Using the life course perspective to study the entry into the illness trajectory: The perspective of caregivers of people with Alzheimer's disease

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Abstract

The research community is showing increasing interest in the analysis of the care trajectory of people with chronic health problems, especially dementias such as Alzheimer's disease. However, despite this interest, there is little research on the initial phases of the care trajectory. The fact that the first symptoms of dementia are generally noticed by those surrounding the elderly person suggests that the recognition of the disease is intimately linked to interactions not only amongst family members but also amongst friends, neighbours and health professionals. This study focuses on the period beginning with the first manifestations of cognitive difficulties and ending with the diagnosis of Alzheimer-type dementia. Interviews with 60 caregivers in Montreal, Canada were used to reconstruct how older people with Alzheimer-type dementia enter into the care trajectory. Our methods consisted of the analysis of social networks, social dynamics and action sequences. Our findings are presented in the form of a typology comprised of 5 pathways of entries into the care trajectory that are structured around the following four principles of the Life Course Perspective: family history, linked lives, human agency and organisational effects. We believe that analyses of the initial phases of the care trajectory, such as this one, are essential for the application of effective early detection and intervention policies. They are also central to informing future studies that seek to understand the care experience in its entirety.

Keywords

Recognition processes; Life course perspective; Social networks; Sequence analysis; Alzheimer's disease; Canada; Caregivers

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Introduction

Alzheimer's disease is one of the five principal causes of mortality in the United States (Katzman, 2008) and there is mounting evidence that the healthcare services offered to those suffering from aging-associated chronic illnesses are not adequate to their needs (Carpentier, Pomey, Contreras, & Olazabal, 2008; Miller, Booth, & Mor, 2008). It is curious, therefore, that little is known about the social interactions that characterize the initial phase of the illness trajectory of people with Alzheimer's disease (Adams, 2006; Pratt, Clare, & Kirchner, 2006; Schulz & Martire, 2004). This period of the illness has attracted increasing attention as of late, with clinicians feeling that a greater understanding of early phase dynamics would improve detection and intervention services not only for those with dementia (Clare, 2002; Goldsilver & Gruneir, 2001) but also for their caregivers and families (Moniz-Cook & Woods, 1997). Researchers are also interested, suggesting that understanding the care experience in its entirety is key to recognizing familial patterns of behaviour and developing more effective professional and community interventions.

Perhaps the most convincing argument for greater attention to the early phases of Alzheimer's disease stem from the characteristics of the illness itself. Because dementia cannot be detected by means of biological markers, diagnosis of the illness necessitates that those who are close to the patient observe and identify the symptoms (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). For a diagnosis to be made, therefore, numerous processes must take place, processes that reflect the personal judgment and observations of actors whose understanding the situation and available responses can vary widely. For that reason, social interactions have an important influence on the help-seeking process that will eventually lead to a diagnosis. The few studies that have analyzed the trajectory of care of those suffering from chronic illnesses have remarked upon the complexity of this phenomenon (Allen, Griffiths, & Lyne, 2004; Birditt & Antonucci, 2008).

In an attempt to help fill this gap, this study analyzed the initial period of Alzheimer's disease—that is, the period that starts with the first manifestations of the illness and ends with the diagnosis. To do so, we draw on the four key principles of the life course perspective (LCP): family history, linked lives, human agency and organisational factors. The primary aim of our analysis was to use LCP, considered one of the most important analytical approaches in social gerontology and the sociology of health today (Pescosolido, 2006; Settersten, 2006), to better understand the pathways of entry into the illness trajectory. The purpose of this study was to track social interactions of caregivers and their entourage in order to understand and map/identify typologies of entry into the Alzheimer's caregiving trajectory. We drew on principles of the Life Course theory to identify five trajectories that incorporated social dynamics. Questions that guide the study include:

- What are the various ways (or pathways) that one comes to enter the Alzheimer's caregiving trajectory?
- How might the principles of the LCP inform our understandings of entry into the care trajectory?

With these questions, we sought to move beyond the analyses of individual trajectories or the creation of typologies based on care-givers' characteristics (Allen et al., 2004, Nolan, Grant, & Keady, 1996) into an analysis that accounts for social dynamics. Interviews with principal caregivers of people with Alzheimer's disease formed the basis for our typology.

Life course principles

That structure entry into the illness trajectory

The first LCP principle that we used to analyze the initial period of the illness trajectory was that of family history. Individuals' lives are structured and affected not only by global events but by family experiences and events within their communities (Price, McKenry, & Murphy, 2000). Family support systems that provide assistance to an ill family member must be understood dynamically in light of earlier experiences and periodic transitions that reflect the changing circumstances of each individual (Szinovacz & Davey, 2007). The manifestation of chronic disease and the decision of some families to care for the ill family member can therefore be seen as one in a series of experiences that prepare the family to cope with such problems. Some families are better prepared than others, according to whether their past experience with disease has been intensive, difficult, relatively insignificant, or non-existent. The trajectory of care is also shaped by the health of the affected person: some patients are in relatively good health, are active and are allowed autonomy by the family, while others may already be living in a facility where they are cared for by health professionals. In other words, the entry into the trajectory of care is moulded by a family history that has been shaped over time.

The second LCP principle used in our study is that of linked lives, namely, the idea that individuals' lives are interrelated (Elder & Pellerin, 1998). Actors position themselves vis-à-vis each other and the actions of one actor influence the experiences of another. Societal and individual experiences are linked by relationships, time and social location (Kahn & Antonucci, 1980). The notion of linked lives thus suggests that the allocation of caregiving responsibilities among family members derives from negotiations within the family system as a whole (Szinovacz & Davey, 2007), with various events either helping to create greater intimacy within the family or exacerbating the distance between its members. In this regard, Antonucci, Sherman, and Akiyama (1996) have proposed the notion of a convoy model, arguing that individuals evolve through time, age and history continually affecting and being affected by others. Furthermore, "people will learn over time who best to turn to when emotional support is needed, which social partners are best able to help with activity of daily living, and who is best suited to help in times of crisis" (Lang & Carstensen, 1998, p. 65). Focusing on linked lives thereby provides one way of understanding entry into Alzheimer's-type Dementia.

Human agency is the third life course principle used here (Hitlin & Elder, 2007). Individuals have the freedom to act, to make choices, and to adopt strategies that help them surmount structural constraints. They have a certain degree of autonomy and a certain ability to reflect upon their motivations and actions in order to better respond to events and protect their long term interests. Various phenomena of contemporary society such as access to education, cultural experiences, the intellectualisation process nurture this reflexivity and enhance an

individual's capacity to take action, find solutions, form coalitions or manage conflict. In gerontology, the concept of human agency has been increasingly used as a means to better understand social phenomena (Kirsi, Hervonen, & Jylha, 2004; Taylor & Bury, 2007).

The fourth and final principle, organisational factors, reflects the fact that individual's living environments are shaped by organisational practices and public policies. At the community level, individuals can be influenced by institutional resources, social organisation and collective socialisation in which relationships of social capital help actors reach goals by bringing new resources into individuals' network (Colclough & Sitaraman, 2005). It is in this context that frontline organisations have developed different strategies to meet various health-related needs, for example by finding proactive means of detecting certain illnesses (van Hout, Vernooij-Dassen, & Stalman, 2007). Institutional practices like these can play a key role in the trajectories of elderly people first experiences of chronic illness.

Methods

To analyze the social processes associated with trajectories of care, this study used an interpretive approach based on network data and the analysis of action sequences as revealed by caregivers' narratives.

Sample

We recruited 60 caregivers in two clinics specialized in the evaluation of the cognitive difficulties of elderly people in Mon-treal, Canada. We attempted to recruit the caregivers as soon as possible after their relative was diagnosed, selecting them purposefully so as to allow for a theory-based investigation of complex and varied care experiences (Eisenhardt, 1989). Recruitment and interviews took place between October 2003 and February 2005. The majority of caregivers were women (71.7%) and most were either the wives (45.0%) or the daughters (25.0%) of the ill relative. The majority were born in Quebec (80%) and just over half were retired (52.5%). The ill relatives averaged 77.9 years old and most were retired (80%): 27 were their caregiver's husband and 19 were their caregiver's mother. In 68.3% of cases ($n = 41$), the caregiver and the ill relative lived together.

Data collection

The qualitative interview was comprised of three sections. In the first, we asked a series of questions focused on the beginning of the care trajectory. The caregiver was asked to describe the context in which s/he lived at the time that the symptoms first manifested and to give his or her impressions of the first manifestations of the disease. In the second section, the caregiver's social network was reconstructed, using a "name generator", derived from seven questions about the composition of the actors providing the care-giver with emotional, instrumental, social or information-related support. For each member of the network identified in this manner, we obtained sociodemographic information as well as details on the duration of the relationship and their experience of caring for an elderly person. In the third section, the question "Tell us what brought you to visit a doctor and seek help from the memory clinic" was used to document the respondent's social relationships as well as the

resources and assistance obtained during his/her entry into the care trajectory. Resources and assistance were provided by family, friends, community groups and/or professionals.

Data analysis

Our qualitative analytical process was informed by the four LCP principles of family history, linked lives, human agency and organisational effects explained earlier. First, we performed categorical content analysis (Miles & Huberman, 1994) and focused on two elements related to family history: family members 'health status and actors' caregiving experiences. We also explored the concept of linked lives by identifying actors both through the network approach (second section of the questionnaire) and through our narrative analysis (third section; Carpentier & Ducharme, 2003, 2005). The combined findings of the social network approach and narrative methodology are illustrated in Fig. 1.

Fig. 1 reconstructs the social relationships at play during the period of study. The left side of the illustration shows the care-giver's social network when the care trajectory first began, that is to say, at the time when the first symptoms of dementia first manifested (T_0). In this particular figure, we see that the network at T_0 was made up of six people: the caregiver (CG), the ill relative (IR) and four individuals who provided the caregiver with support (numbers 1, 2, 3 and 4). In the middle and on the right is a figure that illustrates what our narrative analysis revealed about the relationships between the seven actors involved in the entry into the care trajectory. The actors in question are represented by lines that begin at the moment of the actors' entry into the trajectory and end when the actors are no longer involved. The narrative thus identified both the actors who provided support (actors 1–4) and the actors who did not (according to the "name generator", actors 5 et 6), giving us a more complete picture of those involved. The lines that represent the actors form a background on which we have plotted various narrative codes: our team has developed almost 100 codes to represent the most significant elements in the care trajectory (see Table 2 for a partial list of codes).

To interpret this example, let us turn to a description of the process of entry into the care trajectory. We see that it is the caregiver (CG) who recognizes the first signs of dementia (fm) yet, he does not take immediate action. Almost a year later, the caregiver decides (de) to visit the family doctor (5) to discuss his suspicions. During the consultation (cs), the doctor expresses her opinion that the ill relative (IR) does not have cognitive difficulties. The caregiver decides to consult further, discussing the matter (dia) first with his son (1), then with a friend (6) and a neighbour (7) who had experienced a similar problem. Following these discussions, the caregiver decides (de) to go back to the doctor (cs) and insist that something be done. Feeling pressured, the doctor refers the caregiver (ref) to a specialized clinic. A geriatrician is seen (fcst) and the diagnosis made (dx). During this period, a friend moves away (mov) and two new relationships are formed: one with a neighbour (nr) and one with the geriatrician (fcst).

We then pursued agency and organisational effects using the methods of content analysis and by studying narrative codes that represent intentional actions taken by the actors. For example, we considered the caregiver to be active (i.e., exercising agency) if s/he took decisions (de), discussed matters with others (dia) or telephoned resources (tel). We noted

organisational effects through the elements caregiver's mentioned in their narratives: references to contacts with professionals, clinics or treatments, for example. We also observed these effects by means of a complementary study that shed light on the modus operandi of the two clinics from which we recruited study participants (Carpentier et al., 2008). Both of these clinics are specialized in the detection and treatment of memory problems: Clinic 1 opened recently, is run by a small team and has only just begun research activities, while Clinic 2 has been open longer, employs a greater number of biomedical researchers and has a strong interest in pharmacological research. Clinic 2 has developed a network of over 100 family doctors who promptly refer any elderly patients whom they suspect of having memory problems.

Developing a typology

The four dimensions of the LCP discussed above formed the basis for developing a typology outlining different paths, or ideal types, of entry into the care trajectory. Creating an ideal type allows for the analysis of complex social situations in which numerous dimensions have the potential to impact the social phenomenon under study. Developing a typology is a theoretical exercise in which some elements are stressed and others downplayed in order to create profiles that are more or less uniform. In developing our typology, we created five types characterized as either simple or complex: the simple were types of entry dominated by a particular LCP dimension (e.g., family history or past experience, organisational effects) and characterized by a short delay before the diagnosis, while for the complex, the entry into the care trajectory took longer and involved several dimensions of the LCP.

Validation process and ethical considerations

We analyzed the validity of the network data (Carpentier & Ducharme, 2007). The majority of the interviews were conducted by the same interviewer and the narratives and the action sequences were coded by three different researchers and cross verified. The final versions of the action sequences were determined by team consensus. This project received ethical approval from the two clinics from which the caregivers were recruited (Institut universitaire de gériatrie de Montréal, 2001-0502; Jewish General Hospital #03-032). All caregivers signed consent forms.

Results

Base data

Table 1 identifies the actors present at the time of entry into the care trajectory. The first set of columns lists those actors, including the caregiver, who made up the caregiver's original network. These names were produced by the name generator. We see from the data that at this time, the support network of the 60 caregivers included 475 actors, most of whom were friends (31.2%), siblings (21.1%) and spouses (18.9%). The second set of columns in this table lists the actors mentioned in the caregiver's narrative and corresponds to individuals who played some kind of role in the recognition of the first signs of dementia and in the help-seeking process that led to diagnosis of the disease. Those most involved in this process were spouses (22.8%), geriatricians (17.6%) and family doctors (17.8%). Note that very few friends (4.0%) were involved in this initial stage of the entry into the care trajectory.

Table 2 lists the principal narrative codes and the number of times that the codes were mentioned by our cohort. We found the first symptoms of the disease to be most often detected by the caregivers, although members of the caregivers' informal networks were also involved. We also counted 77 significant decisions (de), 59 significant discussions (dia), 52 medical consultations, 90 new contacts with medical services and 69 referrals between health professionals. This means that over 50 meaningful events took place during the entry into the care trajectory period. The letters A to F that appear in association with certain narrative codes refer to categories of events that are explained at the bottom of Table 3.

Five types of entry into the care trajectory

Table 3 outlines the numerical data that resulted in the identification of the five pathways of entry into the care trajectory. This data is not meant to be used to establish statistically significant differences between types of entry: it merely allows us to discern trends that suggest the existence of the various types. Furthermore, this table only lists dimensions most relevant to the creation of our typology. The five types of entry listed here can be divided into two groups that we differentiate according to the duration of the care trajectory: while the average entry period is 21.5 months, each of the first three types of entry lasts approximately one year, whereas Types 4 and 5 last longer. The first variables listed in this table refer to sociodemographic data and the experience and attitudes of caregivers and members of the network. Next come data on the social networks as observed at the beginning of the care trajectory (T_0): on average, these networks count 7.9 actors, including the caregiver, and have a density of 0.49. In contrast, the average number of actors mentioned in caregivers' narratives is 5.8, again including the caregiver. Our sequence analyses reveal an average of 12.4 codes per life history, with the greatest number of codes appearing in relation to Type 5.

Type 1: families' past experiences

The first type of entry into the care trajectory is centered around families' past experiences. In this type of entry, the onset of dementia is integrated into a trajectory of care for physical or mental problems that are already well underway (Type 1, Line 19 of Table 3, for now on L19). This group has the greatest number of experienced caregivers (L4); often, contacts with the public health system or with the veterans' healthcare system are already established (L12) and the illness is diagnosed relatively quickly, that is to say, within 12 months of first manifestation of the disease (L8). In most cases, the family of the ill relative is already experiencing significant stress and sometimes mistake the first symptoms of the disease for other health problems. Furthermore, the illness has often progressed to a relatively advanced stage. In all cases belonging to Type 1, a member of the network has begun to act as the caregiver even before the diagnosis has been made (L20).

Type 2: watershed events

The second type of entry is characterized by estrangement between the ill relative and his/her family, wherein the ill relative is relatively isolated and his/her family is not in a position to observe the progression of the disease. The caregivers' social networks are relatively small (L9) and the proportion of family members is low (L10), which decreases the networks' density (L13). The care trajectory is initiated by a significant event that brings

the members of the network closer to the ill relative and makes them aware of the degradation of his/her health status. Examples of such events are family reunions, vacations, and returns from a long trip. They can also be more dramatic occurrences such as a car accident or admission to the hospital (L21). The event in question causes the informal network to react and at least one member of the family begins to take care of the elderly person (L20). The evidence of the illness and the feelings of guilt on the part of some caregivers often contribute to rapid action to engage formal services of care and on average, the diagnosis is made within 10 months of the beginning of the trajectory (L8). This group has the lowest proportion of caregivers and network members with caregiving experience (L4, L5).

Type 3: organisational effects

The third type of entry into the trajectory depends on an organisational effect such as that instigated by the practices of Clinic 2 (L3). This clinic, for which recruitment for pharmaceutical studies is an important component of their business, is composed of family doctors who are instructed to promptly refer all elderly people who mention memory problems. This relatively simple sequence begins with a routine visit to the family doctor during which the caregiver or the patient mentions possible memory loss. The doctor then refers the patient to the clinic, when a specialist diagnoses probable dementia. Type 3 cases are characterized by negligible social interactions, as can be seen by the small size of the narrative network (L14) and the low number of narrative codes (L18). Relations with the family doctor are reduced to a minimum and the caregiver consults neither family nor friends to try to shed light on the situation. The type of entry is principally composed of elderly couples (L1) who form high density networks (L13).

Type 4: complex trajectories with gentle negotiations

Type 4 is marked by the slow progression of the disease and—in contrast to Type 5, which we shall describe further—a certain cohesion in the help-seeking actions of the ill person's entourage. While no entry into the care trajectory is painless and exposure to the illness invariably engenders intense emotions, in this type of entry, actors discuss the situation calmly, find grounds for agreement and discover ways to create alliances. Conflict and denial still take place, (L6, L7) but efforts by the support network help lower tensions and mitigate differences. It is not surprising, therefore, that this type of entry has the greatest number of network members with experience in dementia (L5): by sharing this experience, they can convince other members of the network of the importance of holding together in times of crisis. In this group, the first symptoms are identified in a relatively calm environment, where in the best of cases, there is spontaneous consensus as to the existence of the illness. Actors' experiences are leveraged to the advantage of the ill person and those involved agree on the nature of the assistance to be provided. Once the symptoms intensify, the family enters into more intense negotiations. Several caregivers increase their caregiving activities (L20) and find ways to navigate difficulties and dialogue with others concerned. Their meetings and discussions increase their reflexivity and cooperation becomes an effective way for them to solve problems, for example by accessing professional help. Of the 27 contacts established with health professionals by the members of this group, 15 persisted over time (L23, L24). This higher-than-average record can be explained by this group's

contact with health professionals, which stem from two factors. First, many caregivers in this group already have contacts within the clinical environment. These weak links (links with people relatively distant on an emotional plane) reassure elderly people who are reluctant to consult a physician: “We’ll go see the doctor that your cousin talked about”. Second, caregivers from Type 4 are better prepared to deal with healthcare services, having developed relevant arguments and mastered the appropriate terminology in discussions with members of their informal networks.

Type 5: complex trajectories with difficult negotiations

The last type of entry into the care trajectory is characterized by a long wait before the diagnosis and by a large number of unfavourable occurrences that disrupt the initial phases of the trajectory. Complicity and alliances between network members sometimes exist but in general, social interactions are difficult and certain circumstances can be identified that worsen the situation: the elderly person experiences health problems (L19), a series of trying circumstances takes place (L21), there is a history of conflict among network members (L7) or the caregiver has personal problems: “It might be true that I should see a doctor but I’m not sure, I can’t decide, my life is a shambles right now and I’m confused about everything”. The first symptoms are met with ambiguity and the caregiver often lacks supportive people who could help him/her come to terms with the situation. Although the network of Type 5 is larger than the network of other types (L9), few members seem able to comfort the caregiver or give him/her sound advice. Generally speaking, the members of this type of entry can be divided into two sub-groups. In the first, the caregivers are especially active, as can be seen from the high number of action codes (L22). Despite their good will, however, these people often run up against incomprehension, a lack of experience or tension among their family members that undermines their involvement. The second sub-group is made up of caregivers who are less proactive and who have greater difficulty making decisions. This is the group that takes the longest to seek help from the memory clinic. Even once contacts with professionals have been established, negotiations with the formal network tend to be difficult. Again, this group has the largest number of contact with professionals (L23), but its members often enter into conflicts that lead to the breaking of ties (L24). The caregivers of this sub-group feel frustrated by their meetings with professionals and some even claim racism or ageism. Some have exaggerated expectations of public services and alienate the health professionals, while others resist outside aid. In both cases, difficult communications with formal services threaten to propel the caregiver into isolation.

Discussion

The objective of this study was to explore how four dimensions of the LCP may be used to analyze and understand the entry into the care trajectory of families with a relative suffering from dementia. We define the entry into the care trajectory as the period that goes from first recognition of the symptoms of dementia to the point at which the illness is diagnosed, all of which are described by the caregiver. Unlike most typologies, ours is based on social dynamics. This approach allowed us to identify five types of entry into the care trajectory, some of which highlight the importance of one of the four LCP dimensions selected (e.g.,

family history and organisational effects) and others (Types 4 and 5) which reflect the complex, multidimensional and often unpredictable nature of social life.

Our study presents important evidence for understanding help-seeking dynamics and the care trajectories of people with Alzheimer's disease. We first used the LCP to develop an organisational framework that facilitated our study of the entry into the illness trajectory; we reinforced the sociological theory that social interaction can have powerful effects on actors (Pescosolido, 2006); and finally, reinforced the position that caregivers are essential to the provision of care. Basing our analysis on the LCP has resulted in the generation of new knowledge that complements the findings of other studies. For example, like Wackerbarth and Johnson (2002), we found that an average of 2 years passes before families obtain a diagnosis of dementia. Our approach went further, however, in that it distinguishes types of entry in which a diagnosis is made within the first year (Types 1, 2 and 3) from types in which the diagnosis takes longer (Types 4 and 5). It is in this second group that a greater diversity of social interactions takes place.

Type 1 of our typology highlights the fact that all trajectories of care reflect family history and that dementia is not always the only health problem with which actors must cope: the situation is, after all, one that involves the old and the vulnerable. Program of *integrated systems of care* for the elderly reflect awareness of this dynamic and are designed to meet the needs of this population (Kodner, 2002) through new managerial practices that seek to optimize services and care by promoting collaboration, coordination, efficiency and integration. Until now, however, these models seem to be most useful in the advanced stages of dementia. They do not offer interventions for other stages of the trajectory, interventions such as personalized emotional support in the initial phases of the illness.

Type 2 is composed of elderly people who are relatively isolated, at least at the beginning of the trajectory. Fortunately, however, the members of this group still have family members willing to help. Not all elderly people are so lucky and it is important that health-care systems plan the means of caring for the growing numbers of elderly people who lack informal support networks. Perhaps more than other types, Type 2 also illustrates the difficulty of dating the entry into the trajectory with any precision. The nature of dementia is such that the first symptoms usually consist of behaviour that worries the family and friends of the ill person. Often, the behaviour in question consists of harmless acts or gestures, unimportant lapses in memory, or a loss of the ability to perform certain small tasks. If the ill person's network is made up of people attuned to these changes, the dementia is diagnosed sooner than when the elderly person and his/her network are estranged. In the latter case, it is difficult to establish the date of entry into the trajectory with any certitude. In other words, recognizing the first symptoms of dementia is a social construct that depends upon the characteristics of the people involved and their ability to negotiate for (or against) diagnosis of an illness that continues to frighten most families.

Type 3 illustrates an organisational effect, namely, the influence of the healthcare environment on the trajectory. This type of entry is made up of the simplest action sequences with a minimum of social interactions and little decision-making on the part of the informal network. These circumstances sometimes result in families beginning the trajectory before

they are ready. Many authors feel that a diagnosis of probable Alzheimer's disease is not without risks or consequences. An early diagnosis often is "the dark mirror of our own private future that the majority of us are not prepared to face" (Comer, 2008, p. 368). It can also mobilize families earlier than otherwise, forcing them to adopt roles that can jeopardize their older relationships because of the stigma associated with the disease (MacRae, 1999).

Type 4 encapsulates the idea of the convoy model (Antonucci et al., 1996). Over the course of his/her lifetime, the individual builds a support network that is activated when a member of the network exhibits the need. But while the majority of families in our sample activated their networks during the entry into the care trajectory, it was among families belonging to Type 4 that the actions were most successful. Some caregivers are better than others at acquiring skills and putting those skills into practice. Benefitting from access to people with whom they can engage in rich, multi-layered and dense conversations (Boden & Molotch, 1994), these caregivers learn techniques and responses that help them cope with suffering, denial, and ambivalence. Enriching exchanges can occur with family members—similar to the observations of Blay, Furtado, and Peluso (2008), our findings show family to be individuals' primary source of help—but we also witness health professionals acting as important participants in the help-seeking process. Caregivers prepared in this way lower their stress and find it easier to interact with the formal system of care. On a related point, we also observe that past experiences with health services is an advantage for many families, but not for all. Positive experiences allow families to develop strategies and take action but difficult experiences can exhaust families to the point that they are unable to deal with new challenges. This could be what takes place with the families of Type 5.

Type 5 corresponds to dramatic cases in which events are especially disturbing for those involved. Type 5 trajectories are marked by unpredictability and the accumulation of unfavourable circumstances. The apparition of dementia in a member of the network inspires ambiguity and insecurity among his/her entourage and destabilizes networks already rendered fragile by trying events. Those who belong to this type of entry can certainly reap the greatest benefit from professional interventions. Such interventions might begin by rebuilding confidence within the networks. Confidence facilitates decision-making, lowers transaction costs, encourages cooperation, and above all reduces uncertainty in complex situations (Luhmann, 1991). In contrast, a lack of confidence lowers the chance of those involved connecting with formal services. The challenge is to enter into contact with family members, bring them to use resources regularly, and eventually increase the coordination and confidence that grow in their midst.

Theoretical implications and continuity in our study

Our typology of entries into care trajectory now established, the next stage in our study is to continue to monitor the caregivers in our cohort in order to observe the links between the types of entry into the care trajectory and the nature of the trajectories experienced over the long term. That is, how entry impacts the overall trajectory of diagnosis and living with Alzheimer's-type dementia. Examples of questions we may ask are as follows: will caregivers with a more recent history of engagement with the ill person (Type 2) play a role similar to the role played by caregivers with a longer history of engagement (Type 4)? What

are the longer-term consequences of a premature entry into the care trajectory (Type 3)? Are Type 5 caregivers condemned to experience a trajectory fraught with challenges and difficulties by virtue of their difficult entry period? On this last point, the social sciences have produced three schools of thought regarding trajectories' determinist nature. For the first, trajectories leave nothing to chance and early elements can predict the course of the trajectory over the long term. For the second, trajectories are above all complex and easily shaped by contingencies, making them both unpredictable and impossible to control. The third school of thought is an intermediate one that can be associated with the concept of path dependency, the idea that prior occurrences channel and constrain the actor's choices today. This school holds that the extremely vulnerable circumstances of elderly people with chronic disease mean that while care trajectories are characterized by continuity, they are also susceptible to abrupt change by virtue of changes or disruptions in relationships that could occur at any time. In support of this last approach, our typology demonstrates both a certain organisation in the kinds of entry into the care trajectory and the rapidity at which events can modify the trajectory's course: a new health problem or the loss of a job can disrupt a situation that until then had been fairly continuous just as easily as an unexpected meeting can stabilize a trajectory plagued by constant changes in direction.

Conclusion

Few studies to date have analyzed the entry into the care trajectory of people with Alzheimer's-type dementia. Our study reveals the importance of to the entry into the trajectory of four dimensions of the LCP: family history, linked lives, human agency and organisational effects, and the ways in which these dimensions point to differing types of entry into the illness trajectory. We expect that our identification of five types of entry into the trajectory, and our future analysis of the entire course of the trajectory, will generate important information for the creation of interventions that will better meet the diverse needs of elderly people with chronic disease and their families. Creating interventions poses a significant challenge to healthcare services. For this reason, it is essential that we understand the initial trajectory period during which families experience great stress but must nonetheless negotiate with both the members of formal systems and the members of informal systems of care. Families' initial contacts with healthcare professionals and other members of systems of care are of great significance because the alliances forged are likely to last for several years. If healthcare services are to maximize their effectiveness, they must adapt to new realities in new ways. They can do this by investing more time with older people more likely to experience different health problems, by paying close attention to interpersonal relations—by showing respect, for example, and by being attentive and empathetic to the individual needs of each family—, and by holding themselves ready to respond to an ever-growing range of situations in which logistical, medical, human and social challenges are the order of the day.

Acknowledgments

This research was funded by the Canadian Institutes of Health Research (project no. 85031). We would like to extend our sincerest gratitude to the families who took part in this study. We would also like to thank Jennifer Petrela for her translation and her editorial assistance.

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- (fm) First manifestation
- (de) Decision to see a doctor
- (cs) Medical consultation
- (dia) Discussion/dialogue with the son, the friend and the neighbour
- (nr) New relationship
- (ref) Referral by the doctor
- (fcs) First consultation by a team at a memory clinic
- (dx) Diagnosis of Alzheimer's disease
- (prs) Prescription
- (mov) Move of residence

Fig. 1. Relational processes as revealed by reconstruction of the initial support network at basic time (T₀) and analysis of caregivers' discourse.

Table 1

Actors involved in the trajectory according to the social network analysis and the narrative data.

	According to the social network analysis		According to the narrative data	
Spouse	90	18.9%	79	22.8%
Brother/sister	39	8.2%	21	6.0%
Son/daughter	100	21.1%	40	11.5%
Step-brother/step-sister	19	4.0%	4	1.2%
Mother/father	17	3.6%	23	6.6%
Other family member	36	7.6%	5	1.4%
Friend	148	31.2%	14	4.0%
Other informal contact	19	4.0%	5	1.4%
Geriatrician	0	0.0%	61	17.6%
Medical practitioner	6	1.3%	62	17.9%
Other professional	1	0.2%	32	9.2%
Private caregiver	0	0.0%	1	0.3%
	475	100.0%	348	100.0%

Table 2

Frequency of narrative codes related to events that took place between the first manifestations of dementia and the attribution of the diagnosis (partial list).

	<i>n</i>	<i>A^a</i>	<i>B</i>	<i>C</i>	<i>D</i>	<i>E</i>	<i>F</i>
First manifestations of dementia as noticed by...							
the ill relative (<i>fm1</i>)	7						
the caregiver (<i>fm2</i>)	43						
a member of the informal network (<i>fm3</i>)	24						
a member of the formal network (<i>fm4</i>)	9						
Families' past experiences and events							
Caregiving for illnesses other than dementia (< <i>ecp</i>)	7	×					
Health problems before the onset of dementia (< <i>hp</i>)	6	×					
Use of services before the onset of dementia (< <i>ser</i>)	4	×					
Other events before the onset of dementia (< <i>eve</i>)	2	×					
Social relations and role attributions							
The ending of a relationship (<i>er^(F)</i> , <i>bup</i> , <i>dea</i> , <i>sui</i> , <i>mov</i>)	31						×
The beginning of a relationship (<i>nr</i>)	9						
The beginning of caregiving (<i>ec</i>)	35		×				
Action codes							
Decision taken by an actor (<i>de</i>)	77				×		
Discussion between two actors (<i>dia</i>)	59				×		
Telephone call to a resource for information (<i>tel</i>)	5				×		
Mobilization of a family member for help (<i>mob</i>)	22						
Use of services							
Consultation of a general practitioner (<i>cs</i>)	52						
First consultation with other medical service (<i>fcs</i> , <i>fcst</i>)	90					×	
Beginning of an intervention (<i>bin</i>)	13						
Referral from one health professionals to another (<i>ref</i>)	69						
Medical evaluation (<i>mev</i> , <i>mad</i>)	7						
Diagnosis of dementia (<i>dx</i>) or mild cognitive imp. (<i>dxp</i>)	71						
Professional helping reaching a resource (<i>int</i>)	12					×	×
Health problems of the ill relative							
Deterioration of health (<i>m+</i>)	9						
Other health problems (<i>hp</i>)	13			×			
Hospitalisation (<i>hos</i>)	12			×			
Event: Any kind (<i>eve</i>)	37						
Accident/incident (<i>acc</i>)	5			×			
Job loss or premature retirement (<i>emp</i>)	10			×			

^a A, B, C, D, E, F: For an explanation of these codes, see Table 3.

Table 3

Characteristics of the five types of the entry into the illness trajectory.

Line		Type 1 (n = 8) n (%)	Type 2 (n = 8) n (%)	Type 3 (n = 12) n (%)	Type 4 (n = 16) n (%)	Type 5 (n = 16) n (%)
1	Caregivers who are the spouse of the ill relative	6 (75.0)	3 (37.5)	10 (83.3)	10 (62.5)	10 (62.5)
2	Diagnosis provided by Clinic 1	6 (75.0)	5 (62.5)	1 (8.3)	7 (43.8)	12 (75.0)
3	Diagnosis provided by Clinic 2	2 (25.0)	3 (37.5)	11 (91.7)	9 (56.3)	4 (25.0)
4	Caregivers with prior experience of an illness	5 (62.5)	3 (37.5)	6 (50.0)	8 (50.0)	7 (43.7)
5	Informal networks with prior experience of an illness	3 (37.5)	2 (25.0)	3 (25)	10 (62.5)	7 (43.8)
6	Families that experience denial	1 (12.5)	1 (12.5)	2 (16.7)	5 (31.3)	2 (12.5)
7	Families that experience tension	2 (25.0)	3 (37.5)	5 (41.7)	6 (37.5)	8 (50.0)
	<i>mean</i>	<i>mean</i>	<i>mean</i>	<i>mean</i>	<i>mean</i>	<i>mean</i>
8	Duration in months of the observation period (the period between the first manifestation of dementia and the diagnosis-dx)	12.25	10.25	11.17	31.00	29.94
9	<i>Social networks</i> : Total size at T ₀	8.38	7.00	7.92	7.38	8.69
10	Family members	5.63	3.50	5.25	5.06	5.19
11	Friends	2.50	3.38	2.33	2.31	3.44
12	Professionals	0.25	0.13	0.25	0	0.06
13	Social network density at T ₀	0.47	0.42	0.64	0.53	0.44
14	<i>Narrative actors</i> : Total number* between T ₀ and dx	4.88	5.50	4.17	6.31	7.06
15	Family members	2.38	2.88	2.25	3.31	3.13
16	Friends	0.00	0.50	0.0	0.56	0.50
17	Professionals	2.50	2.13	1.92	2.44	3.44
	<i>Narrative codes</i>					
18	Number (<i>means</i>)	11.13	13.50	7.50	13.94	18.88
	Amalgamated categories (A–F) ^a	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>
19	A. Families' past experiences and events	8	1	0	2	8
20	B. Entry into the caregiver career	8	6	1	12	8
21	C. Significant negative events	0	12	1	4	17
22	D. Actor taking action	11	13	12	39	66
23	E. Beginning of a professional relationship	12	11	13	27	43
24	F. Ending of a professional relationship	4	3	1	12	20

T₀ Basic time (time at which the first symptoms of the illness appear).

* Any actor present for any portion of the time period of study counts as one actor.

^aNot all narrative codes are included in these six amalgamated categories (A–F).