Social Network Data Validity: The Example of the Social Network of Caregivers of Older Persons with Alzheimer-Type Dementia*

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Abstract

This article offers reflection on the validity of relational data such as used in social network analysis. Ongoing research on the transformation of the support network of caregivers of persons with an Alzheimer-type disease provides the data to fuel the debate on the validity of participant report. More specifically, we sought to understand the factors that might influence the description of the support network by persons involved in caregiving. The issue warrants special attention, given that social relations – in their form and their content – constitute the raw material of network analysis. We propose that how persons describe their social network corresponds to a subjective process that rests, in part, on their representation of their cultural and social universe.

Keywords

aging; social support network; validity; caregiver; Alzheimer; social representation

Introduction

The social network approach has elicited a great deal of interest among researchers in the field of health and aging wishing to analyse care from a new angle (Antonucci, Sherman, & Akiyama, 1996; Wenger, 1996). However, as social network research constitutes a relatively recent field of investigation, its application in the field of health still raises a number of questions. For example, although the network approach has proven useful in analysing the transformation of support ties over the course of the caregiver career (Carpentier & Ducharme, 2003), further reflection is called for regarding, in particular, the analysis of relational dynamics and the validity of data obtained from participants.

When they engage in care, often over a relatively long period of time, caregivers are confronted with complex and trying tasks during which time they must manage a host of both long-standing and more recent, sporadic social relations mobilized to help with

*This research was funded in part by a Young Investigator Research Grant from the Alzheimer Society of Canada (no. 04-46) and by the Canadian Institutes of Health Research (no. 64189). We also extend our sincerest gratitude to the caregivers who took part in the study.

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caregiving. In this regard, it is widely documented that burden of care leads to deterioration in caregiver mental and physical health (Hirst, 2005; Schulz & Martire, 2004) and that the presence of support ties protects against illness (Pescosolido & Levy, 2002). Caregivers are at the centre of the community care system. They are actively involved in daily decisions, they play a key role in seeking help, they seek out new alliances, and they serve as intermediaries between the cared-for relative and his or her life environment. Consequently, caregivers are called upon, at least in theory, to create and cultivate long-term ties with extra-familial interveners.

Given the prevailing policies geared to maintaining seniors in the community, it is essential to analyse the interactions among the actors involved in the care system and to conceptualize better the fit between formal and informal caregiving support systems. With the development of ambulatory geriatric services and the proliferation of community groups, concerns for the continuity, integration, and humanization of care for older persons with chronic problems have been placed centre stage (Dubé, Ferland, & Moskowitz, 2003; Ducharme, Lebel, & Bergman, 2001; Haggerty, Reid, Freeman, Starfield, & Adair, 2003; Woodward, Abelson, Tedford, & Hutchison, 2004). However, the analysis of social relations poses two challenges for the network approach. First, in a general sense, the network approach developed on the basis of the analysis of stable complexes and, to date, few studies have explored change within relations (Emirbayer, 1997; Moody, McFarland, & Bender-deMoll, 2005). Second, it is reasonable to question the accuracy and validity of the description of support networks made by caregivers in situations characterized by profoundly altered daily lives and by the relational instability that this can entail.

If the network approach is to make a worthwhile contribution to the analysis of available supports and to the fit between formal and informal care systems, it is important to ensure that the instruments developed to account for relations allow us to adequately identify sources and types of support. The purpose of this article is to present our reflections on how caregivers evaluate their supports in caregiving for an elderly relative and, more particularly, to discuss the validity of data obtained through the name generator approach (described below). In the following section, we will look at the issues related to the development of a support network and at how notions of validity have been considered to date.

Two Fundamental Issues Regarding the Network Approach

Our reflections on the network approach involve two key issues. The first concerns the support structure as per participant report, and the second, the validity of the data obtained from respondents in situations of relational instability. Let us begin by briefly describing the first of these.

The social network approach focuses above all on social structure, such as revealed through modes of interaction between individuals and groups. This structure, which is generally composed of relatively stable modes based on prolonged ties (Freeman, Romney, & Freeman, 1987; Scott, 1987), can also allow for ad hoc relations, but they must be observable if they are to be included (Gibbs, 1989; Smelser, 1988). Network structure is not a mental abstraction; it can be presented as a set of concrete ties connecting the units of

analysis. Depending on the field of study, this structure can be relatively easy to identify. This is the case for established distribution networks (in economy), affiliation kinship ties (family studies), and open relations inside a closed space (e.g., a classroom). However, this structure can also be latent, (i.e., comprise ties that were unsuspected or difficult to establish). In this last case, it has often been demonstrated that informal ties between actors in organizational structures can tell us more about behaviours and power relations than do declared hierarchical ties (Lazega, 1998).

In the description of individual support networks, as is the case here for caregivers, identifying the structure is no easy task, given the wealth and extent of relations that a person can entertain within his or her environment. For example, an individual's network can comprise as many as 1,400 ties, of which a very large number are actually weak (sporadic ties, acquaintances) (Killworth, Johnsen, Bernard, Shelley, & McCarty, 1990). It can also be hard to arrive at a precise description of the core network (close ties) because this generally requires obtaining several dozen indices relative to the concrete and symbolic relations between an individual and the actors around him or her as well as between the actors themselves (for a description of these indices, see Scott, 2000).

Whereas some authors have focused on the core network as the space of greatest significance (Dykstra, 1990; Mitchell, 1969), others have deemed it necessary to take into account more sporadic or secondary-ring ties for network analysis (Granovetter, 1982; Hammer, 1983; Uehara, 1994). In short, no information on the network is easy to come by and researchers must realize that they cannot obtain an exhaustive description of the actor's relational structure. Researchers must be strategic and realistic. They must question subjects in order to get at a structure that will allow them to shed the best possible light on the issues under study.

The technique for gathering data on personal networks generally consists in using a name generator. Typically, a local node (ego) is asked to describe his or her social relations on the basis of a certain number of questions. Name generators can emphasize different aspects of a network (interactions, role relations, affective ties), but the social-support perspective is the one most often used. Depending on the name generator and the selection criteria utilized (e.g., persons 18 years of age or over, met in the past 3 months, in face-to-face interactions, etc.), the network will assume a different size, form, and content. In a way, researchers obtain a support network that corresponds to their theoretical expectations.

As a result, there is no consensus on what exactly constitutes social support or the multiple elements that can be attached to it. Most researchers will acknowledge that social support is an interactive process by which emotional, instrumental, or financial assistance is obtained from one's social network (Bowling, 1994). However, theoretical work in the fields of social psychology and sociology has demonstrated time and again that the notion of social support is rich and complex and difficult to grasp entirely by way of only a few questions (Caplan, 1974; Gottlieb, 1983; Martuccelli, 2002; Sarason & Sarason, 1985). From a theoretical point of view, support can derive from various sources, including family members, friends, neighbours, and fellow workers (Thoits, 1995, p. 64), but also from professional interveners, given the practices often inspired by *network interventions* in which interveners are called

upon to temporarily rebuild a damaged support network (pescosolido, Wright, & Sullivan, 1995). In addition, support ties generally comprise elements of ambivalence in which tension, affection, empathy, hostility, and respect are intertwined. Family support is a case in point, as it is often motivated by good intentions but just as often elicits mixed feelings. In this regard, Martuccelli described four types of support: symbolic, invisible, stigmatizing, and pathological. We will describe these in greater detail below.

Furthermore, theoretically speaking, support ties and network ties are not the same thing. Support ties relate to the caregiver's perception of help provided by someone, whereas network ties constitute a much broader concept that encompasses support ties as well as other types of ties between two persons (e.g., superficial contacts, ties perceived as inactive, symbolic, latent, diffused, extended). Generally speaking, these ties are not insignificant; they can be activated or reactivated and, therefore, can have considerable impact on a person's environment and his or her social response in the face of adversity. Researchers can be tempted to merge the two notions of support and network in the hope of covering the greatest possible theoretical space germane to them. Thus, affective ties can be identified via emotional support, and the support system via instrumental supports, among others. The social pathways through which resources can be obtained (Burt, 1992) can be identified via the persons offering advice, and weak ties via companionship and socialization supports. However, these constitute interesting hypotheses that remain to be verified.

These considerations give rise to a series of questions: When a person is queried about support ties, what do we actually obtain? How does the ego treat complexity, particularly when a tie comprises elements of tension or conflict? How does he or she treat new acquaintances, broken friendships, hasty reconstitutions, or separations deemed temporary or caused by a profound disagreement? Is she or he capable of identifying latent support ties that could be mobilized if needed? Can we hope to obtain valid data in line with theoretical expectations?

These questions lead us to the second issue, which relates to the validity of the data obtained from respondents. In this regard, the work by Bernard, Killworth, Kronenfeld, and Sailer (1985) revived interest in the notions of validity and accuracy in the measurement of social networks. These researchers demonstrated that nearly half of the data obtained from respondents about ties (most of which were sporadic) was erroneous or incomplete. Reactions to this finding were mixed, but many researchers rallied behind the idea expressed by Freeman et al. (1987) that long-standing ties, which are reported with greater accuracy, are primarily those significant for analysis, thereby minimizing the consequences of inaccurately reporting more sporadic ties. These two observations appear relevant to the analysis of life situations, such as experienced by caregivers, in which support ties include those cultivated over a long period of time (family) but also more sporadic ones (interveners) utilized in strategically.

The notion of validity focuses on the *veracity* of statements about the empirical world and is related to the delicate operation by virtue of which mental abstractions of social actors are converted into external indicators. Qualitative and quantitative research approaches propose their own data validation systems (Lincoln & Guba, 1985; Ruane, 2005; Whittemore, Chase,

& Mandle, 2001), and researchers working on networks will opt for one or the other approach, depending on whether the emphasis is placed on the stability of numerical measures, the content of social ties, or the symbolic dimension of relations.

To our knowledge, few studies have focused on evaluating the validity of the qualitative aspects of social ties. Researchers have above all explored the notion of “precision”, either by comparing the network described by a respondent with the “objective” network observed independently by the researchers themselves (Bernard et al., 1985) or by asking the members of the network (the alters) to corroborate or document the nature and frequency of the ties identified by the ego. In the latter case, it is important to bear in mind that the alters are not impartial observers and that they have their own take on the situation and issues in question. However, corroboration often reveals more about the reciprocity between two persons than about the accuracy with which a network is described. Rarely has research sought to understand the reasons for the convergence or divergence observed between the points of view of the ego and the alters (but see Pescosolido & Wright, 2004).

In any event, studies seeking to establish the convergence between the perceptions of the ego and those of the alters would be ill-suited to unstable situations in which the actor’s subjectivity cannot be overlooked. The relationship between two persons is an abstract concept in which a respondent invariably formulates his or her interpretation of what constitutes the relationship. Consequently, the social network is a construct that cannot be established definitively, as it comprises a certain measure of subjectivity (Freeman et al., 1987; Richards, 1985). In this connection, several authors have observed that the support network is a system that can be constructed differently as a function of membership in social categories. For example, friendships are perceived differently according to one’s personal experience and life setting (Fischer, 1982). It has also been reported that gender, membership in an ethnic community, and age influence one’s description of the social network (Bansal, Monnier, Hobfall, & Stone, 2000; Burleson & Mortenson, 2003; Due, Holstein, Lund, Modvig, & Avlund, 1999). In other words, structural and cultural elements associated with these social categories are believed to condition one’s representation of the world.

This angle of research focusing on social representations or the cultural universe is being pursued systematically by a well-established school in France (Moscovici, 1998). From this point of view, such representations are forms of knowledge developed and shared socially, the roots of which are to be found in one’s past experiences, attitudes, norms, and values; they allow individuals and groups to make sense of their behaviours and expressions (Abric, 1996; Jodelet, 1989). Where the support network is concerned, these representations affect a person’s description of his or her family responsibilities and obligations, of the role of external help, and of expectations about public services. Accordingly, the description of one’s supports is partially modulated by the presence of concrete ties, but also by one’s vision of the social world.

Considering the different elements presented above, one question bears asking: In the investigation of social support, can a name generator validly account for a caregiver’s network support potential in periods of transformation?

Background, Questionnaire, and Analysis Strategy

For illustrative purposes, we use data from an ongoing longitudinal study of the transformation of the support network of caregivers of older persons with Alzheimer's disease. The participating care-givers were recruited in two cognition clinics in Montreal (Canada) by a convenience sample technique (Ruane, 2005). Though this sampling method does not yield a representative sample, it does nevertheless obtain a theoretical sample in which the situations examined allow us to shed light on the social processes under study (Eisenhardt, 1989). Interviews were conducted from September 2001 to February 2003 with 49 caregivers of persons with Alzheimer-type dementia. The older persons with Alzheimer's disease were 78.7 years old on average and more than half were men (55.8%). The caregivers, who were primarily women (79.1%), were adult children ($n = 19$) or spouses ($n = 30$) with a mean age of 66.2 years.

The questionnaire used to collect data relative to the social network of caregivers was composed of four sections: (1) The interview began with a series of open questions to establish the periods relative to the onset of the relative's problems and the beginning of the caregiver's involvement. Caregivers were asked to describe and define the care context, including their experience or that of alters in providing assistance to impaired persons. (2) The caregiver was asked to document the help resources utilized since onset of illness. These resources could be provided by family, friends, community organizations, or professionals. For each resource used, researchers noted frequency and intensity of contact and caregiver interest in this help. They also discussed how the caregiver established contact with the resources, barriers to service utilization, and needs for emotional support. (3) The caregiver's network was identified by a name generator comprising five questions drawn from the instrument developed by Poel (1993):

- Q1** Suppose you had serious personal problems. With whom would you discuss them? (emotional dimension)
- Q2** If you needed information on your relative's disease, to whom would you turn? (health matter)
- Q3** Suppose you needed advice about a major change in your life, such as switching jobs or moving to another neighbourhood. Whom would you turn to in this case? (general advice)
- Q4** Whom do you go out with now and again; for instance, shopping, for a walk, to a restaurant or to the movies? (companionship)
- Q5** Suppose you needed help with chores in or around the house, such as holding up a ladder or moving furniture. Whom would you turn to in this case? (instrumental).

The caregiver was asked to provide as many as five names in response to each question, which made for a maximum network size of 30 actors. These actors could be family members, friends, neighbours, work-mates, volunteers, or professionals. For each member of the network identified, researchers sought to obtain social-demographic data, frequency of contacts, duration of relationship, and place of residence. (4) In the last section, the caregiver

was asked to discuss the changes that had occurred in his or her relations since the beginning of the relative's illness (reason for dissolution of ties or context fostering new ones). Also discussed were past and present conflicts, their causes and consequences, and the solutions proposed. Interviews lasted on average 1.5 hours.

Our strategy for analysing the validity of the network data obtained consisted in comparing the caregiver's description of his or her support network (as per section 3) against the overall discourse. The validity we sought to determine was defined as the degree of correspondence between the data obtained and theoretical expectations. Qualitative analysis lends itself particularly well to this type of validation. Accordingly, content analysis was conducted following two procedures. First, we used a graphic analysis representing the transformation of support ties. A detailed account of this procedure was included in a recent publication (Carpentier & Ducharme, 2005). It essentially entailed recreating a person's social relations on the basis of his or her narrative and then transposing them in a relational schematic describing the participation of actors in the decisions, actions, and significant events in the life of the person in question. The configuration of the final schematic was validated by consensus by the members of the research team. The construct of the narrative placed events in context, specified their chronology, and observed the contributions of emotional support offered by the alters (Daiute & Lightfoot, 2004). Second, the use of semi-open questions afforded respondents the opportunity to speak freely of their experience and of their relations with others, thereby allowing us to delve deeper into the significance that they lend to supports. With the help of N-VIVO (Bazeley & Richards, 2000), we sought to identify normative statements relative to attitudes and values regarding family, friends, professionals and the state, as such elements can influence the description of a network. Once the normative elements were identified, the description of the supports and the theoretical elements were compared and matched within evidence chains that tended to demonstrate the coherence of caregiver report. The validity criteria were based on notions of likelihood and plausibility (Miles & Huberman, 1994).

Data Validity: An Illustration of the Basis of Empirical Data

We sought in this study to foster reflection on the use of network data in a context where support ties are undergoing transformation. More specifically, we were interested in the support received by caregivers of an elderly relative with dementia of the Alzheimer type in the last years of the relative's life. This situation constitutes an emotionally intense experience for caregivers and often a marking moment in their lives. From our initial question "Can we obtain a relatively accurate picture of a person's support network by means of an instrument serving to reveal support functions?" we are inclined, at least in part, to answer in the affirmative. Caregivers generally express great sensitivity in response to the events they are going through and they seem to provide a coherent picture of their support ties, both perceived and utilized. However, we identified a certain number of situations capable of significantly altering the description of their network support.

Our analyses led us to identify five themes for which the approach imposed by researchers could be ill-adapted to caregivers and thus influence data validity. These are (1 and 2) caregiver degree of cooperation and understanding relative to the logic of a name generator,

(3) caregiver perception of the involvement of professional interveners (PIs) as support providers, (4) relations within the informal network, and (5) situations in which the network shows active signs of transformation.

Caregiver Cooperation in Describing His or Her Network by a Name Generator

In most cases, caregivers agreed willingly to talk about their caregiving experience and their relations with *others*. They also lent themselves readily to the *game* consisting in placing their social relations into functional categories (e.g., “Paul is a confidant”, “Claudine is a card-playing companion”). However, a certain number of caregivers did not feel comfortable describing their network. Some failed to see the relevance of discussing their social relations and were even irritated by the matter: “Why do you want to know about my friends when my relative is the one I’m having problems with?” Others, recent immigrants, appeared just as unforthcoming about their relations outside their family (Interview 25). Needless to say, caregiver reticence to describe their relations constitutes an attitude uncondusive to a detailed accounting of the network, thereby affecting data validity. For example, we observed little enthusiasm in caregivers who, after expressing strong family values, had to describe a network that had lost many of its family member support ties. It was painful for them to discuss in detail a situation experienced as a failure and, in these cases, caregivers clearly evaded questions aimed at arriving at a description of the network. The reticence demonstrated by caregivers might also have had to do with the exercise of description per se, which could be far from relevant to their immediate concerns. What is more, the network approach focuses on complex interactions among people; this requires a certain effort on the part of respondents, who are constantly called upon to pronounce on their relations with others. In a sense, caregivers are generally more at ease with traditional surveys in which they and their relatives are concerned directly.

Caregiver Understanding of the Function Approach Such as Presented by a Name Generator

Breaking down the social network into a small number of functions was not necessarily understood by all caregivers and, in certain cases, appeared quite inappropriate for the purpose of reporting on relations cultivated over several decades. For example, when we asked a caregiver to classify his wife according to our dimensions, his response was very indicative: “What can I say ... we’ve been married 36 years ... it’s not the way it was in the beginning, I mean, I wouldn’t call it love, but ...” (Interview 13). In another case, the caregiver had this to say about her mother:

She was there every day from 2:00 to 8:00, 5 days a week; she kept the books free of charge. She wasn’t a confidant by any stretch, she didn’t give advice, she wasn’t there for recreational activities or for concrete things. She was just my mother.
(Interview 24)

However, this same caregiver ardently wished to include in her support network her *Iama*, someone whom she had never met but who, in her opinion, had a great deal of influence on her life. She felt a close bond with him and, through spirituality, he provided counsel and comfort that helped her make it through trials and tribulations. Hence, though breaking dawn emotional support into different functions may seem a good idea to researchers, caregivers

can have a problem with that. Indeed, when a name generator is used to identify functions, caregivers are asked to compartmentalize their relations with the members of their networks according to a scheme defined by the researcher. Outside this scheme, relations cease to exist. Yet relations can be perceived as fluid, that is, they can be constructed and maintained in a register that evades strict categorization, such as a friend who accompanies someone in multiple daily activities, whose presence is comforting. Even if verbal exchanges remain limited, his or her sole presence in the person's life setting allows the person to cast a more penetrating gaze at the situation, thereby influencing the person's behaviour. It is not easy for anyone to analyse his or her social relations in depth and to expose them through the researcher's instruments. And what of persons who find their supports within the religious or spiritual realms or who recognize literary characters or public figures as such? Supports can be tangible but also imaginary. Indeed, those who are not physically "there" can nevertheless have a significant force of presence (Martuccelli, 2002).

Relations with Professionals

Our analysis leads us to believe that caregivers may underestimate the supports offered by PIs. Caregivers were asked to describe their experiences since the earliest manifestations of their relative's illness. Although our analysis of this period revealed numerous contacts between caregivers and PIs, a considerable number of PIs were not included in the caregiver's network. PIs were totally absent from 25 per cent of the support networks, and there were less than half as many between the narrative analysis and the description of the support network through the name generator. Truth be told, many PIs are specialists consulted to execute a precise task (e.g., neurologists); however, some could pursue a long-term relationship (e.g., family doctor). From a theoretical standpoint, we expected PIs to be represented as advisors or consultants and possibly as emotional supports, as was the case in the following network:

If I have a serious problem, I immediately call his doctor, Dr M., or Mrs F. Even if we turned to our children, what do you expect them to do? They have no resources. If the matter at hand was very important and I didn't know what to do anymore. I would call Mrs. F. (Interview 35)

Nevertheless, although many caregivers presented a rather positive attitude towards services, they tended not to include PIs in their support network. In fact, when it came to seeking advice, caregivers reflexively favoured sources of information already present in their informal network and to overlook PIs. As one respondent put it,

My daughter gives me advice because she's in gerontology and she knows what she's talking about. She works at the H. Hospital. What's more, I dealt with a friend and she was very helpful. She's the one who got me into the community centre and I found that she made a lot of sense. I wouldn't hesitate to contact her again. (Interview 39)

Caregivers recognized the different nature of their relations with friends and PIs. Although the information and advice provided by PIs was important when the relative's diagnosis was being established, information on the prognosis, which remains tainted by uncertainty owing to the unpredictable course of illness, seemed to be offered better by the informal network.

When friends or acquaintances were available and ready to discuss the situation, caregivers appreciated their attentive ear, their experience-based knowledge, and their familiarity with the caregivers' personal life history. Many caregivers sought out information by renewing old ties or by forging new ones through contacts of other friends. Among other things, they drew closer to the cleaning lady or to neighbours who had some experience with the illness. Often, the frequency of contacts with PIs did not really make it possible to address pressing issues. In this event, caregivers turned to written documentation, the radio, or television. Although one caregiver recognized that PIs can provide help, she did not include her doctor in her network:

I would probably go on the Internet for Alzheimer and read a little bit about it ... I guess if it got too bad I'd go to our family doctor. Yes, "What can I do?" and he would put me in touch with all that we need. (Interview 40)

Other caregivers clearly expressed major dissatisfaction with services:

Normally, logic would have it that I should find counsel from doctors. They are the persons with the qualifications, the knowledge, who must advise me. Unfortunately, I'm not satisfied with the relation that we have doctor-wise. I understand that they have a lot of people to see but they should take a certain amount of time to be more human to be able to say this thing and that. I come out of the clinic the same as I went in. That's how I feel – left to myself. (Interview 43)

Many comments were made on relations with PIs and contacts with the public health system. Among other things, caregivers deplored the fact that services were poorly adapted, that relations with interveners were impersonal, and that the social institution showed little interest in the concerns of caregivers and the elderly. PIs were viewed as people who want to make money, are too busy to help, and are more concerned with their image than with the public's well-being. Caregivers also expressed autonomist positions:

For me and for the whole family, it's obvious: We have to take matters into our own hands, we have to take charge of the situation, because the doctors are overworked, as are the nurses. I find that with the system as is, if people don't do things on their own, they might miss out on some very important information. (Interview 1)

You can't always cry for help, you've got to help yourself. I just recently began to deal with the community centre, but I don't think you should go overboard. You can't always be asking for help for every little thing. You've got to try to manage on your own and assume your responsibilities. (Interview 39)

How are we to interpret and deal with this apparent underestimation by caregivers of the support contributed by PIs? By virtue of their training and their social role, PIs are supposed to help persons in need and provide them with significant support. The fact that they are not perceived to do so poses a major ethical and strategic problem for social services. Our observations are in line with an already ample body of literature documenting caregiver discontent with PIs, communication problems, and frustration and dissatisfaction with relations. Such attitudes are believed to account, at least in part, for the under-utilization of services by caregivers (Brodsky, Thomson, Thomson, & Fine, 2005). In our study, caregivers expressed, in numerous remarks, a relatively negative view of relations with PIs and of the

health-care system in general. In this regard, there seems to persist in the collective imagination a rather unflattering representation of the work performed by public organizations, which are all the more discredited in the treatment of chronic diseases. People have a hard time seeing themselves collaborate with PIs who are associated with “waiting lists” and with abuse against the elderly in nursing homes (newspapers regularly cover such stories).

However, other avenues of explanation can be evoked. For example, the notion of support is tied in with the theory of exchange (Poel, 1993), according to which reciprocity conditions and perpetuates the perception of support. Caregivers and PIs are clearly not engaged in an exchange relation. Generally speaking, this may be due to the fact that the relation between the parties never reaches the degree of maturity sufficient to cultivate the necessary trust that often conditions a certain level of exchange. Nevertheless, we observed that advice regarding the illness was markedly more appreciated by caregivers when it was accompanied by a measure of emotion and involvement. Early in the caregiver career, friends and acquaintances were the ones who above all were perceived to be in the best position to convey this type of support. It has already been noted in the literature that support is deemed to be more effective when it is offered by someone who has already gone through a similar situation and who can thus discuss the caregiving experience more openly (Thoits, 1986). As Fortinsky (2001) pointed out, very little research has examined the role of PIs as sources of support, which might be explained by the fact that the notion of support belongs, where social representations are concerned, to the sphere of informal relations. According to another possible explanation, it may be that PIs are perceived as part of a category of invisible support that caregivers fail to acknowledge because they are taken for granted (Martuccelli, 2002). Caregivers do not feel the need to identify social institution supports because they are omnipresent. This phenomenon may even be accompanied by what Martuccelli refers to as stigmatizing supports, such as when older caregivers register a loss of functionality that contrasts with the total autonomy that they have always enjoyed. In these circumstances, caregivers may deny the presence of certain supports that undermine their self-image. Admitting one's dependence on the state chafes these caregivers, even if the support provided is real. In sum, owing to complex and multiform social representations, caregiver identification of formal supports may be underestimated, thereby diminishing data validity.

Relations within the Informal Network

By cross-analysing the different material at our disposal (network, narrative, discourse), we were able to confirm that the support contributed by alters was coherent with their actual presence in the caregiver's support network. Caregivers acknowledged the presence of conflicts and tension and the lack of availability of certain actors, and generally offered plausible explanations to justify the presence or absence of persons in the support network. However, certain contradictory elements did emerge, revealing the possibility of overstating or, on the contrary, of underestimating the network's support capacity. Two networks described succinctly below illustrate this tendency well.

Interview 37

This elderly English-speaking caregiver identified with the Jewish community in her neighbourhood and expressed strong family values. She was a retired nurse who had worked in a hospital. She described a very large network, including her three children, their spouses, many friends, and numerous PIs. At first glance, this was a dense network providing a good deal of support. However, upon closer scrutiny of the caregiver's discourse, we realized that her children lived outside the city, that her contacts with them were limited, that contacts with PIs were very infrequent, and that her friends, often very old, presented serious health problems of their own:

I have a friend, Marianna, but I talk to her only on the phone, because she's not well enough. She has Alzheimer's, but she used to be a very close friend. She goes to Doctor G. also. She started having problems about the same time as my husband. I've known her all my life you know. Now I make a point of phoning her, because she would forget and also to have someone to talk to.

Interview 41

This was an elderly caregiver who looked after her husband. Both were born in Italy. Despite having three children, the caregiver included only her daughter and a daughter-in-law in her support network. Contacts with PIs were just as frequent as in the case of network #37, but the caregiver included no resources from outside the family. However, our analysis of her life situation yielded precious complementary information. We learned that one of her sons was a doctor and that he was very much involved in orienting the caregiver and the cared-for person within the health care system. Yet the caregiver did not wish to include him in her network:

My daughter-in-law is really the one who helps, more than my son. Not that he doesn't want to, but being a doctor, he's always busy and gets home very late in the evening.

The second son lived outside the city and essentially maintained telephone contact with the caregiver. Her daughter's involvement in caregiving was substantial, all the more so owing to her availability, as she was inactive on the labour market despite herself: "Her husband doesn't want her to work outside the house."

Analysis of these two informal networks demonstrates the possibility of an idealized or distorted projection of the support provided, thereby diminishing data validity. We observed that elderly persons can persist in identifying social relations cultivated over numerous years, even though some of these ties had lost some or all of their support function. This phenomenon of social ties in *memory* is not specific to the elderly, having been observed in other persons in other contexts as well (Freeman et al., 1987). However, in the case that interests us, it can have more tragic consequences, particularly when growing needs lead caregivers to turn to supports seemingly ill-adapted to illness-specific complications. In the first of the networks above, family, professional, and community values favoured identification of a wide range of persons who did not necessarily present the same support capacity, and there were signs that the network was actually quite fragile. The caregiver continued to nurture the memory of a very active and functional network, but many of her

support ties were, in all likelihood, no longer as strong as they once were: the adult children were less available, not having a car limited the mobility necessary to benefit from certain types of support, and the caregiver's friends themselves suffered from chronic health problems. In the case of the second network, instead, support ties were underestimated. The caregiver excluded her physician's son, who served as a go-between to access PIs. Though the two networks appeared to be different in size, density, and diversity of ties, they are probably more similar in potential and concrete support than at first glance.

These two examples remind us not to fall for stereotypes that are too easily associated with certain ethnic communities that embrace a collectivist vision (Pyke & Bengtson, 1996). Studies confirm that we cannot automatically make the association between various groups (minorities, recent immigrants, or associated with strong cultural reference points) and large and highly supportive networks in which all the actors contribute actively (Burton et al., 1995; Iliffe & Manthorpe, 2004; Janevic & Connell, 2001). In truth, these groups have never been shown to be uniform in their structure, support capacity, and social representations (Litwin, 2004; Tennstedt, Chang, & Delgado, 1998). This observation is, to our eyes, all the more relevant when it comes to the support networks of elderly persons. It is also interesting to note, in the second family network, the presence of behavioural expectations related to the role of women. For caregiver #41, caregiving was associated with daily life and was a matter for women. She went so far as to overlook the contribution made by her son the doctor, despite the fact that he played a critical intermediary role in the cared-for relative's trajectory. These data in part converge with the observations made by Neufeld and Harrison (2000), who underscored the importance of *social norms* in the establishment of support ties with the informal network. Based on an analysis of a group of women, these authors noted that female caregivers were reticent to ask other family members for help because they estimated that caregiving was an obligation that befell them.

Networks Undergoing Transformation and under Pressure

On the basis of our analyses, we estimated that many networks were undergoing transformation and that caregivers were more hesitant when it came to describing their networks in these circumstances. These are situations difficult for researchers to explore, as caregivers express anxiety about the future, and their psychological distress is often palpable. Many of the respondents in the study admitted without reserve to being troubled, discouraged, or under medication. These were generally caregivers heavily involved in the care of a relative at a relatively advanced stage of illness. In these cases, friends tended to distance themselves, either because it became impossible to sustain the social obligations that maintain relations or because of profound divergences of opinion: "She's my best friend since always, but we haven't spoken since July, because she finds that I do too much for my husband." Having lost a good friend, this caregiver hesitated to recognize new acquaintances as sources of support, though in fact these persons were present and provided much appreciated help. It is hard to replace an old friend; a friend leaves a representation of the nature of friendship ties that must be remodelled in order to forge new friendships. Another one of our caregivers did not want to *beg* for help and preferred to isolate herself. She included no friends in her network:

Me, I never ask for anything and I never complain, I don't like to complain. They know I don't have a car. If I called anyone who did, they'd think, "I bet she needs a car." But that's not my case because I never call anyone. (Interview 39)

As for the dissolution of family ties, this occurred following controversies regarding sensitive topics or major decisions. At the start of the illness trajectory, confrontations can be related to denial by certain persons in the face of the manifestations of the relative's disease or opposition to eventual placement. We observed, however, that family relations were already very complex and multiform, that they broke off more easily when conflicts were latent, and that they persisted when forms of support were diversified. The disintegration of family supports could occur over a long period of time, and all breaks were all the more difficult to accept when the respondent was aware that the family would never be the same after the death of the elderly relative. It was difficult to determine the precise moment of the break in a family tie, particularly when respondents cultivated the hope of reconciliation and when get-togethers (birthdays, anniversaries) were inevitably followed by attempts at mending ties. We also documented situations in which the caregiver painted a picture tainted by her emotional state: "No one was ever there in moments of despair." Other cases exhibited denial. Despite the relative's advanced illness, these caregivers estimated that nothing had changed, in their daily life, in the relation with the relative, or in their social relations. In another case, a caregiver sought to regain a certain degree of normality after a long period of caregiving in isolation; she claimed to have renewed ties with old friends and to have given new impetus to family relations. However, analysis did not allow us to confirm the authenticity of the new ties described: the calls were not returned, the solitude persisted, and the frequency of contacts remained very low. In short, there was no reciprocity.

Needless to say, hazy situations are not conducive to an exhaustive and enlightened description of support resources. It is in this context that the data can present the least validity. A certain degree of serenity is required when identifying one's allies, distinguishing between strained ties that can be reconciled and those that are irrecoverable, and recognizing latent support ties that can be reactivated if needed. Although the borders of all support networks are in constant fluctuation, they are no doubt easier to sketch when the situation is stable. For a nonnegligible proportion of our sample, the immediate and traumatic caregiving experience blurred the perception of social relations. In this period, life clearly shifts into a higher gear and social representations are transformed. People form a completely different vision of the world in periods of intense caregiving, and the complicity in the past based on leisure, work, or shared conception of life will fade to make way for relations that must integrate and understand the experience of help giving. This will especially affect the older people for whom selection might already decrease the network size in favour of an individual providing a social climate in which they feel validated and loved (Carstensen, Isaacowitz, & Charles, 1999). Many see their points of reference knocked out of kilter and, as a result, social roles and supports must be redefined. Ties end up having to be negotiated constantly, and this can take its toll on the parties in question and lead to dissolution. Ties can be broken for many reasons, but all generally follow one fundamental theme: The caregiver wishes to accompany an elderly person in his or her remaining years of life and the caregiver wishes to do so as she or he sees fit, in accordance with the family's history.

In this connection, we observed that in situations of distress, frustration, and continuous failure, chances were that the caregiver harboured a negative perception of the support network and underestimated the help resources. It has been noted that one's negative perception of oneself and of others can be determined by one's state of mental health (Gable & Shean, 2000). If so, this factor diminished data validity in our case all the more.

Discussion

Though the network approach has proved a useful instrument to arrive at a plausible and operational picture of supports, we must recognize that it has its limits and that any definition of social ties comprises a subjective dimension. The network is a representation, a partial, shifting, and transient image of the relational structure that an actor can reshape according to one's way of dealing with problems, one's life situation, or the angle of analysis imposed by researchers. The notion of validity must be considered in the light of this reality. Indeed, the quest for accuracy in network measures must not blind us to the fact that we face an unstable empirical world that does not allow the production of uniform data, no matter how adequate the measurement procedures (Cicourel 1964; Maines, 1993).

In fact, it seems that social relations are intertwined with relations of solidarity and of tension that do not always make it possible to clearly determine a person's support contribution. For Connidis and McMullin (2002), ambivalence is the characteristic at the very core of family ties. In our opinion, the concept of ambivalence can apply also to a broader range of social ties. We believe that it is necessary to more systematically analyse the conditions that can discern differences between a network's actual support potential and the caregiver's own description of the network and, above all, to determine the scope of this phenomenon with a representative sample of caregivers. One fundamental question remains: Although we have observed a certain degree of validity in the construct of support networks in our study, to what extent can these results be applied to standardized questionnaires used with larger samples? Further research will tell.

The reflection proposed in this article is, in our opinion, relevant to population studies, which still remain the main source of data on social networks. Generally speaking, these large-scale surveys do not allow us to obtain detailed data on the support network. Very often, it is assumed that the supports identified are all equally effective, that conflicts are temporarily attenuated in order to meet needs, and that measures of physical proximity are good indicators of a person's implication. For our part, we noted a disparity in the forms of support. Family solidarities were not automatically consolidated in the face of adversity and the mere fact of being present daily was not a guarantee of support. What can emerge, instead, is a close relationship with distant geographic sources of support and the disengagement of proximal ones. This is why it appears necessary to us to pursue field research in order to better understand better the elements that modulate the description of the network. This could eventually help to refine the questionnaires used in large-scale surveys in order to increase their validity. The quick administration of simple questions to establish the support network remains a myth. It is necessary to add "depth" in order to improve our grasp of the nature of the social ties and supports at play (Martuccelli, 2002). Utilizing instruments that yield a better picture of the complexity and variety of support ties would

possibly entail the use of several name generators and the contextualization of certain events in order to arrive at a more exhaustive view of the network. Such a method would lengthen interview times, but this would perhaps be the price to pay in order to apply a network approach with large populations.

Another major point should be borne in mind; though name generators can help to identify a significant portion of the supports, they do not yield a picture that is complete enough to identify the strategic actors involved in care. Some ties can be inactive and on hold (Phillips, Bernard, Phillipson, & Ogg, 2000), which is probably the case for PIs. Professional service providers are, at the very least, weak ties with the potential nevertheless to redirect people and thus substantially affect the trajectories of caregivers and their relatives. They have decision-making authority, expertise, and contacts. Moreover, they can offer advice and are a possible engine of social action. Their presence structures the caregiver's life and their omission constitutes a flaw in the analysis. Consequently, the network is stripped of key ties when only the caregiver's representation of supports is taken into consideration.

It appeared to us in this study that the caregivers could describe their life setting and their relations to others in a relatively satisfactory fashion, although certain elements as yet poorly understood intervene to modulate the perception that caregivers have of their support structure. These include caregiver state of health, caregiver career stage, and caregiver attitudes and expectations (social representations). However, still others need to be identified and analysed in order to gain a firmer grasp of networks in transformation and thus ensure data validity. We are convinced that a network approach coupled with an understanding of the field are valid tools for arriving at a better understanding of the fit between formal and informal supports of caregivers who provide community care to relatives with dementia.

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