

# ‘Homemade’: Building, mending, and coordinating a care network<sup>☆</sup>

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## ABSTRACT

In recent decades, longer life expectancy, the consequent greater number of patients with often concurrent diseases, and the need of healthcare institutions to reduce the costs of services, have engendered changes in all European healthcare systems. On one side, healthcare systems increasingly rely on the self-management skills of patients, who undertake a growing amount of ‘sickness work’ from which they are relieved only in the case of severe illness. On the other, the inability of public healthcare systems to satisfy the increased demand for care has led to the growth of private healthcare organizations as well as cooperatives of health professionals who offer their services privately. The care of citizens, therefore, is increasingly distributed across networks of actors with very different objectives, logics of action and professional backgrounds (public and private healthcare organizations, community medical services, voluntary organizations). Despite the attention devoted by social studies of medicine to the work done by citizens in supporting the work of clinicians and nurses, the work performed in connection to the management of care networks have been only marginally investigated. Drawing on a qualitative research carried out in the Province of Trento (Italy) and focused on the different ways in which elderly people with chronic conditions manage their conditions outside the healthcare and welfare institutions, in this paper we are interested in deepening the understanding of the invisible work citizens perform in connection to the management of care services and professionals. That is, the work needed in order to activate, mend and coordinate complex networks of care.

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## 1. Introduction

In recent decades, longer life expectancy, the consequent greater number of patients with often concurrent diseases, and the need for healthcare institutions to reduce the costs of services have engendered changes in all European healthcare systems. Old Public Administration has been gradually abandoned for more decentralized management models in which hospitals mainly provide specialized services and acute care treatment (Dunleavy and Hood, 1994; Gray and Jenkins, 2006). Moreover, in recent years the increased demand for care has favored the growth of private healthcare organizations as well as cooperatives of health professionals who offer their services privately or in collaboration with the public sector (Maarse, 2006; Maresso et al., 2015; Torchia et al., 2015).

In this scenario, the management of chronic diseases and complex medical cases is increasingly delegated to patients, their informal networks, and primary healthcare providers (general practitioners,

pediatrics, visiting nurses, and so on). Patients are treated at home, thereby lightening the workloads of hospitals and assigning them management of only the acute phases of pathologies (Altenstetter and Björkman, 1997; Saltman and Bankauskaite, 2007). Healthcare systems increasingly rely on the self-management skills of patients, who undertake a growing amount of “sickness work”, a term Carl May uses in order to highlight all the activities and healthcare practices “distributed horizontally and vertically through networks that extend a long way from the doctor’s office” (May, 2010: 142).

Contemporary social studies of medicine have devoted attention to the role played by patients and their informal caregivers (with particular reference to their relatives) in articulating medical practice, focusing primarily on the “invisible work” (Star and Strauss, 1999) they perform in order to support the work of clinicians and nurses (Danholt et al., 2013; Langstrup, 2013; Piras and Zanutto, 2014; Ancker et al., 2015). In this paper, we want to highlight the invisible work performed by patients and their relatives in relation to a more specific though

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crucial feature: the everyday management of diverse healthcare and welfare services.

Despite the fragmented and dispersed nature of contemporary healthcare systems, little attention has been paid to the invisible work required of patients in their interactions with various organizations and professionals (such as public and private healthcare organizations, community medical services, voluntary organizations, social services, cooperatives or associations for the care of non-self-sufficient persons). To this end, we will present the results of a broader piece of research carried out in a northeastern region of Italy aimed at analyzing the different ways in which elderly people with chronic conditions – with the help of formal and informal caregivers – can care for themselves outside the healthcare and welfare institutions. As will be shown, the work carried out by patients and their relatives is crucial for activating and coordinating complex networks of healthcare professionals and services, as well as for remedying the lack of services in the network itself. The management of healthcare services thus appears as something ‘homemade’, in that it is an activity that is ‘made at home’, relying on a ‘familiar’ dimension, and involving actors (elderly people and their relatives) with no professional organizational skills, but who are genuinely committed to care for the well-functioning state of the network.

### 1.1. Invisible work and its articulations

Originally coined by Leigh Star and Anselm Strauss in relation to computer-supported cooperative work and information system design, the notion of “invisible work” points to understanding the “ecology of visible and invisible work” (Star and Strauss, 1999) and, more generally, to put under scrutiny the notion of work itself. As Star and Strauss note (1999: 12), “what exactly counts as work” varies a lot: some knowledge and skills are immediately recognized as formal work, while others are neglected or relegated to the background. One of the first examples they make to foster their argument is particularly apt to our discussion:

“Are tasks done in the home to care for a chronically ill spouse really work? No one who has carried bedpans, negotiated with insurance companies, or re-designed a house for wheelchair navigation would deny that it is, indeed, very hard labor in some sense. Yet such work has often been invisible. It may be invisible both to friends and family, and to others in the paid employment workplace. It is squeezed in after hours, hidden as somehow a shameful indicator of a faulty body; it is redefined for public definition as time away from work.” (Star and Strauss, 1999: 12)

**In other words, what counts as work is a matter of categories, definitions, expectations, and cultural assumptions. In particular, paraphrasing Nardi and Engeström (1999), the work performed by transparent actors (such as domestics or nurses); which takes place at hidden times or in invisible places (as with all activities that take place behind-the-scenes); defined as routine or manual, although it requires considerable expert knowledge and ability to improvise (such as the work of call center operators); and which is not part of anybody's job description (despite its importance for the maintenance of the correct functioning of the workplace – as with informal meetings, conversations, and organizational storytelling), often tends to remain invisible.**

But the work that remains invisible *par excellence* is the one that already in 1985 (and in reference to hospital settings) Strauss identified as “articulation work”, referring to the activities needed to “assure that the staff's collective efforts add up to more than discrete and conflicting bits of accomplished work” (Strauss et al., 1985: 151). It was later defined – in reference to the work within projects – as: “the specifics of putting together tasks, task sequences, task clusters – even aligning larger units such as lines of work and subprojects – in the service of work flow” (Strauss, 1988: 164). In this sense, articulation work is part of a broader ‘articulation process’, “the overall process of putting all the work elements together and keeping them together” (Strauss, 1988:

164).

As noted by Star (1991: 275) the concept of articulation work is probably the most important of Strauss's contributions to the sociology of the invisible. It is the “work that gets things back ‘on track’ in the face of the unexpected, and modifies action to accommodate unanticipated contingencies. *The important thing about articulation work is that it is invisible to rationalized models of work*” (Star, 1991: 275, italics in original). It is the type of work people must perform to be able to cope with ‘real-and-proper’ work: we all do articulation work, because it is constitutive of keeping our work going (Star, 1999). Moreover, it is exactly the kind of work that holds together visible and invisible work, setting a continuum, while keeping the boundaries between the two.

### 1.2. The invisible work of patients and caregivers in contemporary healthcare systems

The work of patients' relatives and informal caregivers in the management of care was already acknowledged in 1984 in a paper by Corbin and Strauss on the management of chronic illness at home. Patients' relatives perform three types of work (Corbin and Strauss, 1985):

- 1) illness work (such as “regimen work, crisis prevention and management, symptom management, and diagnostic-related work” - Corbin and Strauss, 1985: 226);
- 2) everyday life work (such as housekeeping, cooking or eating);
- 3) biographical work (the continual or occasional reconstruction of patients' life in medical and personal terms).

Since then, various studies have acknowledged the crucial role played by patients, their relatives and other informal caregivers in healthcare practices (e.g. Chapple and Rogers, 1999; May et al., 2005; Townsend et al., 2006; May et al., 2014). Informal caregivers and patients themselves facilitate and make possible the work of healthcare professionals, replacing them if necessary through informal practices of care and guaranteeing the achievement of their institutional goals (Morris, 2008; Jowsey et al., 2016). The studies interested in invisible work performed by patients and their informal caregivers have focused on some recurrent issues, which we now summarize.

First, patients and their informal caregivers must reconstruct their routines around the disease and its prescriptions. While professionals provide therapeutic schemes and general directives for the management of illness, patients (especially if they suffer from a long-term illness) must plan their daily lives to follow clinical prescriptions. For example, they often strategically emplace medications and other objects of care in their daily routines, arranging care and mundane practice to improve medication adherence (Hodgetts et al., 2011). Sometimes patients radically manipulate home spaces with the support of family members, introducing large items of equipment such as hospital beds (Exley and Allen, 2007), oxygen cylinders (Willems, 2010) or patient lifts (Lindegard and Brodersen, 2010). Through the connections among everyday routines, care activities, mundane artifacts and objects of care, patients and their caregivers build and keep alive heterogeneous “chronic care infrastructures” (Langstrup, 2013). In such cases, the invisible daily work of these actors is essential to foster continuity between clinic and home and making home treatment possible.

Along this line of reasoning, some authors have highlighted the “homecare work” (Bratteteig and Wagner, 2013) entailed in moving healthcare to the home. Caretaking in the home implies that the latter becomes the center of a whole set of activities and actors, which need to be coordinated. Family members, friends, neighbors, people for support with day-to-day activities (house cleaning, shopping) or professional care (nurses, physiotherapists, dieticians), pharmacists, doctors – they all contribute to the homecare work and to the care network (Bratteteig and Wagner, 2013: 143). In reference to family caregiving, other authors have underlined the ability of informal caregivers in “crafting”

care (De la Cuesta, 2005). That is, in finding a language to communicate with the person to be assisted, together with ruses, spaces and devices for caregiving. From this perspective, “ageing in place is collaboratively accomplished – ‘co-produced’ – by the efforts of both formal and informal networks of carers and older people themselves” (Procter et al., 2014: 263).

Other studies have shed light on the invisible work of patients in the management of their data (Winkelman et al., 2005; Civan et al., 2006) and in integrating medical and domestic workflows (Tang et al., 2006). Piras and Zanutto (2010), for instance, describe how patients work on medical records, writing annotations and reminders on them (e.g. symptoms that they want to report to the doctor), directing the doctor’s attention to particular information (e.g. highlighting certain values in order in a blood test) and, finally, matching and integrating materials (e.g. clipping printouts from the internet to official health records). Therefore, through work interwoven with daily routines and objects, patients manage and produce information useful for healthcare professionals in face-to-face encounters (Bruni and Rizzi, 2013).

Finally, the increasing and progressive use of Information Communication Technologies in medical practice and healthcare services (Timmermans and Berg, 2003) has attracted attention to tele-medical technologies and the consequent changes they bring for professionals (Berg, 1999; Aanestad, 2003; Mort et al., 2003; Oudshoorn, 2005; Lehoux et al., 2002; Bruni, 2005) and patients (Mort and Finch, 2005; May et al., 2005; Oudshoorn, 2008; Langstrup 2013; Mort et al., 2013). Devices for self-monitoring entail a redistribution of responsibilities (Willems, 2010) negotiated by doctors with patients and their relatives (Piras and Miele, 2017). Patients become “diagnostic agents” (Oudshoorn, 2008) that produce, select and manage the data necessary to make clinical diagnoses. In this renewed geography of responsibilities, patients are not just users of a new technology that requires instrumental skills; they are also agents who must perform the invisible work required to make these new healthcare services effective (e.g. monitoring their symptoms, measuring clinical parameters, reporting side effects of medications, recording significant shifts in their conditions and alerting healthcare professionals if necessary).

If, on one side, all these studies provide evidence about the work of patients and their informal caregivers in putting ‘care in practice’ (Mol et al., 2010), they tend to limit the idea of invisible work to the ways in which patients and their networks support healthcare-related activities (as in learning and performing specific medical practices or in producing and keeping track of medical data). But, as from the very first quote from Star and Strauss referred to earlier, even negotiating with an insurance company can be conceived as a form of invisible work. Patients and their relatives can play an active role in the management of different services and not only in supporting the work of professionals. In managing chronic illness at home, articulation work performed by patients’ relatives is vital for establishing the sequence of tasks and for coordinating the actions carried out by different actors (Corbin and Strauss, 1985).

More recently, Unruh and Pratt (2008) underlined how the invisible work of patients with cancer is also addressed to coordinate the actions of the professionals involved in their care network (e.g. transmitting information from one healthcare institution to another or scheduling appointments with different specialists in the ‘right’ order). In the same way, Jowsey et al. (2016) focus on the strategies enacted by patients and their caregivers to cope with the absence of coordination and communication among healthcare professionals (e.g. transmitting information from a professional to another, monitoring the course of the illness and its symptoms, or contacting services vital for understanding and managing them).

These studies note how patients and informal caregivers often manage and actively coordinate the actions of care services, but they are somehow ‘exceptions’ of a wider literature that – as we have seen before – is usually more attentive to the ways in which patients and their relatives fulfill and co-produce (Procter et al., 2014) the work of

healthcare professionals. In the literature interested in the invisible work of patients and informal caregivers, the management of care services have been only marginally investigated, mingling it together with other forms of invisible work. This paper is thus interested in deepening the understanding of this further kind of invisible work that subjects and informal caregivers perform, not directly related to the performance of healthcare practices, but more oriented towards the management of care services and professionals. That is, the work needed to activate, mend and coordinate complex networks of care.

## 2. Methods

### 2.1. Setting the context

In Western countries, the rise in life expectancy has led to a steady increase in the elderly population suffering from chronic illnesses and hence in need of care by national health systems. Italian society, in particular, seems to be at the center of a steady ageing process that has led to an increase in persons aged over 65 and a decrease in those aged under 15. Statistics issued by the Italian National Institute of Statistics (ISTAT, 2017)<sup>1</sup> show that the ageing index (i.e. the ratio between the over-65 and the under-15 sections of the population) grew from 131.7 in 2002 to 161.4 in 2017. In this time, moreover, men’s life expectancy has increased by 3 years and that of women by 2 years.

Furthermore, in the elderly Italian population, chronic diseases and motor and cognitive difficulties that prevent full daily autonomy seem to be increasingly frequent. Elderly people with chronic diseases are particularly in need of both clinical services to treat their pathologies and social services to assist them in everyday tasks concerning personal hygiene, nourishment and physical movement (Miele et al., 2016). The attempt of the national health system to develop procedures and organizational structures to coordinate healthcare and social services has encountered considerable difficulties (Barretta, 2009; Tousijn, 2012; Lusardi, 2015): most notably, the complexity of the sectors involved (consisting of a wide variety of services and practitioners already difficult to coordinate); the shortage of public funding; and the scant human resources able to coordinate social and health services. In this scenario, as we will show, patients and their relatives play a crucial role in managing the network of services and professionals.

The empirical material we present originates from research carried out in the region of Trentino (Italy) on the support networks of elderly patients and the different ways in which elderly people, with the help of formal and informal caregivers, can care for themselves outside healthcare and welfare institutions. The Trentino region is characterized by scant coordination between health and social care services (Di Nicola and Pavesi, 2012). At the same time, the most recent ISTAT data on home care services, furnished in 2011 – social-welfare care, integrated home care, vouchers, and care allowances – show that Trentino is above the average with respect to other regions in the North-East of Italy in regard to both coverage and uptake (97% of the Trentino municipalities furnish home care services as opposed to 36% of municipalities in North-East Italy).

In other words, Trentino appears to be a territory characterized by a good amount of social and healthcare services, but at the same time by weak connections between these services. Thus, it constitutes an interesting case to investigate whether and how the invisible work of patients and their relatives enables the performance of successful visible work (i.e. by professionals) and organizational action (i.e. by healthcare organizations).

<sup>1</sup> <http://dati-anziani.istat.it/?lang=en&SubSessionId=cf97b054-9949-4c4e-a4f9-ee702c62d8be&themetreeid=-200>.

## 2.2. Data collection

Data presented in this work has been collected during Aetas (Active aging, empowerment, tecnologia, salute), a research project that involved Fondazione Bruno Kessler, the University of Trento and the School of General Practice of Trento. The board of the School of General Practice, a research and training institution for GPs, approved the study, which was conducted applying the guidelines for students' theses.<sup>2</sup> Informed consent was obtained from all interviewees who took part in the study.

44 semi-structured interviews were carried out with elderly patients with chronic diseases (11), with their caregivers (15), or with the presence of both actors (18). Interviews developed around three main areas: 1) the subjective experience of the disease; 2) the everyday management of the therapy; and 3) the relationship with healthcare institutions, services and professionals. All interviews were audio-recorded and transcribed.

The theoretical sampling (Glaser and Strauss, 1967) of the interviewees followed two main criteria: territorial (proximity to healthcare facilities); and subjective (level of patient autonomy and predominant source of support if the patient is not autonomous) as seen in Table 1. It was thus possible to approach patients that differed as much in the forms of care and assistance delivered as in the network of services and professionals in which they were inserted.

Finally, because the interviews were conducted in patients' homes, they provided opportunities for impromptu observations of minor episodes of daily life. On other occasions, the interviewees themselves 'detained' the researchers to show them the drugs and artifacts that marked their everyday routines. In other cases, the researchers were subject to questions, requests or complaints, perhaps because they were perceived as representatives of the institutional system. All these situations, although not recorded as 'data', added meaningful insights to the interview analysis.

## 2.3. Data analysis

The interviews were analyzed using *template analysis* (King, 1998, 2004), a model for coding the content of textual data coming from transcripts of interviews, fieldnotes or collected documents. Starting from the literature and their expectations, the researcher sets *a priori* themes expected to be relevant to the analysis. Reading through the data, the researcher codes fragments of text related to these themes and, at the same time, defines new themes to categorize data which do not fit with *a priori* themes. Through this, after the coding of a few interviews, an initial template of themes is defined. This template is then applied to the whole data set, although it can be modified in consideration of what emerges from transcripts. Thus, a template emerges: a system of interconnected categories aimed at interpreting the phenomenon at stake. In our case, as the empiric section will show, the final categories have focused on the practices patients and their relatives activate to build, mend and coordinate their network of care services.

## 3. Findings: building, mending, and coordinating a care network

In this section, we describe the three main practices that distinguish the invisible work of patients and their family members in the everyday management of diverse healthcare and welfare services: building a network of services and assistance; mending the network's holes; and coordinating the network.

As a preliminary consideration, it should be noted that, from the

<sup>2</sup> Approval from the ethical committee of the local healthcare trust (Azienda Provinciale per i Servizi Sanitari) is not required for exploratory studies that do not involve medical devices and drugs (see <https://www.apss.tn.it/comitato-etico-per-le-sperimentazioni-cliniche>, in Italian).

point of view of the patient, social and health services are only a part of a care network that may be broader and comprise other actors, and whose composition changes over time, also in relation to disease trajectories. Hence the everyday management of various services transcends institutional logics of coordination and involves a ceaseless organizational process which requires constant maintenance.

### 3.1. Enrolling actors and building a care network

Constructing a care network first requires that subjects and/or their relatives enroll other actors vital for supporting them in the management of health issues. This often means trying to access the resources offered by the welfare system:

In fact, we had to get things sorted by asking around what we had to do, because the doctor didn't give us any precise information. Very vague, always very vague. [Daughter of a 67-year-old woman with Parkinson's disease].

Once I was queuing at ASL [the local health district] for booking an appointment, and there were two people behind me that were talking about these issues [ambulation problems]. One says to the other: "I knew that in Pisa ... " – at that time I was living in Latina – "there are good surgeons who do this kind of operations." [77-year-old man with diabetes, cardiovascular diseases and serious ambulation problems].

Accounts like those above are frequent and evidence how access to welfare resources, even if regulated by detailed legislative provisions, requires additional work by the patient and their family. The information provided by the general practitioner (the citizen's guide through the network of health and social welfare services, especially in Italy) may be insufficient to understand the institutional interventions to which one is entitled, and moreover, which of them may be combined. Patient and caregivers thus start what is sometimes a long process of information gathering through formal and informal channels, so that they can later apply for social and/or healthcare services.

In cases where the patient is unable to construct a care network by themselves, it is usually the closest family members who intervene and help by activating the necessary services, which can be furnished by public or private organizations, as well as by the market:

Then this winter [the patient] had several problems. This winter was really the *clou*, like ... problems with her legs ... in addition she had an attack of shingles ... and so we hired a *badante* [caregiver]. In the sense that all the medicines and ointments had to be applied. It was tough, and she was very poorly ... so in the morning we're helped by an outside person. [Daughter of an 89-year-old woman with serious ambulation problems and early-onset dementia].

As in the case just described, the patient's loss of autonomy may be sudden: the patient is abruptly deprived of the physical and cognitive skills indispensable for both self-care and interaction with local institutions able to provide welfare aid. In these cases, the role of family members becomes crucial, both to buffer the immediate aggravation of the situation and to undertake new actions and mobilize new actors in the care network. As also observed by van Hout et al. (2015), the caregiver can closely observe the 'signs' of a change in the patient's essential practical and cognitive abilities (e.g. personal cleanliness, taking medicines, upkeep of the home), accessing information that is difficult for an external person (such as a social worker) to acquire so rapidly.

Frequently, this can mark the beginning of a phase of evaluation of the patient's overall situation: gathering diagnoses from general practitioners and specialists; constructing a representation of the patient's condition and their degree of autonomy; trying to understand which tasks can be carried out by the family members (compatible with the time available to them), which tasks require a professional, and which can be delegated to other figures (such as paid caregivers). The family members will then begin exploring the interventions made available by the national health service, social services and/or the private market, assessing which of them may be suitable for the patient and applying

**Table 1**

Criteria of theoretical sampling of interviewees.

Territorial context	Autonomous patients	Non-autonomous patients mainly supported by informal caregivers	Non-autonomous patients mainly supported by institutional services	Total
Urban (with hospital)	7	5	7	19
Valley (with hospital)	5	5	3	13
Valley (without hospital)	3	4	5	12
Total	15	14	15	44

for them or, as in the above extract, ‘purchasing’ them directly.

### 3.2. Mending holes in the network

As mentioned, the province of Trento is characterized by a good number of services and, at the same time, by scant coordination between these services. Consequently, there are often ‘holes’ in the emerging care networks, i.e. situations characterized by a total or partial lack of coverage of the patient’s healthcare and social needs. However, patients and their family members are responsible for a series of activities that are often interstitial in nature, being essential to fill the holes left by the services:

We have the cooperative for 25 h a week, which are those of the municipality’s domestic services. For 30 h a week I have a contract [ ...] with a private *badante* [carer]. So we have a total of 55 h of assistance. Everything else, of course, I do. These hours from the cooperative, which should give me some respite, which the social worker granted also to relieve me, don’t in fact give me very much relief, because I still have to stay at home if my husband wants to go out. [Wife of a 65-year-old patient completely paralyzed due to cardiac arrest].

The networks constructed by patients and their family members are often complex ones in which public and private social workers alternate, with their actions flanking those of general practitioners and home care nurses (and, more sporadically, the interventions of specialists). Despite coordination efforts (on which we focus in the next subsection), the complexity of the needs of elderly patients, the cost and rigidity of some of the social and health services used, require constant action by the patient and their caregivers in the performance of nursing tasks for assuring the continuity of care (see also Jowsey et al., 2016). In the case considered above, for example, despite the high presence of caretakers, the interviewee was forced to be co-present with the latter for most of the time. This was because public assistants are authorized neither to carry out medical tasks nor to take the care recipient outside the home should they request it, thus producing ‘holes’ in both treatment and assistance that only the informal care networks can remedy.

Observed from the perspective of the patient and of the family members in particular, care appears to be work that requires someone’s constant presence:

So, my daughter lives upstairs and sees me every day ... [and everyday asks me] “Mom, how are you?”. I have also a very helpful son-in-law who prepares the medications, putting them in little bags, one for each day [ ...]. If I ask something they immediately come to me. Therefore, I try to not to ask for anything, because I would not want to burden my son. [92-years-old woman with asthma, maculopathy and hypertension].

Also this morning, the nurse came [to cure his wife’s wounds due to diabetes] ... he said: “Why did you do this dressing change?”. Then I replied: “I did as the doctor taught me two years ago, I did this, this and this ...”. [And the nurse said] “You did well, because you’ll see that slowly ... [the wounds will heal].” [Husband of 73-year-old woman with both legs amputated due to diabetes].

‘Filling the holes’ may have the sporadic nature of availability when needed. On other occasions (as in the second excerpt) it means coordinating daily lives to compensate for the absence of services and/or health professionals. When coverage takes place systematically, family caregivers can develop skills that replace the work of a professional.

This leads to a paradox: whilst family members perform tasks that pertain to health professionals (and which family members themselves would prefer to delegate), because of the acquired expertise and the routine nature with which some tasks are performed, they no longer feel the need to access social-health services.

When my husband died, I was left alone, because my children got married and I did not want to live in the apartment where I lived for many years with him, so I moved here [in a sheltered housing] [ ...]. Day by day my illness is getting worse, but above all what I hate most is the loneliness and lack of assistance [ ...] I’m trying to see what to do, because now I can hardly make the bed, wash and get dressed ... but I have a fee-paying caregiver who come twice a week. [85-year-old woman with diabetes, arthrosis, osteoporosis and maculopathy].

[In my block of flats] we help each other. If someone is ill, they rush to help. They run. Indeed, when I was in bed with flu they brought me the soup. [80-year-old woman with diabetes and maculopathy].

In the first case reported, the patient does not have a sufficiently dense family network to rely on and the institutional services to which she can accede are insufficient to ensure an overall satisfactory quality of care. Elderly people of this type seem constantly to be at risk because of the holes in the care network: in this case we see how such risks can be reduced, at least in part, by integrating public welfare interventions with a private caregiver designated to carry on some well-defined tasks in housework. The second subject has neither the family network, nor the economic wherewithal to afford private care. In this case, a mutual assistance network helps the interviewee in managing minor and major aspects of everyday health and care practices. Beside the flu and the soup quoted in the second excerpt, the patient emphasizes that, thanks to those accompanying her to medical examinations, she is at less risk of falling (with all that a fall may mean for an elderly person), just as thanks to those who assist her taking drugs she avoids confusing medicines.

Therefore, we see how in different situations patients themselves (or, if they are unable to do so, their family members) ‘patch’ the holes left by institutional action and services. This is linked to another activity that patients often must deal with: the coordination of different services and professionals.

### 3.3. Coordinating the network

Once the constructed network is put to work, it must be coordinated. As mentioned earlier, the actors involved have different tasks, abilities, and time availability. On the one hand, there are professionals working for organizations whose regulations and action plans may sometimes complicate the care of the patient and the assistance provided by family members:

It’s absurd ... to accompany my mother to medical examinations in the ambulance, I’ve had to call the doctor three times because there was incorrect notification of the family member accompanying her in the ambulance. [Daughter of an 89-year-old woman with serious ambulation problems and the onset of Alzheimer’s disease].

As already seen, professionals are authorized to perform only certain types of actions (e.g. in the case of nurses, allowing into the ambulance only family members present on a list signed by the patient), which should help to protect both the patient from physical risks and themselves from legal ones. On the other hand, there are various

informal caregivers who look after the patient and plug the gaps in the services.

We've organized ourselves so that in the mornings there's my sister-in-law; in the afternoons I'm here. My aunt also sleeps with her because she's on her own as well. There are lots of us in the family, and we take turns ... when we can. [Daughter of an 89-year-old woman with serious ambulation problems and the onset of Alzheimer's disease].

The task of coordinating these actors (characterized by different life rhythms, attitudes and commitments) usually involves the patient themselves or a family member, who schedules access to the healthcare system (e.g. making appointments for specialist examinations or dealing with the general practitioner), checks whether informal caregivers can look after the patient consistently with their commitments, and intervenes if unexpected events occur. However, the various actors are orchestrated according not only to their availability but also to the opinions shared about them by the elderly person or their relatives over the years and which may lead to their marginalization in the care network:

Well, I don't go often to my general practitioner, I need him merely for certain requests ... also because if I ask something he says: "Okay, you need to do this ..." [...] It seems to me they [general practitioners] act more like bureaucrats than doctors, so ... Before I had one that was good enough, but I had a problem with him and I changed. [77-year-old man with diabetes, cardiovascular diseases and serious ambulation problems].

Similar assessments about the family members involved in the patient's everyday care are made by the network coordinators. These assessments concern abilities closely tied to the care sphere, such as sensitivity and attention to the patient's needs:

Spontaneously, my older daughter has some attentions that perhaps others should be told about. [...] Maybe it's a question of age. Let me give you an example: on Sunday we were all having lunch together. Obviously, the grandmother was there. It was my daughter who said: "Granny, shall we go and have a pee?" ... this would have never come to others' minds. [Daughter of a 74-year-old woman with Alzheimer's disease].

From this excerpt it is possible to note how instances of informal caregiving easily reflect gendered expectations.<sup>3</sup> We believe it is no coincidence that in many cases (such as this one) female family members deploy what appears as 'spontaneous attentions', while they carry out the burden of care (May et al., 2014). Unfortunately, in this way stereotypical gender attributions are reproduced and the ability to detect subjects' needs and to act appropriately is reframed as a purely individual attitude.

But the choices made by family members concerning the network's construction and its coordination also reveal how assistance and care are linked to more general assessments of the patient's history, seeking to preserve pre-existing social ties. Tasks that could be delegated to a single person may be assigned to several actors to stimulate the patient and maintain a positive set of relationships – or also to give social and relational gratification to the caregivers:

There's a lady, a friend of ours, who for years has come every morning to see her, and until we hired the *badante*, she came to help me give her the medicines. But she still gives her the insulin [...]. It was my choice so as not to turn away people who'd been around the house before the *badante* came. Because I didn't want to leave out people who used to come here since years ... so the choice of keeping this lady who came to do these things was deliberate. Then there's my aunt who drops by every day [...]. And then I've kept the house-assistants for personal hygiene once or twice a week. They come as well. And for the same reason, because the *badante* could do these things herself. [Daughter of a 90-year-old woman with Alzheimer's disease].

This excerpt demonstrates that sometimes the coordination of the

network does not follow a rational canon of maximum efficiency, but one of maximum inclusion, to retain as many actors and resources as possible within the network and to cope with diverse contingencies.

#### 4. Discussion and conclusions

Whereas most of the existing debate concentrates on the invisible work patients and their caregivers perform to articulate medical practice, in this paper we have focused on the invisible work played by elderly people and their caregivers in the everyday management of complex networks of healthcare and welfare services. In particular, we have identified three main practices:

- enrolling actors and accessing the social-healthcare resources offered by the local welfare system (*building the network*);
- filling the gaps left by the healthcare and welfare organizations (*mending the network*);
- coordinating the work of the organizations involved in patient management, as well as that of informal caregivers (*coordinating the network*).

Detailed analysis of these practices leads to four main considerations concerning the role of patients and of their informal caregivers in the contemporary welfare systems.

First, patients and their caregivers must continuously intervene to connect and hold together the action of the organizations and the professionals involved in the care network. Professionals and organizational facilities intended to help citizens in choosing, activating and coordinating services (public health facilities, social services, medical practitioners, private and third-sector cooperatives) appear sometimes of scant utility (if not as obstacles) in the process of caring for the patient. Faced with such shortcomings, family members often make up for professionals in reference to some basic practices or, as already witnessed in other studies (Jowsey et al., 2016), assist them in information gathering and coordination efforts.

Secondly, results show that, in response to the rigidity of institutional rules, informal caregivers constantly supplement the action of healthcare and social services. Through practical experience, coupled with continuous and close interaction with healthcare professionals, they acquire professional skills and perform care practices in a 'correct' way, even in the eyes of the professionals themselves. Especially when they acquire long-standing experience in managing chronic illness, the ability of caregivers to perform some of the tasks of healthcare professionals demonstrates the relative overlap between professional and lay knowledge. If, therefore, processes of delegation from the public health system to the patient have been repeatedly analyzed from a macro perspective (Altenstetter and Björkman, 1997; Saltman and Bankauskaite, 2007), this paper sheds light on some of the effects of such delegation at the micro level.

Third, although the existence of institutions and organizations is crucial for the well-being of citizens, equally important is the role played by informal care actors, whose action is driven by short-term goals and constantly shifts between social and health care. The rigid organizational and professional boundaries between social and healthcare services are blurred so that some activities can be carried out by a home-helper, a neighbor, a family member, or the subject themselves. Family members orient their action considering the overall well-being of the subject, seeking a balance between healthcare and life quality. As noted by Mol et al. (2010: 13): "Unlike medical ethics, the ethics of care never sought to answer what is good, let alone to do so from the outside. Instead, it suggested that 'caring practices' entail a specific modality of handling questions to do with the good". Consequently, those who coordinate the care network aim to ensure that the medical treatment of individual pathologies is always accompanied by attention to the subject's social, affective and emotional dimensions. In the nursing practices reproduced by informal caregivers, healthcare and

<sup>3</sup> We thank an anonymous reviewer for having raised this point so clearly.

social skills intertwine, blurring the rigid distinction between healthcare and well-being.

Finally, in cases where patients are not self-sufficient and cannot rely on strong social ties, the range of services available suddenly becomes insufficient or inaccessible. Consequently, the subject and their social network, as also found by other studies (Oudshoorn, 2008, Langstrup 2013), performs articulation work essential to ensure the coordination among healthcare organizations, and between these and other organizations in other spheres of welfare. This dynamic highlights the struggle of existing organizational structures to coordinate their actions and to adequately cover the health and social needs of patients. The production of healthcare services is therefore only partially supported by the organizations formally assigned to this task and entails a much more fragmented and dispersed network of actors and relations.

A focus on the invisible work performed by citizens in building, mending and coordinating the care network they look for, conveys an image of the management of the overall process of healthcare assistance as something 'homemade'. With this expression we want to stress both the 'familial/familiar' and 'private' component that sustains the well-functioning of the care network, and the dimension of 'genuineness' and 'authenticity' inherent in actors' (elderly people and their relatives) commitment. As seen in several situations, it is the homemade nature of certain interventions and/or practical solutions that ensures coordination of the network and its capacity to adapt to the subject's care needs. On the one hand, this is inevitable because the boundaries among different organizations and the standardization of professional practices do not match the singularity of needs and attention to the subject's social and emotional dimensions. On the other, this indicates the ever-increasing skills required of citizens: not only skills related to care, but also ones oriented to the management of services and different professionals.

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