidelines for data analysis developed by Lofland, Snow, Anderson, and Lofland (2006), emerging initial codes were identified from the transcripts and the field notes. Memos were used as supplementary notes and background information to inform the analysis. After an iterative process of refining the initial codes, focused codes were applied to "clean" transcripts in an attempt to identify gaps or missing codes. The final steps in the analysis involved the development and refinement of the major themes and the identification of phrases that most accurately illustrated these themes. An additional analysis strategy included diagramming, a process that facilitated an understanding of how the focused codes related to each other in order to conceptualize the larger picture (Lofland et al., 2006).

## Findings

By and large, the family caregivers and PWD in this study described the consequences of making care decisions, paying particular attention to the relational effects that decisions would have on the family unit. Comparatively, the health care providers and case managers tended to focus more on the constraints of making care decisions – for example, the unavailability of resources. The differences observed over time related to imminency of potential crisis and making care decisions to avoid crisis as much as possible. For example, the potential for crisis tended to increase over time, and the participants would tailor making care decisions accordingly.

In home-based dementia care, we found that making care decisions was a contextually shaped process for our study participants. Three themes related to decision making in home care were apparent: (1) *accommodating clinically defined incompetence*, (2) *making untimely decisions*, and (3) *reinforcing exclusion in decision making*. Accommodating clinically defined incompetence meant dichotomizing the capacity of the PWD, with negative consequences for some network members. For instance, system pressures forced untimely decision making, rendering family caregivers unable to make decisions related to the health of the PWD. More often than not, timing constraints related to the availability of services and wait lists were superimposed on families. Third, the context of decision making rendered an exclusive process, one that privileged certain network members and certain types of knowledge/skill.

### *Accommodating Clinically Defined Incompetence*

As suggested by previous literature related to decision making in dementia care, the tendency to dichotomize “competency” (competent versus incompetent) was enacted by the study participants. This dichotomy oversimplified the appraisal of the decision-making capacity of people with a complex, often unpredictable and varied illness such as dementia. As a result, family caregivers and persons living with dementia struggled in the decision-making process to accommodate this notion of competency. Indeed, even those who represented the home care system (case managers) recognized the legal and moral challenges and consequences for both the clients and their family caregivers. The case manager in the following quote revealed the valuing of “capacity” and how it is imposed on the family, describing a combative process of negotiating the rights of individuals with dementia.

We are responsible [for] capacity, and there’s a legal aspect to that, an ethical aspect to that. A very difficult moral aspect occurs with some of these families [when] you are taking away someone’s

right to make a decision for themselves. Rarely do I find ... there isn’t tears and falling apart in caregivers when they are doing that. There is also sometimes, depending on the way the dementia is exhibited ... really severe anger and physical acting out at times and sometimes it’s so bad that the people completely withdraw, you know they completely give up. And then we’re back to meeting them at the beginning [starting the process of reviewing the circumstances necessitating this decision all over again].

Some family members felt removed from the decision-making process once their relative had been declared incompetent. In the following example, a granddaughter described how she was unable to change the outcome of her grandfather’s admission into LTC. Because the granddaughter did not have the power of attorney, the decisions were not hers to make, and she felt that there was nothing she could do to change the outcome of the decision.

It was the decision that grandpa made that put those people in charge of his life, if he ever were to become incompetent. Then she [mother of granddaughter] said: “It’s out of your hands, you know? I know you feel bad for him and you don’t want that [admission to LTC] to happen, but it’s just going to make things worse if you try to fight it”. ... And uh... it’s not my decision. There’s nothing I can do. All we can do is help them [people with dementia] feel as comfortable as we can while they’re at home, visit them at the nursing home, and whatever it takes. Those specific decisions weren’t up to us.

The previous quotations shed light on some of the struggles related to the dichotomy of capacity in decision making: for example, conflict between family members and the potential for early admission into LTC. In this case, the structurally produced dichotomization was problematic for those family members who were ultimately rendered without authority in the decision-making process. And yet, substitute decision makers (SDMs), including those with the power of attorney, have a legal responsibility to seek input from family members/friends of the person with dementia. Family members and/or friends of the person with dementia can challenge decisions made by the SDM by seeking to replace them through a legal process or by reminding the SDM of the duty to include and consider his/her comments. Unfortunately, in this case, despite the legal safeguards to promote dialogue among the family members, the legal responsibilities of the SDM had not been communicated to the family.

### *Making Untimely Decisions under System Pressures*

Similarly, the structural mechanisms that dictate the timing of decision making are manifestly problematic

for PWD and their caregivers. Our findings indicated that the home care system dictated the timing of decisions, leaving family caregivers and PWD obliged to live within time constraints. The timing of decisions played a tremendous role in whether the decisions were viewed as feasible, good or bad, and whether they were reactive or proactive. For instance, decisions related to relocating the person living with dementia into LTC were not based on health needs at that particular point; instead, the timing of such decisions reflected the challenges posed by the home care system's wait lists. Workers of the home care system rarely challenged these time constraints; instead, the burden for meeting this timeline became the family's problem. As one case manager explained:

We know that in six months they [the client] may not be [able to make decisions] and [that] ... it would be nice to get their name on the list [for long-term care] now in preparation. But we can't get their name on it, because they [clients and family caregivers] won't do it. So you actually probably spend a lot of the time going out there more frequently because things do change and deteriorate ... An elderly person with congestive heart failure knows that she will not be able to walk any longer, [that] she needs to go to a nursing home, and she will make that decision [so] she is going readily. But the dementia people, it's that "in between" phase that's the most challenging, I've found.

In the previous example, the case manager described the challenges inherent to persuading PWD and/or their family caregivers to sign up for LTC six months in advance. In this case, system structures such as wait lists are assumed to be immutable, as conveyed by the study participant's language: "we *can't* get their name on a list". What were not challenged by the study participants were the system structures that imposed the timing constraints in the first place. Consequently, the timing constraints continued to be reproduced and imposed on family caregivers, as suggested by this spousal caregiver:

I don't know how it worked. Whether he was on his last time to deny that [i.e., turn down the offer of a bed in LTC when his name was at the top of the wait list] ... it was still an option. So I'm thinking "well, you know what the problem is, if it comes to the point where you can't deal with it, then it's a hospitalization that has to come first before that [LTC]" ... It might take a little bit longer to get him in [to LTC] now that he's off that [wait list].

In the previous quotation, the caregiver described how she worked around the issue of timing to make a decision about LTC placement. Hospitalization was perceived as an alternative to admission into LTC, or a loophole in the wait-list approach that would enable the family to cope with the time constraints of the home care system.

The timing constraints of the system had become such a dominant aspect of decision making, particularly related to LTC, that these constraints ultimately determined care decisions for families. In the next example, the case manager described what happened when families did not comply with the system's timing requirements.

Is it a crisis or not? And where is that? Sometimes our conversation has to be, "You might have to accept a bed anywhere in Ontario", and that usually backs them off really quick [that is, forces them to make a decision in the moment for the potential eventuality of having to place the person with dementia into LTC].

According to the case manager, if families wanted service based on their needs, the system rules meant that they might have to accept a placement in an LTC facility anywhere in the province, possibly a facility at great distance from the family. It is important to recognize the case manager's use of positional power, to privilege some over others and enforce compliance with the wait-list approach. The consequences of challenging timing constraints are punitive, forcing families to "try their luck" to receive a bed close to home. Such structurally imposed conditions constrain families' decision-making processes by creating power imbalances related to controlling the timing of significant, life-altering care decisions. Additionally, the enforcement of such timing constraints is incongruent with Ontario law. Family members or PWD have the right to select up to five LTC facilities and be placed on their wait lists. Furthermore, the community service delivery agencies can provide high levels of home care until the placement of the PWD or their family's choice becomes available.

### *Reinforcing Exclusion in Decision Making*

Similarly, home care structures dictate whether persons or families living with dementia were included (had access to, or could participate) in decision making. Home care policies in Ontario recognize people as autonomous, unconnected individuals rather than people rooted in relationships with family, larger social circles, and work networks. As a result, the decision-making process in dementia home care often gives primacy to the individual (rather than the collective), thereby excluding other members of the client's network from decision making.

In the following quotation, the case manager described her preference for working with one individual (rather than a group) for ease of her own work.

I want one identified person – I will put them all on the consent [form], but, I mean, I want one person to communicate with so [that] the family takes [the

initiative], like that one person gets all this information and then they call me and let me know what's going on. And oftentimes, that is the person, who is going to [have] power of attorney.

Compounding the issue, inclusion in decision making is shaped by social location such as age, gender, and class. In the following quotation, the caregiver's son acknowledged that his economic situation influenced his role in decision making because it enabled him to be independent from the family and ultimately not rely on the family as a financial resource.

I think maybe that I was a little bit more distant and a little bit more objective. And I would be fairer as to the administration of everything because I didn't have any personal financial pressures myself. Like, I am independent of the family and have not had to ask for money for 50 years and so on. So they were saying, "Well, he knows what he's doing", and so on. And, "If someone is going to look after my affairs then ... I'll ask [my son] to do it, so."

This caregiver continued to describe how his sister would also be an ideal person to include in the decision-making process because of her professional standing as a nurse. Excluded from the decisions were these siblings' three other sisters.

My dad made his will, I think maybe when he was 85, relatively recently. I think they [the executors of his will] decided that he didn't have an up-to-date will, or should have an up-to-date will. And I was there, my mother was there, my father was there, and I believe maybe one or two of my sisters as well, although I can't remember who. They asked my dad, you know, "Who do you want to be the executor?" and he said "My son", and they asked who they wanted to be the power of attorney. And then the lawyers said, "Well, somebody else should go on [the paperwork] as well." And ... I think it was Kim as well. It might be my sister, Sally, though, I'm not sure. And then they asked who was going to be the power of attorney for personal care, and I think there was kind of a general discussion. And they said, "Well, Kim's a nurse." They put her down. And then they put myself down as well.

Thus, familial and societal values, beliefs, and practices such as valuing expertise, ranking people in a hierarchical way based on social standing, and ultimately excluding persons from decision making occurred in family decision making, reflecting and reproducing the decision-making patterns of the formalized home care system. Identifying a family spokesperson may be a strategy to address conflict; however, it is not necessarily legally enforceable or appropriate and in some cases may even be illegal.

According to the Province of Ontario (1992; 1996), SDMs have the legal responsibility to obtain input

from the person living with dementia with regards to the decision-making process. In many cases, the study participants with dementia felt as though their family member consulted with them on major decisions, particularly related to their health.

*Interviewer:* When there are things that need to be decided about your health care – for example, do you feel that you are able to put forth your ideas, or is it something that you and your daughter talk about?

*Person with dementia:* Oh sure. Oh yeah. I'm not afraid of speaking up.

Some home care providers acknowledged how they attempted to keep the PWD included in the decision making by offering small mundane choices. Although this practice was intended to maintain participation in decision making, ultimately the process was not inclusive because the contributions of persons with dementia were not equally acknowledged. As one personal support worker (PSW) explained,

But I always ask him what he wants to do, and if that's all right, sometimes I'll give him choices, like limited choices so that he doesn't [choose not to do things] if he doesn't really want to do exercises, he doesn't want to go for a walk ... he doesn't like doing those things [so he doesn't have to do them]. But [instead] I just go, "Okay, do you want to have your sponge bath first, or do you want to do your exercises first," that kind of question or – and he'll choose one or the other and – both are what we want to get done.

## Discussion

Home care structures and processes shaped the enactment of decision-making patterns. Participants' acquiescence to the home care system reified the immutability of the home care structures. This reification is problematic for Canada's aging cohort because, in an attempt to meet the needs of many people and ensure that they received minimal service the home care system has compromised tremendously on quality. The system's wait-list approach exemplifies this point. In this context, seniors with dementia and their families were forced to make decisions for the person with dementia to enter into LTC prematurely or too late, or more importantly, not on their own accord. Instead of challenging the system, case managers served as enforcers of the home care system's constraints, socially constructing a no-win situation in which they, as well as the PWD and their families also struggled with the legal, ethical, and moral challenges of being the enforcers.

Interestingly, several authors have suggested that the era of medical "paternalism" in decision making is over, yet these same authors have reported that the



roles of family and client were often minimal at best in medical decision making (Caron et al., 2005; Hertogh & Ribbe, 1996). As our findings with this study suggest, *who* and *what* is valued as good decision-making practice hegemonically controls the decision-making process. The notion of competency is prevalent in home care, revealing the need for re-conceptualization. Furthermore, our study findings illuminated the limitations of operationalizing competency as a dichotomous outcome with “being competent” equated with good decision making. Rather, decision making should also be evaluated by the degree to which participation or membership in the process transpires and by placing greater value on more inclusive practices.

Another important consideration within dementia care decision making is how frequently decisions are assessed. Once a decision for care is made, it is important to evaluate whether the decision is still appropriate for all members. Additional resources to assist families and health care providers with participatory and inclusive decision making and to enable them to work through, and live with, the consequences of decisions ultimately taken may help enhance health for all network members.

Furthermore, timing constraints within the system are closely linked with the decision to relocate a person living with dementia into LTC, and issues such as wait lists determine when a person with dementia and their family caregivers should consider LTC (Gaugler et al., 2000). Although Caron, Ducharme, and Griffith (2006) found that decisions related to institutionalization were the most difficult decisions for caregivers, the authors only examined the decision itself and did not account for contextual factors such as timing and involvement. The findings of our study expose many negative consequences for people with dementia and their families when decision making is pressured by time constraints. Family conflict, caregiver stress, and the psychological burden of uncertainty about where one’s relative will be placed are all threats to health that are contextually created by a system that is, instead, intended to promote health and provide health care.

In order to create health-enhancing conditions for decision making in home-based dementia care, there is a significant need to improve existing health care services. Issues that need to be addressed, for example, include issues that are significant predictors of admission into LTC: caregiver stress related to living separately from the relative requiring care, having time conflicts because of employment, and having to provide increasing amounts of care (Tsuji, Whalen, & Finucane, 1995). Providing families with optimal home care service, including fostering an environment for inclusive and timely decision making based on the needs of PWD

and their family members, may ultimately allow for more alternatives related to LTC.

Finally, our study findings suggest that socially constructed decision-making patterns within the home care structure give primacy to certain members (i.e., those with power of attorney) over others in decision making. Covert paternalistic patterns shape decision making by reinforcing hierarchical power relations, offering limited choice, and imposing certain policies and practices that constrain decision making for PWD and their caregivers. Consequently, some members are excluded from dementia care decision making entirely. Consistent with the findings of other researchers (Armstrong & Armstrong, 2004; Mui, 1995; Szinovacz & Davey, 2007), gender of caregivers and their socioeconomic status shaped not only involvement in care but also decisions related to care. Home care policies and procedures need to reflect the more inclusive practices suggested by the stated goal of family-centered care. This requires the overhaul of practices rather than endorsing what is conveniently operationalized – for example, having one primary contact for system ease of access.

Home care organizations also need to increase their awareness of the family’s role in decision making and, ultimately, the inclusion of all family members. As stated in the law (Health Care Consent Act, 1996; Substitute Decisions Act, 1992), the SDM has an obligation to consult with family and/or friends of the person with dementia as well as to consider the wishes expressed by the person with dementia when the person had the cognitive capacity to make decisions. However, many home care managers do not advise SDMs of this obligation; perhaps an under-resourced home care system which finds it is more time efficient to consult one person is in part responsible for this omission. Instead, a better understanding is needed on law and decision making in order not to inadvertently reinforce exclusion. Allotting adequate resources, including time and funding, to support practitioners who work towards family-centered dementia care is imperative (Cranswick & Thomas, 2005; Forbes & Neufeld, 2008; McWilliam & Ward-Griffin, 2006).

## Conclusion

This critical ethnographic study examined how the context of the home care system shapes decision making for PWD and their caregivers. The findings revealed three themes: (1) *accommodating clinically defined competence/incompetence*, (2) *making untimely decisions*, and (3) *reinforcing exclusion in decision making*. These themes shed light on how the values (competency), beliefs (immutability of the system), and practices (timing of decisions) of the home care system ultimately determine decision making for PWD and caregivers. Nurses,

home care organizations, and researchers have long recognized the need for family-centered care; however, more attention to collaborative processes and inclusive practices that involve all family members in dementia home care is necessary. Finally, practitioners, administrators, educators, policy makers, and researchers need to consciously, consistently attend to the marginalizing hegemony of decision-making practices and collaborate in order to optimize the health of families in home-based dementia care.

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