

Entry Into a Care Trajectory: Individualization Process, Networks, and the Emerging Project

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Normand Carpentier¹

Abstract

A broad range of services are developing in response to the needs of an aging population. Although most interventions are carried out in the patient's living environment—at the heart of society—few studies on service utilization refer to social theory. This paper suggests that studies on older people with chronic health conditions would benefit from a stronger theoretical foundation. Drawing on 15 in-depth interviews, it highlights the relevance of individualization processes and the network society, 2 central theoretical concerns in sociology. The research provides a unique perspective on the entry into the care trajectory and expands our comprehension of the emergence of a social organization that can respond to the needs of elderly patients. Data of this nature may be useful in service planning and the development of a care-centered approach.

Keywords

care trajectory, dementia, individualization processes, netdom, network society

Introduction

Population aging is a source of concern to many health care observers and planners. Numerous services and a wide range of interventions are being developed for seniors, including home support services, multidisciplinary teams, psychoeducational programs, and innovative chronic care practices (Kasl-Godley & Gatz, 2000; Martin & Sturmberg, 2009; Moniz-Cook, Vernooij-Dassen, Woods, Orrell, & Interdem Network, 2011). This interest in assisting the elderly and their families is encouraging; however, a sociologist reviewing the literature would be surprised to note the absence of references to social theory in most studies. This might seem strange, given that most care, even for those living with severe disabilities, is delivered in the community, in other words, at the heart of society. This absence of grounding in social and theoretical considerations would appear to be a major shortcoming that could jeopardize efforts to adjust services to the needs of elderly patients.

Many studies analyze and assess intervention programs, but few researchers interest themselves in the complex question of the linkage between formal and informal care services. In fact, many observers emphasize the difficult relations between the State and civil society (Martuccelli, 2006), the existence of divergent logic models underpinning the functioning of the public care system and the family sphere (Godbout, 2000), caregivers' reluctance to use services (Brodsky, Thomson, Thompson, & Fine, 2005; Schout, de Jong, & Zeelen, 2011), and the negative or unexpected

consequences of professional interventions on caregivers and their families (Capra, 1996; Lloyd & Stirling, 2011).

From our point of view, the problems of establishing linkages between formal and informal services may arise from the notion of care itself. This notion has been the subject of extensive study and has led to the development of many different currents of thought. According to one of these currents, care is a moral and individual experience, a vocation the central components of which are associated with cognition, competence, and emotions. Other currents consider care as an individual experience and a social phenomenon. Care is thus a complex amalgamation of experience and actions, the purpose of which is to meet another person's need, while taking into account the social organization surrounding the user-caregiver-health practitioner dynamic (Fine, 2007; Tronto, 1993). From this viewpoint, the relation does not consist simply of a single individual and a health professional. It is rather a relationship between a person who is located within a myriad of relations—sometimes supportive, other times affected by rivalries and family conflicts (Connidis & McMullin, 2002)—and a health professional,

¹Université de Montréal, Québec, Canada

Corresponding Author:

Normand Carpentier, Université de Montréal, CSSS de Bordeaux-Cartierville—Saint-Laurent, 11822, Avenue du Bois-de-Boulogne, Montréal, Québec H3M 2X6, Canada.
Email: normand.carpentier@umontreal.ca

who is also part of a complex network of relations, including interprofessional struggles (Nugus, Greenfield, Travaglia, Westbrook, & Braithwaite, 2010).

These complex social relations may be investigated by means of two central theoretical orientations in sociology: the individualization process (Beck, 1992) and the network society (Castells, 2000; Wellman, 2001). We will illustrate our process by drawing on the interviews we conducted with people who were experiencing the onset of memory loss or with their caregivers. The entry into the trajectory of chronic illness is an intensely emotional human experience during which people seek different types of support. The goal of this study was to analyze, in the ambiguous conditions that characterize a chronic illness, the emergence of a social organization of care, including formal and informal care networks. Comprehension of these phenomena is crucial to intervention planning and public policy development. This type of research, combining theoretical considerations and field data, has been neglected by sociologists for reasons that we will now briefly present.

Sociological Theory and Medical Empiricism

The growing disconnects between academia and research centers have created a gap between theory and empirical research. This is certainly true in the field of health, especially the social dimension that is central to chronic care (Foss, 2002). Many explanations have been put forward for the difficulty in linking social theory to empirical research. First, there is the enormous pressure exerted on health researchers—even those in the social sciences—to fit themselves into the dominant biomedical paradigm (Dean, 2004). Statistics and experimental designs are still considered to be the best tools for knowledge advancement, by funding bodies and scientific journals. Second, because traditional medical research was conducted with patients who were confined, mostly for short periods of time, to a hospital, social theory seemed to be less relevant in the case of patients who were institutionalized for a long period (see Foucault, 1963; Goffman, 1961).

Moreover, sociologists themselves have exhibited little enthusiasm for this area of research. The influence of Parsons, in the 1950s, may have caused sociologists to turn away from the field of medical care. At that time, it was believed that role of the family was declining in society, while that of medicine, which was rapidly gaining momentum, could potentially replace that of many institutions. As a result of some pioneering work, however, the social approach in medicine gradually gained ground. Freidson (1970), for instance, emphasized the importance of lay knowledge and the lay referral system. In the 1980s, Anselm Strauss's team restored to patients an active role in healing and in death. Their work also contributed to the recognition of the complexity of care work, particularly chronic illness care provided in the home (Strauss, Fagerhaugh, Suczek, & Wiener,

1985). In the 1990s, Bernice Pescosolido broadened the debate considerably, positioning care in the schema of social networks dynamics and illness careers (Pescosolido, 1992).

These studies helped to highlight the social dimensions of the medical sphere, including actors' action strategies and decision-making processes. Most importantly, they resituated health problems within a dynamic of social relations and care networks. Systems of care would now have to be conceived within an active and evolving social organization, composed of the numerous actors who are involved in providing care. The complexity of the situations associated with chronic care for the elderly thus necessitates the resumption of a closer dialogue between empirical data and social theory.

Individualization Process, Networks, and the Emerging Project

Individualization theories play a predominant role in sociology. Individualization should not be confused with the process of formation of a psychological individual, or associated with the pessimistic tendency that imagines the dissolution of social solidarity and its replacement by egotistical individualism. It is rather a theoretical attempt to deepen our understanding of different movements: one, related to the individual's desire for freedom, and the other, manifested by an institutional repositioning that favors the individual over the community (Beck, 1992; Beck, Giddens, & Lash, 1994). This process takes into account individuals' desire to shape their lives, take control of their biographical trajectories, respect their own values, and choose their interpersonal relations. As a consequence, the experiences and processes of socialization are so diverse and complex that individual attributes (in terms of class, ethnicity, gender, etc.) can no longer adequately account for the behavior of social actors. Within the same social categories, we find an increasingly diverse range of life courses, characterized by uncertainty and creativity. At either extreme of this social positioning, we still find those who enjoy numerous structural advantages (higher education, social protections) and their opposites, who have accumulated a series of disadvantages throughout their lives (health problems, social marginalization). But for most people, those in the "middle," the patterns are more complex, and we are observing a destandardization of their life courses.

The network thus becomes the most appropriate representation of society (Castells, 2000), replacing the traditional view of a social structure based on individual attributes. Social phenomena can be better understood through analysis of the complex patterns of affiliation and association emerging from the interactions of individuals seeking greater freedom. The network is composed of multiple connections: temporary and fluid ties that adjust to the context and to difficult episodes in an individual's life. This is what prompted Boltanski and Chiapello (1999) to introduce the concept of "projects." They describe life as being composed of a series of projects rather than predetermined

stages (such as school–work–retirement). Projects are multiple and of varying scope, and they dot an individual's life course: starting a family (and a second family), preparing for a sailing trip or a play, joining the army or a neighborhood activity, moving from one occupation to another. Periods of hardship such as divorce, grief, or an illness may also be viewed as a project.

The network provides essential support for the project; in other words, the project takes shape when particular connections are established. Transitions from one project to another engender relational changes: Ties are formed, broken down, or solidified. While certain hierarchical subsystems may be present, the network is the ideal forum for negotiations among equal partners. In their continual coupling and decoupling of ties, relations carry meaning and animate cultural domains (White, 2008). Projects are individuals' way of dealing with a risk society in which they are continually confronted with hazards and insecurities (Beck, 1992) while creating a space of ontological security (Giddens, 1992).

Entry Into a Care Trajectory and the Research Question

The experience of witnessing the deterioration of one's memory is profoundly disturbing to the person concerned and generates uncertainty in their immediate circle. Managing a chronic condition in the home is a complex activity, and usually involves different social actors at different stages of the illness. Entry into a care trajectory thus represents a new project in which many connections must adapt to create a positive environment for dealing with this challenge. To use network terminology (White, 2008), there is a "switch" from a domain constituted in response to existing life projects to a new domain that will be defined in relation to the illness (more details are given in the next section about network switching).

Our research was inspired by the following premise: Successful linkages between formal and informal care networks might be better understood using an empirical process to analyze the creation of a care support project. The principal question could be formulated as, "How does the social tie—essential to care—form or dissolve at the onset of a chronic illness?" In this study, our concern was the entry into the illness trajectory and the emergence of the project.

Method: Setting a New Research Agenda

In response to the complexity of the phenomena associated with health and chronic care, more contextualized, qualitative, and process-oriented approaches have been developed (Abbott, 1995; Carpentier & Bernard, 2011; Dean, 2004; Pescosolido, 2011). More emphasis is placed on trajectories and also on a social structure conceptualized as an evolving dialectic of ties and meanings (Fuhse, 2009; White, 2008). In this context, a narrative mode of explanation would seem to

be a viable alternative to the dominant variable-centered explanation approach (Abell, 2004). Temporality is the first key to such an analysis—in other words, recognition that the order of events and the occurrence of impromptu events are central to understanding actors' behavior (Abbott, 1995; Chamberlayne, Bornat, & Wengraf, 2000; Smart, 2007). Narrative approaches or the life story perspective provide an opportunity to observe the transformation of social relations and associated meanings. The second analytical key is the network, specifically, the mixed methodology that formerly characterized social networks research (Knox, Savage, & Harvey, 2006). The structural approach that dominated from 1960 to the 1990s barely addressed the cultural aspect of networks. Networks need to be understood as being embedded in domains. A domain is an array of stories, symbols, and registers that characterize a field of interaction (Mische & White, 1998). The concept of netdom offers a bridge between network relation (net) and cultural domain (dom); a netdom is a group of entities that share conversation topics. From this perspective, the network and its linkage system emerge from the stories and the meanings attributed to them.

Our study focused on the initial phase of entry into a chronic illness, conceptualized as an emerging project. We were thus especially interested in the actors' active roles, their interpretations and their changing identities. The analysis consisted of identifying specific cognitive competencies (ways of managing risk or dealing with the unknown) in the respondents' discourse, and above all, in revealing their capacity to activate ties and mobilize resources that enable them to deal with adversity. The initial interview, which was the first phase of a longitudinal study, will enable us to observe the evolution of networks and modeling of social representations over time (Carpentier, Ducharme, Kergoat, & Bergman, 2008).

Respondents were recruited by means of advertisements posted in public locations like churches, restaurants, and shopping centers. With this type of sampling, it was possible to meet people at the beginning of the trajectory, before they contacted any public services. The goal was to obtain the most diverse portrait possible of life situations, and for this, the strategy was to meet elders with cognitive impairment (ECI) and close family members (CFMs). We decided to include family members to learn about situations involving an older person who is in denial about his or her illness. Four selection criteria were used: The elderly person had to be 65 or older, live in a private residence, live in the geographic territory of the study, and have a cognitive disorder. The existence of a cognitive disorder was determined using the Clinical Dementia Rating (Hughes, Berg, Danziger, Coben, & Martin, 1982). This instrument evaluates the subject's memory, orientation, judgment and problem-solving abilities, participation in community and home activities, and ability to perform personal care. A score of 0.5 indicates an uncertain diagnosis or mild cognitive impairment. A score of 1 indicates mild dementia. Elderly individuals, evaluated

directly or through the caregiver as having a score of 0.5 and above, were invited to participate in the study. The recruitment period lasted from November 2008 until August 2009. We accepted the first 15 individuals who met our selection criteria to participate in the study. The sample was made up of 12 women, 6 first- or second-generation immigrants, and 5 caregivers. A semistructured interview comprising four sections was used: Respondents were asked to (a) discuss significant elements in their lives, (b) discuss their experience of health problems, (c) assess the existing human and social resources, and finally (d) discuss how they envisioned their future. The narratives revealed social networks consisting of 0 to 12 individuals.

Results

The respondents knew they were entering a new phase of their lives—what we refer to as a project—either a trajectory of illness or a caregiver career. All of them considered themselves to be at the start of the project. This was true even though some respondents had recently acknowledged memory problems, while others had postponed the diagnosis of a cognitive problem as long as they could. Memory loss was manifested in the form of forgetting names and appointments or losing things. However, respondents' main fear was losing control over their lives and losing contact with people. This period is one of great anguish, and generates a lot of worry and confusion, especially because many individuals already suffer from other physical or mental problems. Moreover, the five caregivers we met said they had also had memory problems, although our instrument for assessing cognitive problems indicated no problems in this respect. This reflects the deep anxiety experienced by the whole network.

The entry into the project occurs in various social contexts, in keeping with the diversity and complexity of society overall. The respondents lived alone, with a partner, or in a multigenerational setting. In one case, a couple had been separated for 15 years, but lived in the same building and had resumed a supportive relationship. One woman, a recent immigrant, said she was well integrated socially, while other native-born respondents felt completely abandoned by their communities. In another case, a female immigrant had university degrees but had hardly ever held a job because she was immobilized by personal and family problems. In fact, the respondents had a diverse range of social backgrounds, some favorable, others unfavorable, making each of them unique, and frequently resulting in the development of unexpected action strategies.

Creating One's Own Life

The respondents were asked to talk about their lives. In one case (elder with cognitive impairment, Case 8; for now on [ECI#8]), a woman had made her own life choices: She did not marry or have children. She focused on her personal

development, establishing a network of friends, and doing volunteer work. She worked as a nurse and is now retired. She indicated her desire to take control of this new project and organize her care, saying she was terrified by the thought of having to depend solely on public services, given her lack of family. A female caregiver (CFM, Case 9; for now on [CFM#9]) came to the interview alone, although originally, she was supposed to be accompanied by her sister who was experiencing memory loss. The sister canceled at the last minute, saying she found the situation awkward and denying her functional difficulties. This caregiver was from one of the Pacific islands. She had married a veteran of the Vietnam War and lived in the United States. She is now divorced and lives in Montréal with her two children. She worked in the field of education. In another case, a woman who is now retired lived for 15 years in a religious community before finding a job as a secretary. She did not have children of her own, but described how she had found a meaning in life by helping a family with six children through difficult times. She chose to lead a life of solitude, contemplation, and charitable works. The entry into this project is terrifying for her. She is aware that her social relations are limited and cannot imagine how she will succeed in establishing a support system during this period of her life [ECI#2]. Another respondent devoted her whole life to her family; caring for others was the central focus of her life. She believed that her family was very supportive and would be able to deal with this new project [ECI#3].

Projects Related to Health Problems

When confronted with memory loss, the respondents sought their first markers in their own personal experience and in the experience of people in their immediate circle. The entry into the project is the continuation of a life story and past experiences in which individuals have mobilized different types of support, involving family, social services, or a combination of both. The interviews revealed complex lives, many of them marked by traumatic or trying episodes and social isolation. One 78-year-old woman cared for her dying mother 20 years ago. Her knowledge of the public system dates from that time, and her discourse revealed intense anxiety. She felt abandoned by the system when she was caring for her mother, but she also mentioned recent observations concerning individuals suffering from Alzheimer disease: "Lots of my women friends are caregivers, and it never ends well" [ECI#10]. Another respondent referred to a loss of trust in health system practitioners. When her son was in psychological distress, he felt he was being treated like a child rather than as a responsible adult in his encounters with practitioners. He told of being treated by practitioners who were incapable of properly assessing his situation: "They wanted me to think like them; I felt completely useless" [CFM#9].

A recent project of many respondents is related to the move to a new home. After retirement, many of them moved

to areas where there were more health services. Several respondents then realized there was a new problem. One couple, for instance, had just moved into a neighborhood that was known for a good quality of life and activities for seniors, but, as the caregiver mentioned, “We moved to be closer to health services, but we lost our friends and neighbours” [CFM#6]. Similarly, another respondent reported that while she was getting better care for her heart condition because she had moved close to a large hospital, she missed her neighbors. She is unhappy about the loss of the familiar community reference points that gave her a sense of reassurance [ECI#3].

Assessing Existing Resources

Our study centers on an analysis of the transition between two projects. In this way, we hoped to gain a better understanding of the emergence of a social organization to accompany an individual suffering from dementia. The concept of netdom seemed appropriate, especially because the project unfolds in a context of confusion that distorts the perception of relations. The respondents’ major projects, connected with employment or family, have been replaced by smaller projects, which are frequently unpredictable, being subjected to life’s hazards (i.e., health problems, bad weather that restricts mobility, etc.). Stories serve to describe the ties in networks (White, 2008); ties can then be traced through symbols, emotional expression or narratives. The goal here was to observe the transition from a set of projects in an individual’s life to the new project, which will gradually end up taking almost all the space. The respondents now view social ties from the perspective of illness.

Only two respondents were able to describe ties in a fairly clear manner, both of them asserting their confidence in the possibility of a social organization eventually emerging from their existing ties. One woman said that her family had already dealt with a similar crisis and that the family has a strong sense of responsibility for each other. She believed that the family would pull together in a crisis and that tried and tested mechanisms meant that tasks would be shared among family members and the family physician [ECI#3]. An unusual case was that of the wife of high ranking diplomat. This case illustrates the system’s capacity to take care of citizens who benefit from a high degree of social protection. After the diagnosis, the military medical unit quickly stepped in to assist the wife. This caregiver was provided with support in practically every area: daily living assistance, residential, and medical assistance. Benefiting from such support, the wife was more easily able to maintain her long-standing social relations [CFM#13].

These two cases were the exceptions. For most of the respondents, the possibility of a social organization providing them with care was far from certain. For them, the entry into the trajectory is terrifying. The respondents were anxious about the partners who might accompany them in this

project. They were extremely uncertain about the reactions of other people, because the existing ties were already relatively fragile: children living in other cities, friends who had moved away, others who had died, and members of the network who suffered from psychosocial or health problems. One case is a good illustration of the ambiguity and anxiety inherent in this situation. A couple came to see us: a mother who had devoted her life to her family [ECI#3] and her husband [CFM#4]. The two came to us separately, without consulting the other, after spotting the poster in a church. Both of them believed they were suffering from dementia and viewed their spouse as the caregiver. Although she mentioned nine individuals in her network, the woman described herself as alone and was particularly worried that her husband would leave her when he found out about her memory problems. The husband’s account was totally different. He was also worried he had Alzheimer disease, but emphasized that if his wife had Alzheimer, he would never leave her.

There are numerous other examples of respondents who describe large networks, but their stories mostly reveal flimsy, weak, and unpredictable ties. The respondents worried about their family members’ reactions to the onset of illness and stressed the unpredictable nature of the situation. Many participants maintained ties through telephone contact, but did not expect that these individuals would offer much support once the illness was fully established. One man had been rejected by those close to him and was trying to understand why: “Is it because I’m old or because I’m sick? I don’t see anyone anymore” [ECI#2]; “People avoid me, it scares them” [ECI#1]; “I used to go out to lunch with my women friends, but they don’t call me much now” [CFM#6].

Projecting Into the Future

Reflexivity, which allows an individual to project himself or herself into the future, is considered to be one of the motors of the individualization process. But in this context, few respondents were able to imagine the future. The future is frightening because it is obvious that this project is not going to end happily. They are confronting death or, worse still, a long period in which they will gradually lose their capacity to interact with others. One female participant nonetheless insisted on fighting, “I’m not giving up” [ECI#8]. Another respondent was also quite positive and manifested a desire to develop a safety net before becoming incapacitated [ECI#3]. But, most respondents live from day to day. The respondent who had formerly lived in a religious community manifested her intense distress when she said she wanted to return to the community to live out the end of her life [ECI#2]. Another woman, who had suffered health problems for much of her life, and who had even raised her children in her mother’s home, could see no other option than to call on her mother for help once again. But her mother’s advanced age [ECI#5] made her very anxious about this prospect. A caregiver expressed her anguish about the decision on whether to

embark on this new project, but family pressures and her guilt feelings will probably persuade her to become involved [CFM#9].

The health system is omnipresent in all the narratives, and the respondents had different attitudes about the prospect of closer involvement with health services. The accounts reveal their reservations and also their openness to the health system. Some respondents knew they had to establish a relationship and find the right gateway into the system. One woman said her family doctor considers her memory problems unimportant; she describes the system as a machine that is incapable of providing love [ECI#3]. Meanwhile, several other respondents had a more nuanced vision of health care services, saying that meeting the right practitioners at the right time could lead to new possibilities. Some were aware of the different approaches of families and the health system, saying that this awareness helped them adopt a more realistic attitude about the new partner they would be taking on.

Discussion

In everyday life, a project usually refers to a leisure activity like a holiday or home renovation. Here, it has a more serious character, but as with any project, it is a time for forming new ties and renewing meanings. This project takes place at the end of life, at a time when relations are frequently weakened due to various processes associated with aging. The prospect of death has a symbolic meaning that is specific to each life story. This is the context in which we wanted to investigate the emergence of a care network. Because our sample was voluntary in nature, and composed of seniors and caregivers, we were unable to generalize the findings to the general population, but we were able to obtain a unique perspective on a pivotal period that until now has been relatively unexplored.

This research was based on the idea that people's behavior, often qualified as surprising, like the nonutilization of services or reluctance to seek help, can be understood from a set of stories. We analyzed these stories from the perspective of individualization processes, networks society, and the emerging projects that dot people's lives.

The veracity of the individualization process has not gone unquestioned (Duncan, 2011), but it is nonetheless reasonable to believe that modernity has enabled individuals to assume more control over their own biographies, and that reflexive processes enable them to intervene in and shape the world (Mische, 2007). Our study confirms that many respondents were the architects of their lives, that social arrangements are multiple, complex, and, at times, unexpected, and that each story is imbued with its own meaning. Some respondents learned how to take an active role in their projects, mobilize resources, and make the decisions that would transform their network. The capacity to manage ties is of fundamental importance. Epidemiological surveys of seniors have shown that the lack of social ties (isolation, small network) is associated with the perception of a greater

number of health problems (Cornwell & Waite, 2009) or the early appearance of dementia (Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000). Ties, which together, form networks, are essential to a caring society.

It is clear, however, that networking skills are not distributed evenly throughout the population. A highly connected society may exist on the Web, in certain industrial sectors, and in private life, but this is less true in situations of uncertainty or transition. The gains in freedom associated with individualization are also accompanied by a multiplication of temporary ties and periods of solitude between projects. In the case of a stimulating project, ties form spontaneously, while uncertainty attracts few partners. The establishment of a project, in which care is the principal activity, is a complex process, suggesting the formation of new ties, management of departures, and attempts to maintain longstanding links. In our sample, the respondents were concerned about the commitment of actors close to them and their own ability to provide resources that might ease the burden of care and psychological distress. In many cases, an older person's immediate circle exhibits little interest in becoming involved.

New actors may appear, from formal and informal networks, but these new ties will be of little use if no trust has been established. With the transformation of families and the multiplication of life projects, we can no longer assume the presence of a large number of ties based on trust. Establishing trust also becomes an ongoing project (Giddens, 1990). Trust has to be earned and developed through experience and action; it is rooted in a common understanding or outlook. Building trusting relations becomes essential because dementia is a devastating chronic condition with an unpredictable and unstable course. Trust reduces complexity while compensating for information that is lacking (Luhmann, 1991). Feelings of trust are above all, subjective, based on individual experience and the meaning the individual accords to the relationship. Even actors who are privileged in terms of education and economic and social background are confronted with the unpredictability of relationships. A situation may be perceived completely differently by individuals of equivalent social status. The entry into this project is a psychological ordeal, eliciting multiple meanings and ways of functioning, some contradictory, which can no longer be associated with fixed identities or individual attributes (i.e., personal norms, gender, ethnicity).

The feminine dimension of care is also confirmed in this study, where more women were involved in caregiving work. The landscape is nevertheless becoming more complex. Numerous women have now been able to exercise real choice over their life course, have turned their backs on the traditional roles, had careers, and opted to do something other than raise a family. The growing diversification of women's activities will almost certainly have an impact on care. As many women are experienced in building projects, creating links, and delegating work, they may deal with their caregiver role differently and use more services. Furthermore,

the decrease in family size leaves fewer alternatives in the choice of caregivers, which may force men to become more involved.

Implications for Intervention

Interventions should be rooted in, or at least, take into account, the underlying trends that characterize our societies. People have determined their life courses and they want to continue doing so when it comes to their end-of-life projects. People's reluctance to use services may be explained in part by their need to maintain control over their lives. Users are put off by authoritarian medical systems or systems using standardized approaches. The respondents understood the importance of relations. In the absence of clear and effective medical solutions for dementia-related problems, intervention should be rooted in an understanding of the trajectories of elderly patients and the types of family support available to them. This means that assistance programs need to be developed to prevent the collapse of informal care systems. Above all, ways must be found to maintain actors who will promote positive attitudes and recruit others who will be capable of creating innovative solutions. Practitioners must be capable of creating spaces for dialogue and involving users in service planning (Killeen, 2001), managing disagreements, supporting the existence of diverse options, and encouraging the small actions that will bring members of the care network closer together. Practitioners need to provide technical and instrumental support as well as comfort and emotional support. Above all, they need to be able to handle uncertainty. For this, however, they must possess specific skills that are undervalued in the academic world: kindness, patience, empathy, and reciprocity. Practitioners are currently being called upon to be efficient and effective rather than altruistic and skilled at engaging emotionally (Fisher & Byrne, 2012).

Moreover, the individualization process is a trend that is out of step with a caring society (Fine, 2007). Institutions have fragmented to respond to the projects of free and autonomous individuals. People individually select the resources they require to carry out their projects. As a result, the health system has developed an à la carte approach: specialized clinics for every disease and aesthetic or rehabilitation needs. In contrast, care is comprehensive and demands the interdependence of ultraspecialized treatments and basic assistance that is associated with life maintenance functions.

This observation gave rise to a rich geriatrics literature on the integration of services and interorganizational partnerships. It became clear that service fragmentation would not work for the complex situations associated with chronic illnesses. However, this literature adopted a managerial perspective, with concerns about resource distribution, service coordination, and the creation of channels of communication. The sociological dimensions were in large part neglected, in particular, face-to-face relations between practitioners, users,

caregivers, and the extended support network. The linkages among all these actors must nonetheless be addressed to obtain an understanding of how services should be coordinated. It is also important to recognize the specific nature of care and the difficulties of applying practices traditionally associated with acute illnesses. For instance, early detection has turned out to be a good practice for numerous illnesses, but this is not necessarily the case with dementia. The fact that time may elapse before people ask for professional help may be explained in many ways, for instance, the need to assess the resources available within their network, or the fear of embarking on a painful new project. In addition, it is essential to provide assistance to informal care networks as soon as they contact public health services, regardless of the stage of the person's illness. Intervention must not be restricted to a crisis situation, when the elderly individual is isolated from their network or their needs are so acute that the only option is for the public system to take complete responsibility for the patient's care.

Implementing such a support system is not a simple matter, and it should be developed gradually. Dujardin's team (Dujardin et al., 2011) observed that support for informal care is associated with social contexts that have been constructed over a long period, based on the development of a national care integration strategy, the targeting of vulnerable groups, the involvement of the voluntary sector and the development of labor market participation programs. All of these elements should be integrated into a "structured collaborative care model" (Ashley, 2008).

Methodological Concern

The theoretical concepts raised in this paper should be developed through a mixed method investigative approach that includes the dimensions of temporality, meaning, and structure. While the treatment of acute illness may not necessarily suffer from the absence of an analysis of social dynamics, the specific natures of chronic illnesses and networks require a consideration of time: Projects unfold over a period of time. In fact, more researchers are calling for the adoption of a longitudinal approach to take into account the stages of development of the illness (Carpentier & Bernard, 2011; Pavalko & Woodbury, 2000). The emergence of a social organization in these cases makes the social network approach a suitable option because of its usefulness in analyzing the dynamics of relational structures. Yet, it is necessary to go further than what we have been able to present in this paper. By considering the connections between the network members, for instance, it would be possible to analyze the influence of the subsystems underlying values and attitudes that could either support or represent an obstacle to professional intervention plans. These subsystems may be a key to understanding linkage problems. Still, the network approach should not be restricted to the production of structural indicators (size, density, multiplexity); the meanings associated with each tie are of primary importance. White (2008) says that meaning is

ascribed to the switching from one netdom to another. Such a conceptualization casts a new light on concepts like the sense of responsibility, family duty, or the standards of mutual aid. These concepts could be analyzed in the context of actual relationships, based on the flow of interactions that facilitates or impedes care work. The researcher's work would consist in establishing a precise picture of human relations in all their complexity, taking into account the evolution of the illness, impromptu events, and the changes in social supports, whether tangible or symbolic.

This methodological approach, that could be qualified as a trajectories-networks approach, would, however, have significant consequences. With the emergence of care organizations that are functioning in complex and ambiguous contexts, it is difficult, even impossible, to properly measure the effect of a treatment or intervention. An intervention is carried out in a precise temporal and relationship context, but it is also located within the boundaries of daily life. Here, we are far from the clinical or laboratory context; the effect of interventions is extremely approximate—in the short and long terms—given the determining influence of individual perceptions and unanticipated events. Change can result from multiple and unanticipated sources and can be interpreted in unexpected ways. Researchers can no longer operate solely in terms of “outcomes,” with indicators to illustrate an intervention's success or lack thereof. Everything that has been constructed one day can be deconstructed the next day. The effect of an intervention to reduce a caregiver's stress may be canceled out after a single destabilizing event. The analysis of social connections is therefore a key issue for research, to understand the mechanisms involved in the creation of optimal support ties to protect the elderly person and their network from adverse events.

Conclusion

Leading-edge medical services have been developed without regard to social theory, but the chronic health problems confronting the elderly demand that researchers draw closer links between theory and services. The turning point in chronic care is propelling public services into the situations of ambiguity and unpredictability described in contemporary sociological literature. But we cannot allow ourselves simply to observe and criticize our societies, we must actively search for solutions. The answers will not be simple, and they will have to found within the paradoxes we have described in this paper. Care must become a central focus of research. We must further our understanding of social links formation processes that enable the emergence of a social organization and linkages among care systems. The complexity of social situations, the diverse manifestations of illness, and the gradual accumulation of health and social problems result in the individualization of life courses. Trajectories are unique, marked by different levels of complexity, and rooted in an individual's daily life: Services must adjust to this reality. The

development of helping resources for the elderly must be informed by a social vision that encompasses individualization processes, networks, and life projects.

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Author's Note

This study has received ethical approval from the Ethics Committee of the Institut Universitaire de Gériatrie de Montréal (ref. 2008-0402). Fictitious names were used for the two individuals whose cases were presented.

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References

- Abbott, A. (1995). Sequence analysis: New methods for old ideas. *Annual Review of Sociology*, 21, 93-113.
- Abell, P. (2004). Narrative explanation: An alternative to variable-centered explanation? *Annual Review of Sociology*, 30, 287-310.
- Ashley, P. J. S. (2008). Living with dementia. In R. Jacoby, C. Oppenheimer, T. Denning, & A. Thomas (Eds.), *Oxford textbook of old age psychiatry* (pp. 417-422). Oxford, UK: Oxford University Press.
- Beck, U. (1992). *Risk society: Towards a new modernity*. New Delhi, India: Sage.
- Beck, U., Giddens, A., & Lash, S. (1994). *Reflexive modernization: Politics, tradition and aesthetics in the modern social order*. Stanford, CA: Stanford University Press.
- Boltanski, L., & Chiapello, E. (1999). *Le nouvel esprit du capitalisme* [The new spirit of capitalism]. Paris, France: Gallimard.
- Brodsky, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, 20, 537-546.
- Capra, F. (1996). *The web of life*. London, England: Harper Collins Publishers.
- Carpentier, N., & Bernard, P. (2011). The complexities of help-seeking: Exploring challenges through a social network perspective. In B. Pescosolido, J. K. Martin, J. D. McLeod, & A. Rogers (Eds.), *The handbook of the sociology of health, illness, & healing: Blueprint for the 21st century* (pp. 465-479). New York, NY: Springer.
- Carpentier, N., Ducharme, F., Kergoat, M.-J., & Bergman, H. (2008). Barriers to care and social representations early in the career of caregivers of persons with Alzheimer disease. *Research on Aging*, 30, 334-357.

- Castells, M. (2000). *The rise of the network society* (2 ed.). Malden, MA: Blackwell.
- Chamberlayne, P., Bornat, J., & Wengraf, T. (2000). *The turn to biographical methods in social science: Comparative issues and examples*. New York, NY: Routledge.
- Connidis, I. A., & McMullin, J. A. (2002). Sociological ambivalence and family ties: A critical perspective. *Journal of Marriage and Family*, 64, 558-567.
- Cornwell, E. Y., & Waite, L. J. (2009). Social disconnectedness, perceived isolation, and health among older adults. *Journal of Health and Social Behavior*, 51, 31-48.
- Dean, K. (2004). The role of methods in maintaining orthodox beliefs in health research. *Social Science & Medicine*, 58, 675-685.
- Dujardin, C., Farfan-Portet, M.-I., Mitchell, R., Popham, F., Thomasa, I., & Lorant, V. (2011). Does country influence the health burden of informal care? An international comparison between Belgium and Great Britain. *Social Science & Medicine*, 73, 1123-1132.
- Duncan, S. (2011). The world we have made? Individualisation and personal life in the 1950s. *The Sociological Review*, 59, 242-265.
- Fine, M. (2007). *A caring society? Care and the dilemmas of human services in the 21st century*. Houndmills, UK: Palgrave MacMillan.
- Fisher, P., & Byrne, V. (2012). Identity, emotion and the internal goods of practice: A study of learning disability professionals. *Sociology of Health & Illness*, 34, 79-94.
- Foss, L. (2002). *The end of modern medicine: Biomedical science under a microscope*. Albany: State University of New York Press.
- Foucault, M. (1963). *Naissance de la clinique* [The Birth of the Clinic]. Paris: Presse Universitaire de France.
- Fratiglioni, L., Wang, H. X., Ericsson, K., Maytan, M., & Winblad, B. (2000). Influence of social network on occurrence of dementia: A community-based longitudinal study. *Lancet*, 355, 1315-1319.
- Freidson, E. (1970). The lay construction of illness. In E. Friedson (Ed.), *Profession of medicine: A study of the sociology of applied knowledge*. New York, NY: Harper & Row.
- Fuhse, J. A. (2009). The meaning structure of social networks. *Sociological Theory*, 27, 51-73.
- Giddens, A. (1990). *The consequences of modernity*. Stanford, CA: Stanford University Press.
- Giddens, A. (1992). *The transformation of intimacy*. Cambridge, UK: Polity.
- Godbout, J. T. (2000). *Le don, la dette et l'identité* [Gift, Debt and Identity]. Montréal, Quebec, Canada: La découverte.
- Goffman, E. (1961). *Asylums*. New York, NY: Doubleday.
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566-572.
- Kasl-Godley, J., & Gatz, M. (2000). Psychosocial interventions for individuals with dementia: An integration of theory, therapy, and a clinical understanding of dementia. *Clinical Psychology Review*, 20, 755-782.
- Killeen, J. (2001). Involving people with dementia and their carers in developing services. In C. Cantley (Ed.), *A handbook of dementia care* (pp. 278-294). Buckingham, UK: Open University Press.
- Knox, H., Savage, M., & Harvey, P. (2006). Social network and the study of relations: Networks as method, metaphor and form. *Economy and Society*, 35, 113-140.
- Lloyd, B. T., & Stirling, C. (2011). Ambiguous gain: Uncertain benefits of service use for dementia carers. *Sociology of Health & Illness*, 33, 899-913.
- Luhmann, N. (1991). *Trust and power*. Chichester, New York: John Wiley.
- Martin, C., & Sturmberg, J. (2009). Complex adaptive chronic care. *Journal of Evaluation in Clinical Practice*, 15, 571-577.
- Martuccelli, D. (2006). *Forgé par l'épreuve. L'individu dans la France contemporaine* [Forged by the test: The individual in contemporary France]. Paris, France: Armand Colin.
- Mische, A. (2007). *Partisan publics: Communication and contention across Brazilian youth activist networks*. Princeton, NJ: Princeton University Press.
- Mische, A., & White, H. (1998). Between conversation and situation: Public switching dynamics across network domains. *Social Research*, 65, 695-724.
- Moniz-Cook, E., Vernooij-Dassen, M., Woods, B., & Orrell, M. Interdem Network. (2011). Psychosocial interventions in dementia care research: The INTERDEM manifesto. *Aging & Mental Health*, 15, 283-290.
- Nugus, P., Greenfield, D., Travaglia, J., Westbrook, J., & Braithwaite, J. (2010). How and where clinicians exercise power: Interprofessional relations in health care. *Social Science & Medicine*, 71, 898-909.
- Pavalko, E. K., & Woodbury, S. (2000). Social roles as process: Caregiving careers and women's health. *Journal of Health and Social Behavior*, 41, 91-105.
- Pescosolido, B. A. (1992). Beyond rational choice: The social dynamics of how people seek help. *American Journal of Sociology*, 97, 1096-1138.
- Pescosolido, B. A. (2011). Organizing the sociological landscape for the next decades of health and health care research: The network episode Model III-R as cartographic subfield guide. In B. Pescosolido, J. K. Martin, J. D. McLeod, & A. Rogers (Eds.), *The handbook of the sociology of health, illness, and healing: Blueprint for the 21st century* (pp. 39-66). New York, NY: Springer.
- Schout, G., de Jong, G., & Zeelen, J. (2011). Beyond care avoidance and care paralysis: Theorizing public mental health care. *Sociology*, 45, 665-681.
- Smart, C. (2007). *Personal life: New directions in sociological thinking*. Cambridge, UK: Polity.
- Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1985). *The social organization of medical work*. Chicago, IL: The University of Chicago Press.
- Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. London, England: Routledge.
- Wellman, B. (2001). Physical place and cyber place: The rise of personalized networking. *International Journal of Urban and Regional Research*, 25, 227-252.
- White, H. C. (2008). *Identity and control: How social formations emerge* (2nd ed.). Princeton, NJ: Princeton University Press.

Author Biography

Normand Carpentier is a researcher at CSSS Bordeaux-Cartierville - St-Laurent and associate researcher at the Université de Montréal's Faculty of Sociology. He has led a longitudinal study on caregivers of people with Alzheimer disease for a number of years. This project involves diverse social science methodologies, in particular, social networks analysis, social representations theory and life story techniques.