Reconstructing the Temporal-Relational Context:
Trans-Action Patterns of Caregivers of an Ill Relative with Alzheimer’s Disease

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Abstract
The evolution of a social model of care has been accelerated by a range of factors such as new technology, a change in political parties, and lobbying activity. Further complicating the emergence of the new paradigm is the fact that providing effective care within the community requires an understanding of the context that surrounds the family and the ill person, who must often cope with illnesses that require specialized services and the caring for another person’s basic human needs. Using the relational sociology perspective, this study aims to better understand the care trajectory of caregivers of people with Alzheimer’s disease. We have adopted a methodologically innovative approach that explores two life histories from the viewpoint of social networks, social representations and action sequences. Only once researchers and policy-makers better understand help-seeking processes in the unpredictable context of chronic illness and social life, can they hope to develop social policies adapted to a population whose multiple needs require long-term community care.

Keywords: Alzheimer's disease, caregiving, chronic illness, event analysis, health behaviour, longitudinal studies, microsociology, narrative analysis, network analysis.

Introduction
The ageing of the population in Western societies has occasioned unprecedented reflection on the elderly, their condition, their future and the best means of helping them through the challenges that face them and their families (Biggs, Lowenstein, and Hendricks, 2003). One such challenge is the appearance and aggravation of chronic illness, particularly illnesses for which medicine does not yet have an answer and which necessitate psychosocial interventions. Alzheimer-type dementia is one such illness. Alzheimer’s causes progressive memory loss and a decreasing ability to function. Family members are generally the first to notice the manifestations of the disease and the family is often involved throughout the trajectory of care (Aneshensel, Pearlman, Mullan, Zarit, and Whitlatch, 1995). Alzheimer’s disease confronts caregivers with intense and demanding situations, often with emotional and physical repercussions. In addition, it requires those involved to make numerous decisions about the use of community-based services. The nature of family members' and
caregivers’ involvement, the structure of services and different life events all have an impact on the care trajectory (Brubaker and Brubaker 1989; Robles-Silva, 2008).

Over the past 20 years, research on Alzheimer-type illnesses has identified some of the conditions that favour the emergence of the disease and established several parameters for pharmacological and psychosocial interventions. Qualitative and quantitative studies have revealed some of the hardships experienced by family members as a result of the specific nature of Alzheimer’s disease: high rates of caregiver distress (Hirst, 2005), low service use by caregivers and family members (Brodaty, Thomson, Thompson and Fine, 2005), poor results of professional intervention programs addressed to caregivers (Zarit and Femia, 2008), and a thorny interface between formal and informal systems of care (Carpentier, Pomey, Contreras and Olazabal, 2008; Lyons and Zarit, 1999). These revelations have led to a search for a better understanding of the diversity and complexity of family systems (Silverstein, Bergtson and Litwak, 2003). Working in this vein, our research team has recently launched a research program based on the principles of relational sociology in which social actions can be understood as part of a chain of trans-actions initiated by interconnected social actors (Emirbayer, 1997).

The main objective of this article is to analyze the trajectories of two caregivers of elderly people suffering from dementia, from the perspective of relational sociology. We hope this work will further the understanding of the medical, psychological and social mechanisms underlying the trajectory of care. Our analytical technique is based on the network approach, the social representation perspective and narratives that focus on action sequences. Although in this article we examine two life histories, our goal in the future is to develop a method that combines the processes in play within a larger group of trajectories that we are currently studying as part of an ongoing research project (Carpentier & Bernard, 2011). We believe that the development of a social model of care has been limited by an incomplete understanding of families’ care experiences, assessed too often from a static rather than dynamic viewpoint. It is our view that by obtaining data on the relational and temporal dimensions of the caregiving experience we will be able to develop more effective intervention practices and lay the groundwork for social policies that meet the complex and changing needs of the families and caregivers of sick elderly people.

**Multiple, contingent and fractured conceptions of society**

Much of the sociological research after the Second World War focussed on collective processes and the analysis of large groups. To a large extent, mainstream sociological theory of the past sixty years has revolved around class *habitus*, role theory, and the mechanics of socialization (Bourdieu 1998; Parsons 1951). A growing number of sociologists have rejected this approach as being inadequate to account for the complex phenomena that occur within smaller social groups confronted with unusual situations. What many consider to be a statistical, determinist or generalistic form of sociology is thus being replaced by a new brand of sociology closer to the individual and to social dynamics. The new sociology sees roles as more flexible and accords greater importance to subjectivity, personal experience and the construction of individual identity. Indeed, today we are seeing a myriad of sociological theories and a tendency to reposition the individual at the centre of social analysis. Marcuccelli (2006) refers to an accelerating process of individuation and the fact that social change can be more clearly perceived through the analysis of individual trajectories. Archer writes about “internal conversation” (2003) and the importance of reflexivity in social processes. Dubet (1995), for his part, proposes a sociology of experience and notes that the plurality of forces determining individual behaviour leaves less and less room for the dominant elements of social organization. Last, more and more network theorists are proposing models that combine structure, process and identities (Skvoretz & Fararo, 1996; White, 2008).
This modern orientation of sociology has had repercussions for the evolution of conceptual models of help-seeking processes in health care. Beginning in the 1990s, these models have generally complemented traditional approaches that came under growing criticism for their reliance upon a static and individualistic approach founded on the concept of rational choice (Biddle, Donovan, Sharp, and Gunnell, 2007; Pescosolido, 1992; Shengelia, Tandon, Adams, and Murray, 2005). In contrast, the new models emphasize the dynamics of change and account for historical events and exchanges at the microsocial level (Berkman and Glass, 2000; Messeri, Silverstein and Litwak, 1993; Pescosolido, 1992). These new “complex” models draw largely on classic research of the 1960s and 1970s that, while appealing, has remained secondary to survey-type approaches (Coleman, 1986; Maines, 1993). Notions developed in this classic material include the pathway to care (Claussen and Yarrow, 1955; Horwitz, 1977; Zola, 1973), the career model (Suchman, 1965), multiphase decision-making (Elder, 1978), and the importance of the lay referral system and network influences (Freidson, 1970; Kadushin, 1966; McKinlay, 1972) in which modes of consultation can be either simultaneous or sequential (Fabrega, 1970). Recently, Pescosolido (1991, 1992) synthesized and reorganized these concepts in her Network Episode Model (NEM).

These suggestions of conceptual frameworks in health care appear compatible with Emirbayer’s Relational Sociology Perspective (RSP) (1997). According to Dépelteau (2008), RSP is founded on five principles. The first principle is trans-action: social actions should be understood as links in a chain of events in which interdependent actors complete certain trans-actions. The elements “involved in a trans-action derive their meaning, significance, and identity from the (changing) functional roles they play within that trans-action” (Emirbayer, 1997: 287). The second principle is primacy of process: social phenomena should be analyzed in terms of continuity and with an emphasis on processes. The third principle is dereification: one must avoid all reification of concepts or thingification of social relations. RSP considers social phenomena to be ongoing, open processes and suggests that we attempt to understand the ways in which human actions produce and reproduce these processes (Giddens, 1984). RSP also suggests that we refuse to adhere to fixed normative categories such as individualism, familism or collectivism but rather understand those concepts as ideas embedded in complex relational networks that are both public and intersubjective (Emirbayer, 1997). The fourth principle is relational perspective: the idea of refusing to see the social universe from an individual/egocentric standpoint but conceiving of the individual as an actor in perpetual negotiation with his/her changing environment. The fifth principle is emergence: the undetermined and unpredictable nature of the evolution of trans-actions invalidates the formulation of all social laws that attempt to dictate social processes.

Naturally, these theoretical developments must be supported by methods and techniques that allow research to take place, and in this regard, we felt that a combination of three techniques would be useful. First, the social network perspective is tailor-made for the exploration of interpersonal relationships. As a technique, it allows the researcher to identify actors, map the ways in which actors relate to one another and determine the nature of the links between them (Antonucci, Sherman and Akiyama, 1996; Carpentier and Ducharme, 2003). Networks can be analyzed according to their structural dimensions (size, density, multiplexity) or according to content (attitudes, beliefs, values); it is through social links that ideas and symbols are transmitted (Pescosolido, 2006).

In this context, it is promising to consider network content using a second technique, the social representations approach (Moscovici and Marková, 1998). Representations refer to the processes that characterize commonsense thinking, that is, practical thinking that has been socially elaborated based on values, codes, ideologies or day-to-day interactions (Jodelet, 2003). Social representations generally have two basic functions: “First, to establish an order which will enable individuals to orient themselves in their material and social world and to master it; and secondly, to enable communication . . . by providing a code for social
exchange and a code for naming and classifying unambiguously the various aspects of their worlds and their individual and group history” (Moscovici, 1973). The universe of representations may not constrain actors outright, but it still has undeniable effects: these vary in a context that is continually shaped by systems of communication and trans-actions.

Our third technique is based on the acknowledgment that trans-actions take place over time, within the sphere of networks. To account for this relational temporality, we turned to authors like Abell (2004) and Abbott (1992) who suggest a narrative approach based on the analysis of action sequences. Griffin (1992) has defined narrative as the portrayal of social phenomena as temporally ordered, sequential, unfolding, and open-ended “stories” fraught with conjuncture and contingency. In this context, narratives are a means of explaining social processes, revealing chains of events and/or actions that lead to an outcome that is not necessarily predictable as the consequence of a conjunction of contingent events. Health care studies are making increasing use of narrative as an analytical perspective (Cappelletto and Merler, 2003; Uehara 2001).

Using these techniques, we based our study on the following question: given the complexity of care trajectories and recent theoretical developments that reposition the individual at the centre of social analysis, how do different temporal-relational contexts influence the adoption of a particular agentic orientation? Emirbayer and Mische (1998: 962) conceptualize agency “as a temporally embedded process of social engagement, informed by the past but also oriented toward the future . . . and toward the present.” This study paid special attention to individuals’ experiences and hardships, to the fluid nature of structures, and to people’s ability to take action in an unpredictable and restrictive environment. In this article, we present two case histories using an innovative methodological strategy that draws on the formal methods of networks, representations and sequence analysis.

Methods

At a methodological level, the adoption of the relational, temporal and process-oriented framework is a challenge (Emirbayer, 1997). As Pescosolido has pointed out (1992), we have yet to perfect dynamic, multi-method data collection protocols that capture both social processes and the influence of networks. Because of the innovative nature of our approach, we limited our analysis to two life histories. The individuals whose cases are presented here were interviewed on two occasions, 18 months apart.

Questionnaire

Our questionnaire consisted of an interview template made up of three principal sections. In Section 1, we included open-ended questions about the time that the illness first presented and the nature of the first symptoms. We also asked respondents to describe their social context at this time and to discuss how they perceived their ability to help the ill person. In Section 2, we asked respondents to identify the assistance resources they had used to date, for example, family, friends, community groups or professionals. We noted the frequency of respondents’ meetings with these resources, the intensity of respondents’ use of the resources and respondents’ appreciation of each resource; and we explored respondents’ reasons for use or non-use of the resources in light of factors that included family values and attitudes. In Section 3, we asked respondents to describe their support networks. We used a name generator composed of five questions that helped respondents to identify the people who provided them with emotional and instrumental support, information, and/or companionship. We also asked for sociodemographic information and the place of residence of each social actor and for information about each actor’s experience with elder care, the frequency of his/her contact with the respondent and the nature and length of their relationship. The questionnaire was adapted after the first interview: Section 1 was withdrawn and Section 2 was reformulated to focus on assistance resources used.
since the first interview (questionnaire available on demand, in French and English). The interviews, which averaged an hour and a half, were tape recorded, transcribed in full and managed with N-Vivo software.

**Data analysis**

We analyzed the data obtained from the interviews using two qualitative approaches. First, we applied a structural approach to social representations in order to reveal network content. Our methods were based on a systematic identification of dimensions drawn from the literature on barriers to, and facilitators of care, which resulted in the definition of 50 dimensions (Carpentier, Ducharme, Kergoat, and Bergman, 2008). These dimensions corresponded to individual and collective factors that we grouped into four categories: structural, relational, cognitive and cultural. Examples of dimensions include the ill relative’s reluctance to seek help, uncertainty on the part of the caregiver, and a negative experience with services. The principal investigator and other members of the research team coded the interviews individually according to mentions of each dimension. Following the content analysis, we created a table that classified dimensions according to frequency of mention. This table provided the material basis on which we formulated our interpretation.

We employed narrative as our second qualitative approach. Our questionnaire was designed to elicit historical landmarks, especially with respect to referrals, appointments with health professionals, and social links with the various actors involved in care. Using the data thus obtained, we used a procedure that maps significant life events and social relations (Carpentier and Ducharme, 2005). This tool analyzes actions sequentially in order to show how events/decisions influence the life course. We also developed a coding system for action-sequence trajectories, identifying over 100 kinds of events that could significantly influence a trajectory. Examples of codes are the first signs of dementia, the beginning of the caregiver role, the creation of new social relationships, the end of relationships, the assistance-seeking process, family resources, and conflict resolution. We then inserted the codes into an illustration representing a relational-temporal framework.

**Figure 1: Schematic Representation of the Temporal-Relational Context Using Networks and Narratives**

In Figure 1, the starting point of the illustration is the support network at T0 as identified by the name generator. This network was obtained retrospectively. We can see that for this narrative, T0 consisted of four supporting actors (Actors 1 to 4), with the narrator identified as Actor 0 (actors are subsequently noted as a0, a1…aN). The narrative mentioned the arrival of three new actors (a5, a6, a7), who were placed to the right of the network as it existed at T0 (processes in motion). The placement of these actors in the figure corresponds to the time at which they were mentioned in the action sequences. The lines of the illustration represent the length of time over which an actor appears over a given period, with action codes (x, y, z, s) plotted along these lines. The narrator is represented by a thin line, supporting actors are represented by a thick line and actors mentioned in the narrative are represented by a double line. At the time of the first interview (T1), the
network consisted of two supporting actors (a1, a4). At the time of the second interview, only one actor appeared (a4) and the respondent’s discourse referred to a new actor (a8) who was present only for a short time. Keep in mind that the “Network at Time 0, 1 and 2” shows supporting actors drawn from the name generator (Questionnaire Section 3), while the actors listed in the diagram under “Processes in motion” are actors mentioned in the action sequences (narrative analysis). Supporting actors can be excluded from this diagram because they are not mentioned in the action sequences.

Figure 1 can be interpreted in two ways: horizontally and vertically. A horizontal interpretation emphasizes action sequences over time. In the case of Figure 1, for example, a1 is involved in event x that leads to action y and solicits the appearance of a6 who initiates move z. A vertical interpretation reveals the relational context that surrounds a given event. Still referring to Figure 1, event s takes place when a8 appears in the life of the respondent and supporting actor a1 leaves the network. This twofold method of visualizing relationships allows the observer to better contextualize and understand complex situations within a temporal and relational framework.

This research received ethical approval from the Institut universitaire de gériatrie de Montréal Ethics Committee (ref. 2003-0404). We used fictitious names for the two individuals whose cases were presented.

**Two case studies: Trans-Action at the empirical level**

Using the procedures just described, we were able to reconstruct and analyze the temporal-relational context that surrounds the caregivers’ trajectories. Due to the length restrictions of this article we cannot analyze all of the data obtained from our interviews, so we have elected to evaluate two episodes from each trajectory. One is evaluated horizontally and the other, vertically (although each episode could be treated both horizontally and vertically).

These two trajectories reveal both similarities and differences. Both caregivers are women and both are of approximately the same age; one is the daughter of the person with dementia while the other is the ill person’s wife. The structure of their respective networks suggests different connective capacities and different orders of representations, one of which is characterized by a series of breaks in relationships and the other, by continuity. We will start by briefly describing each case before analyzing the episodes and discussing elements that better explain the two trajectories.

**Claudia’s Story (Case 1)**

Claudia’s parents emigrated from the Middle East soon after their children were born. Claudia lives alone and works full time in communications. Her two brothers are health professionals. At the time of our first meeting, Claudia reports that her mother has had memory loss problems for almost three years. As shown in Table 1, Claudia describes an initially small support network that includes her mother (actor 1, or a1) and three friends (a2, a3, a4). The actors do not know each other and network density equals 0.1. Claudia’s narrative at the time of the first interview mentions 20 people: 5 family members (25%), 4 friends (20%) and 11 actors outside the family (55%). At T1, her network is composed of two friends who were also present at T0 (a2, a3) and two professionals who provide her with counselling (a13, a14). At T2, Claudia’s network is composed of two friends and two unpaid caregivers (a18, a19); her narrative at the time of the second interview identifies 18 actors, of whom 6 are professionals and 5 are members of the community.
Table 1: Social Actors Involved in Case 1 as Identified by the Name Generator (Networks at Time 0, 1, 2) or by the Narratives (Interviews 1 and 2)

| Network T_0 1999 | Interview 1 | Network T_1 2005 | Interview 2 | Network T_2 2007 |
|------------------|-------------|------------------|-------------|------------------|
| a1. mother       | a1. mother  | a2. friend       | a2. friend  |
| a2. friend       | a2. friend  | a3. friend       | a3. friend  |
| a3. friend       | a3. friend  | a5. brother      | a4. friend  |
| a4. friend       | a4. friend  | a6. brother      | a5. brother |
|                  | a7. family doctor | a6. brother   | a6. brother |
|                  | a8. neurologist | a8. neurologist | a7. family doctor |
|                  | a9. geriatrician | a9. geriatrician| a8. neurologist |
|                  | a10. medical doctor | a10. medical doctor | a9. geriatrician |
|                  | a11. medical doctor | a11. medical doctor | a10. medical doctor |
|                  | a12. counsellor (AS) | a12. counsellor (AS) | a11. medical doctor |
|                  | a13. nurse | a13. nurse | a14. geriatrician |
|                  | a14. geriatrist | a14. geriatrist | a14. geriatrician |
|                  | a15. staff at the clinic | a15. staff at the clinic | a14. geriatrist |
|                  | a16. brother | a16. brother | a16. brother |
|                  | a17. neighbor | a17. neighbor | a17. neighbor |
|                  | a18. unpaid caregiver | a18. unpaid caregiver | a17. neighbor |
|                  | a19. unpaid caregiver | a19. unpaid caregiver | a18. unpaid caregiver |
|                  | a20. father | a20. father | a21. social worker |
| Family : 25%     | Friends : 75% | Family : 0%     | Friends : 50% |
| Friends : 20%    | Professionals : | Professionals : | Friends : 50% |
| Professionals : | 40%          | 50%             | 50%          |
| Informal : 15%   | Total Actors : 20 | Total Actors : 4 | Total Actors : 4 |
| Density : 0.0    |              | Density : 0.17  | Density : 0.0 |

Table 2 shows the dimensions that help form the caregiver’s representations. At the moment of the first interview Claudia is primarily concerned about the ill relative’s resistance to acknowledging the illness and accepting treatment. This attitude undermines Claudia’s capacity to act: were she to make too rapid or too direct contact with services, she would put the patient/caregiver relationship at risk. A sense of family responsibilities surfaces repeatedly in Claudia’s discourse and she has taken several steps to keep her mother at home. Her desire to keep her mother at home does not meet with the approval of the rest of the family and tension with members of the informal network results. Claudia is also generally anxious about the future and worries about the costs associated with the resources that she expects her mother will soon need. At the time of the second interview, new dimensions surface, particularly with respect to the dignity of the elderly person and Claudia’s concern that she reside in the most humane environment possible. Reciprocity, which we define...
as the feeling of complicity and mutual assistance between actors caring for the ill person, is mentioned by Claudia with respect to her relationship with the two unpaid caregivers. Claudia adopts various strategies (coping) to adjust to the practices of the two unpaid caregivers (for example, she distributes tasks according to each one’s abilities) and reports relative satisfaction with outside help (outside help, positive experience(s) with professionals). The emergence of elements of individualism, control and over-participation demonstrate the caregiver’s need and her capacity to control her environment.

Table 2: Social Representations (Case 1): The Ten Dimensions Most Frequently Mentioned

|                | First Interview | Second Interview |
|----------------|-----------------|------------------|
| N             | %               | Description      | N           | %               | Description          |
| 8             | 7.2%            | Ill relative’s reluctance to receiving help | 5           | 9.6%            | Dignity               |
| 7             | 6.3%            | Family responsibilities | 5           | 9.6%            | Reciprocity           |
| 7             | 6.3%            | Tensions with members of the IN | 4           | 7.6%            | Coping                |
| 6             | 5.4%            | Anxiety          | 4           | 7.6%            | Outside help          |
| 6             | 5.4%            | Cost             | 4           | 7.6%            | Positive experience(s) with professionals |
| 5             | 4.5%            | Empathic         | 3           | 5.7%            | Anxiety               |
| 5             | 4.5%            | Outside help     | 3           | 5.7%            | Comparative judgement |
| 5             | 4.5%            | Positive experience(s) with professional | 2           | 3.8%            | Individualism         |
| 4             | 3.6%            | Looking for autonomy | 2           | 3.8%            | Control               |
| 4             | 3.6%            | Fear             | 2           | 3.8%            | Task division         |

Mary’s Story (Case 2)

Mary has been married for 15 years and works full-time. She is 20 years younger than her husband, Paul, who has children from a prior marriage. Around the time that Paul retired, Mary began a new career in business: she enjoyed her work, logged many hours and was frequently on the road. As a consequence, Paul took on more and more of the domestic chores, leaving Mary to invest more time in her job. Table 3 shows the caregiver’s network composed of 7 actors at T0, 2 actors at T1 and 8 actors at T2. Her narrative at the time of the first interview mentioned 17 actors; at the time of the second interview, 19 actors were mentioned.

Table 3: Social Actors Involved in Case 2 as Identified by the Name Generator (Networks at Time 0, 1, 2) or by the Narratives (Interviews 1 and 2)

| Network T_0 1998 | Interview 1 | Network T_1 2002 | Interview 2 | Network T_2 2003 |
|------------------|-------------|------------------|-------------|------------------|
| a1. spouse  | a1. spouse | a10. stepdaughter | a1. spouse | a2. friend |
| a2. friend | a2. friend | a15. geriatrician | a2. friend | a10. stepdaughter |
| a3. friend | a3. friend | Family: 50% Professionals: 50% | a9. stepson | a15. geriatrician |
| a4. friend | a4. friend | Total Actors: 2 | a10. stepdaughter | a25. step brother |
| a5. coworker | a5. coworker | Density: 0 | a15. geriatrician | a26. sister |
| a6. coworker | a6. coworker | Family: 14.4% | a16. staff at the clinic | a27. niece |
| a7. coworker | a7. coworker | Friends: 42.8% | a17. unpaid caregiver | a28. niece |
| Coworker: | | | a18. nurse | a29. stepdaughter |
| | | | | Family: 75% |
Table 4 lists the elements underlying the caregiver’s representations. The dimension most mentioned during the first interview was the idea of social distance, that is, Mary’s sense of an absence of reciprocity and complicity with others. Mary’s dissatisfaction with the members of her network causes her to adopt individualist practices (actions that require little involvement on the part of others) and assert that she does not need services. Paul’s reluctance to accept the illness is present but not pronounced enough to undermine the relationship between himself and his wife. By the time of the second interview, Paul’s physical difficulties have contributed to a representation of greater dependency; he now manifests both cognitive and physical problems and Mary has undertaken numerous coping manoeuvres to try to help. The largely failed nature of these strategies can be inferred from Mary’s sentiment of social distance, her uncertainty, her dissatisfaction with services and her impression of a lack of sensitivity on the part of professionals. This particular trajectory is characterized by an absence of complicity between the caregiver and her co-workers and family members.

Table 4: Social Representations (Case 2): The Ten Dimensions Most Frequently Mentioned

| Description                                      | First Interview | Second Interview |
|--------------------------------------------------|-----------------|------------------|
| N       | %    | Description                                      | N       | %    | Description                                      |
| 8       | 15.6%| Social distance                                  | 7       | 14.2%| Physical difficulties                           |
| 4       | 7.8% | Individualism                                    | 5       | 10.2%| Coping                                         |
| 4       | 7.8% | Ill relative reluctance to receiving help        | 4       | 8.1% | Uncertainty or ambivalence                       |
| 3       | 5.8% | Coping                                          | 4       | 8.1% | Social distance                                 |
| 3       | 5.8% | Informal network non-acceptance                  | 3       | 6.1% | Over-participation                              |
| 3       | 5.8% | No need of services                              | 3       | 6.1% | Service not providing proper information         |
| 2       | 3.9% | Social history                                   | 3       | 6.1% | Lack of sensitivity                              |
| 2       | 3.9% | Acceptation                                      | 3       | 6.1% | Tensions with professional                       |
| 2       | 3.9% | Over-participation                               | 2       | 4.0% | Consequences                                    |
| 2       | 3.9% | Dissatisfaction with services                    | 2       | 4.0% | Positive experience with professionals           |
The first signs of illness and diagnosis-seeking

We will use a temporal/horizontal perspective to analyze how the first signs of illness are managed in two different contexts. The signs are plotted in Figure 2. In our first case, Claudia (a0) observes behaviour changes and cognitive problems on the part of her mother (a1, fm). She talks to her brothers about the situation, but they feel that the changes are the normal result of ageing and are in keeping with her mother’s personality (a5, a6; dia). Lacking validation from her family, Claudia does not seek further explanation for the changes in her mother’s behaviour (a1). Two years later, however, Claudia receives a phone call from the family doctor who states that Claudia’s mother is manifesting pronounced signs of memory loss (fm, dia). The doctor suspects dementia (dxp) and refers Claudia’s mother to a neurologist (a8) for diagnosis (ref->mev). After a series of minor but unusual incidents, like letting food burn on the stove (eve), Claudia consults (de->cs) the family doctor in person: the doctor prescribes medication (prs) and refers Claudia’s mother (ref) to a specialized clinic to confirm the diagnosis (dx). At the same time, one of the caregiver’s brothers (a5) independently initiates help-seeking procedures (de). This consultation (cs) with a doctor (a10) results in a diagnosis of probable dementia (dxp) and referral to a different specialized clinic (ref). Following an evaluation (fcst), specialists from the second clinic confirm the diagnosis of Alzheimer’s disease (dx) and prescribe medication (prs).

Figure 2: First Manifestations – Horizontal Reading
In our second case, Mary’s (a0) identification of the first signs of the disease brings us back 5 years (fm). At that time, Mary and Paul (a0, a1) had established a tradition of discussing cultural events (“We enjoyed talking about films we had seen together”) but Mary had begun to notice that Paul seemed less and less interested in talking. She gave little importance to his taciturnity at first but over time, she began to remark that he was having difficulty articulating and that his functioning seemed to be slowing down. When in company with others, she began finishing his sentences for him and took to changing the subject when others paid him too much attention. A family reunion at which Paul’s children (a8, a9, a10) found themselves alone with their father (a1) confronted the children with the extent of his difficulties (“They were shocked at how bad he had become”) (fm). The children (a8, a9, a10) asked Mary (a0) to do something about the situation (dia). Mary talked to a friend (a11, dia) who knew someone who worked at the Alzheimer’s Society. This discussion led Mary to consult a hospital specialist (de>fcs); Paul’s children accompanied the couple to the first appointment. The specialist referred (ref) Paul to a neurologist (a13) and to a speech-language pathologist (a14) for his worsening articulation (bin). The neurologist (a13) advised Mary to involve Paul’s family in his care and to continue working (dia-dia). Paul attended a few speech therapy sessions but discontinued treatment (er) after his son committed suicide (sui). The speech therapist then urged Mary to seek more specialized services (ref). Mary consulted the cognition clinic (fcst) whereupon a geriatrician (a15) diagnosed Paul with Alzheimer’s disease (dx).

Entry into the caregiving career and conflict management

In this section, we analyze an episode vertically, meaning that we observe the variation in relationships at the time of a given event. The episode in question is the caregiver’s entry into her caregiving career (ec), defined as the time when the caregiver first assumes tasks that pertain specifically to the progression of the disease. As
shown in Figure 3, Claudia (a0) begins her caregiving career with no disturbance to her relationships. Her initial involvement consists of increasingly performing her mother’s chores, doing more and more of the cooking, the shopping, and the administrative tasks. A certain tension with some members of her network develops nonetheless, especially with Claudia’s brothers (a5, a6), who do not accept her involvement and insist that their mother be placed in a home (a1). Claudia keeps her distance from her brothers and excludes them from her support network but avoids open conflict.

Figure 3: The Entry Into the Caregiving Career – Vertical Reading

| Claudia (Case 1) | Mary (Case 2) |
|------------------|--------------|
| 2003             | 2000         |
| a0 caregiver     | a0 caregiver |
| a1 mother        | a1 spouse    |
| a5 brother       | a8 stepson   |
| a6 brother       | a9 stepson   |
| a7 medical doctor| a10 stepdaughter |
| a8 neurologist   | a11 friend   |
| a9 geriatrician  | a12 medical doctor |
| a10 medical doctor| a13 neurologist |
| a11 medical doctor| a14 speech therapist |
| a12 medical doctor| a15 geriatrician |
| a16 staff        | a5 coworker  |
| a17 neighbour    | a6 coworker  |
| a18 unpaid caregiver| a7 coworker  |
| a19 unpaid caregiver| a2 friend   |
| a20 father       | a3 friend   |
| a3 friend        | a4 friend   |
| a4 friend        | a16 staff at the clinic |
|                  | a17 unpaid caregiver |

Glossary

(bup) Break-up of relationship
(ec) Entry into the caregiving career
(emp) Loss of employment
(m+) Increase of symptoms
(er) End of relationship
In contrast, Mary’s (a0) decision to begin her caregiving career is marked by a significant break with her prior life that affects both her network structure and her representations. Prior to deciding to take care of her husband, Mary lauded independence and women’s right to equal work. Given her position on these matters, all of the health professionals who met Mary (a12, a13, a15) encouraged her to keep working and to prepare to place her husband in a home. After an increase in the symptoms of her husband’s illness (m+), however, Mary decided to quit her job (emp) and devote herself entirely to the role of caregiver (ec), cutting herself off from her co-workers (a5, a6, a7, er). In the months that followed, friends also gradually drifted away (a2, a3, a4). Discussing these events, Mary claims she wanted to surround herself with positive people who agreed with her decisions and did not pressure her to change her mind. She felt that her husband’s receptiveness to care depended on her own well-being and she preferred to distance herself from people who made her unhappy.

**Looking at the entire trajectory and at unexpected events**

An overall view of the two trajectories reveals key and unpredictable occurrences that changed the course of events in each case. At the time of the second interview, Claudia had been helping her mother for over seven years, doing whatever was necessary to keep her at home as long as possible. Nonetheless, a conversation with a neighbor (a17) who had had a similar experience propelled Claudia into using the services of two unpaid caregivers (a18, a19); this event was the first turning point in her trajectory. A second event transformed the trajectory even more deeply: Claudia’s father (a20) was diagnosed with Alzheimer’s disease as well. With both parents sick, a new dynamic emerged. More social services and more family resources were mobilized with a view to keeping both parents at home.

Mary’s caregiving trajectory ended after eight years of caregiving, when Paul died barely three weeks after being moved to a home. A tragic and unforeseeable event affected the trajectory: Paul’s (a1) son (a8) committed suicide. Confronted with her husband's grief, Mary was powerless and he ceased to accept medical treatment. This trajectory was marked by difficulties, ruptured relationships and representations, and by the caregiver’s determination to keep the ill person at home. Mary used the services of one unpaid caregiver during several months but never left the house out of fear that Paul would react badly. Paul’s move to a home was also traumatic (“It was almost worse than his death”) and it was not long before an antagonistic relationship between Mary and the staff developed (a18 to a24). After Paul’s placement, several family members (a9, a25 to a29) got back in touch with him and with Mary. The family's involvement was well received by Mary and her links to the family strengthened after Paul’s death. This reconciliation also helped her in the grieving process. It is interesting to note that Mary continued to include the geriatrician (a15) in her support network several months after the death of her husband. The geriatrician was a part of Mary’s recent life history and had lent an attentive ear during her hardest times. Notwithstanding these positive relationships, however, Mary remained bitter about her experience, especially about her network’s lack of support for her decision to care for her husband (“I know what I wanted to do and I’m happy to have done it; if I hadn’t done it I wouldn’t have felt right”; “They told me to keep working, to put him in a home; I didn’t listen to any of them and I don’t regret a thing.”). Mary’s trajectory is thus characterized above all by significant breaks in representations. She went from a work-oriented life to a life devoted to ensuring the comfort of an elderly person. Once she had placed him in a home, she turned her attention back to recreating and strengthening family ties after the traumatic experience she had experienced.

**Discussion**

The objective of this study was to attempt a practical application of the relational sociology perspective (RSP) by reconstructing the relational and temporal contexts of the help-seeking trajectories of caregivers of people with Alzheimer-type dementia. A growing number of studies have turned to analyses like this one in order to
better understand complex trajectories associated with chronic care (Allen, Griffiths & Lyne 2004; Berger 2008; Biddle et al., 2007). The analytical procedure applied here is still in the exploratory stage and has only been applied to two episodes drawn from two trajectories of care. We nonetheless feel that the results are promising in two ways. First, the procedure allowed us to conduct an in-depth analysis of individual trajectories that took place over a number of years; second, it laid the groundwork, through our attempt at formalization, for combining a larger number of individual trajectories in the future and in so doing, revealing a broader pattern. The innovative methodology presented here has the potential of aggregating individual trajectories and pinpointing general tendencies that could lead to useful solutions in the field of chronic illness. Important challenges remain. We cannot simply combine life histories without risking a loss of the subtlety and richness of each unique experience. In this respect, the envisioned aggregation procedure must not be combined with statistical methodology. Analysis must draw mainly on interpretive methods.

The two case histories presented here remind us that accompanying an elderly person in the last years of his or her life is one of the most demanding experiences a person can face. We have approached this experience from the perspective of relationship dynamics, social representations and agentic capacities. In the next pages, we will see both the advantages and shortcomings of these three techniques.

First, the structure of relationships was measured using tools developed by social networks analysis. Transactions take place within a relational system in constant movement. Our network data serve as guidelines that allow us to better analyze phenomena such as negotiation, exchange or coalition formation. Network analysis is well suited to aggregation procedures: structural data can be transposed into numerical data (such as size of the network, density, homogeneity, and so forth) and permits the manipulation of a large number of cases. Furthermore, our study contributes to the debate on social capital, a debate that has drawn substantial attention and criticism over past years (Kadushin 2004; Koniordos 2008). Coleman (1990) considers that an actor can manipulate social capital to attain his or her objectives, while Bourdieu (1986) sees social capital as structural, something that locks the actor into an inherited system. Possibly the most accurate definition refers to arrangements and combinations that vary over time, sometimes giving the actor great freedom, sometimes constricting him/her by their structural rigidity. An interesting tool for analyzing social capital is the position generator, which enumerates the resources in an individual’s network at any given time. If we were to look at our two cases from this perspective, Claudia appears to be more fortunate than Mary because her network includes actors who are already part of the health care system. But this indication of social capital does not reflect the nature of Claudia’s links nor the potential for conflict that could undermine her relationships. Our observations thus show that a simple calculation of social capital is misleading: to be accurate, we must also consider the potential for conflict, the potential for reconciliation, the family's value system, expectations of network members, and willingness or unwillingness to activate support links. In order to take these dimensions into account, we introduced two additional tools.

Next, we considered network content. In this study, content was examined by means of a social representations approach, focusing on individual representations. This technique can be applied to an individual trajectory and to a larger sample, to reveal social representations (Carpentier et al., 2008). This approach gives weight to redundancy in the units of meaning mentioned by caregivers and operates on the assumption that repetition of any given point reflects the importance of that point in the caregiver’s representations.

Social representation is an interpretative approach design to evaluate the extent of social obligations, constraint or cultural influence in the context of social relationships. In this study we observed that the ill person’s reluctance to accept his/her illness is unquestionably a crucial factor in how caregivers represent their latitude to intervene. When an ill person refuses to acknowledge his/her illness, the caregiver's hands are tied.
Likewise, it can be complicated to intervene when family and friends notice nothing amiss. Once the family becomes involved, however, the caregiver’s representations of his/her latitude to act can change dramatically. The study’s longitudinal design allows us to observe the dynamic aspect of network content.

Individual and collective representations are powerful motivators of caregivers’ actions or inaction. The intense nature of these situations, however, incites us to widen our interpretive perspectives further and investigate symbolic dimensions as well (see, for example, Navon & Weinblatt, 1996). One of the limitations of the social representations approach is the importance attributed to the frequency of themes mentioned by the actors. Yet, a simple sentence or decisive statement expressed only once can take on major symbolic importance and redirect caregivers’ actions with life-changing results. It is therefore relevant to take our quantitative analysis a step further and, for instance, identify the unspoken elements of a caregiver’s narrative.

Finally, we used a third technique to reveal action sequences of entire care networks during the trajectory. The aggregation process consisted in the enumeration of action codes from the narrative. Each network could then be classified and typologies could emerge (see, for instance, Carpentier, Bernard, Grenier & Guberman, 2010). For example, the presence of codes reflecting dialogue, conflict resolution and use of services could lead to the identification of more active family profiles, with particular identities and styles of behaviour. Relational diagrams for mapping relationships are visual tools that can stimulate interpretive analysis. They allow for a clear visualization of networks’ evolution, from relatively stable networks to those where social relationships fluctuate violently. The distribution of action codes denotes highly active periods and those that are calmer.

Following caregivers over several years is an excellent way to obtain a better understanding how family history and life events influence families’ decisions to seek or eschew assistance resources. An actor’s individual autonomy, or identity as an agent, manifests itself within the context of the structure and content of his/her network. We believe that it is by becoming aware of his/her representations and of the significance of his/her trans-actions that the actor becomes free to exercise agentic capacity.

As previously noted, the notion of agency refers to an individual’s capacity to act independently of the constraints imposed by his/her social organization. Individuals’ actions are the product of past experiences, expectations about the future, and current appreciation of existing resources. When crises occur, people seek to act and to express themselves in accordance with their past life history and the identity they have forged thus far.

We have used an interpretive, biographical approach to test our theory that agency depends on the actor’s interpretation of his/her psychological, moral and social conditions. It is true that the researcher's ability to gain access to the inner life of an individual through his/her narrative is only partial and possible only at specific times in the trajectory. This makes our action sequence approach a useful tool for exposing, if only in part, an individual’s motivations. The sequential figures developed here illustrate the context of the trans-actions that help explain the behaviour of Mary, our second case.

In reflecting upon the past, Mary feels that society has been generous with her, that her professional career has been successful and that she has had a good life overall. But she blames herself for not having acted quickly in identifying Paul’s illness and for not having given him adequate support at the time of his son’s death. In reflecting on the present, Mary feels that the resources offered by public services are disorganized and inadequate and she prefers to isolate herself rather than to experience repeated frustration. In looking towards the future, Mary sees that the illness is advanced and feels that she has the financial, physical and mental resources to give herself fully to her husband for the little time he has left to live. Wishing to take part in this
last stage of his life and give him the human warmth that she alone can provide, she prefers to isolate herself rather than to deal with conflict. She therefore goes into survival mode until the crisis passes. Help-giving at the end of her husband’s life is an experience that Mary does not wish to miss. This is, of course, an interpretation. No procedure in the social sciences or the humanities can allow us to plumb the depths of an individual’s inner life and understand all of their conscious and unconscious motivations. Nonetheless, we remain convinced that the methods explored here help to understand families’ experiences and evaluate the likelihood that networks will self-activate or fragment at times of rupture, or react, when confronted with dramatic life events. It is essential to understand these phenomena because maintaining relationships and communication is an effective means of coping with uncertainty (Babrow and Mattson, 2003).

We believe that the tools we have used to analyze the two trajectories contribute to the development of RSP, but there will always be limitations. The trajectories we investigated reflect different life courses and cannot easily be mathematically compiled: complexity is the word of the day. Dynamic analysis of health care trajectories will always pose numerous challenges. As we assemble data that reflect relational dynamics we must always keep in mind that trajectories are unique expressions of individual and social challenges that can only be partially understood, compared and compiled. At an operational level, it will also be difficult to obtain homogenous samples, ensure regular follow-up with respondents and collect valid data for every important transition. For this reason, we must be prudent in our interpretations.

We believe that this kind of analysis is valuable in that it could lead to effective solutions in the field of chronic illness. It is by means of the diverse strategies developed by social actors that social services can create appropriate measures to help the elderly and their families. Health care reform is frequently founded on high principles such as the promotion of multidisciplinary teams, the furtherance of proactive interventions and the encouragement of an innovative care culture. But to be effective, implementation must be based on a solid understanding of the interactions between health professionals and the clientele (Weinberg, Lusenhop, Gittell, and Kautz, 2007). Composed of the elderly, caregivers and family members, this clientele is frequently grappling with intense emotions, uncertainty and a desire to protect their personal privacy. It is therefore incumbent upon us to pay attention to concepts closer to the individual and to his/her interactions with daily life; concepts such as confidence (Weber and Carter, 2002), respect (Martuccelli, 2002) and reciprocity (Moody, 2008).

Conclusion

In this article, we have presented an interpretation of individual and social actions based, not on individual characteristics, individual roles and normative systems, but rather, on complex social mechanisms based on trans-actions. We have employed a method that uses the information gleaned from narratives to see how actors negotiate with their environment, express their ideology (their representations), cope with crises, live through transitions, and access or fail to access resources. While we acknowledge that theoretically and empirically, RSP is in the developmental stages, we also demonstrate that it affords researchers the opportunity of looking at social phenomena from a different angle and helping them to formulate original research questions. For example, do certain intervention practices, such as proactivity or the contracting of private services, have negative consequences over the long term? In cases where treatment is resisted, are there windows of opportunity in which services can intervene with greater effectiveness? Is it possible and realistic to compensate for social liabilities (in terms of social position, resources, cognitive predisposition, and so forth) with individual or group strategies?
On an empirical level, there is no doubt that the techniques we suggest for answering these questions, although in keeping with the principles of RSP, are complicated. Complications aside, however, these techniques have the advantage of generating valuable information about clinical situations. Taylor and Bury (2007) have shown that the failure of social policies can be explained in part by decision-makers’ difficulties in adequately understanding the complex nature of chronic illness. The development of a social model of care is rooted in both social history and individual agentic orientations. Central to both is the delicate issue of the sharing of responsibilities among families, government, agencies and the community.

Notes

1 Our density calculation refers solely to the relationships among the alters, excluding the ego. It is a normal practice for egocentric networks. The presence of relationships between the ego and the alters facilitates the understanding of the graphics, but I do not consider these relationships in calculating density.

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