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Original Investigation

The caregivers' iceberg: qualitative narratives of Italian caregivers' roles and challenges

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Despite the crucial role of informal caregivers of dependent persons to ensure the sustainability of our welfare systems, only few European countries have so far recognized their pivotal role in care provision. The aim of this study is to provide additional evidence in this regard, based on the experience of Italian caregivers, analysed via a qualitative methodology, to take into account behaviours and perspectives of both spouses/partners and children/children-in-law. Six semi-structured face-to-face in-depth interviews were carried out. Five themes emerged: 1) the diseases and the need of information; 2) the caregiving role; 3) the organization of care; 4) the impact of caring; and 5) the social recognition of the role. The study confirms that the impact of caregiving can be enormous and affects all aspects of one's life and of our society as a whole, thus suggesting that appropriate measures are needed to provide accessible information and adequate support services to informal caregivers.

Key words: Informal caregivers, Qualitative interviews, Older people, Loneliness, Care burden

INTRODUCTION

Background

Estimates suggest that 80% of care to dependent persons with chronic illnesses or disability is currently provided by informal caregivers, such as family members, friends or neighbours [1]. This role, often taken for granted by governments, represents today an important component of welfare systems, which are facing major sustainability challenges due to the aging of the population [2]. If, on one hand, the share of older people and the prevalence of chronic conditions and multimorbidity – now affecting about 50 million of European citizens [3] – are both expected to increase in the next decades, on the other hand governments' financial constraints, demographic and social changes are leading to a decline in the number of people potentially able to provide care. This trend is due, for example, to the increase of old age dependency ratio, the decrease in families' size, the increasing living distance between children and parents, and the growing women's employment rate [4]. Among the European countries, Italy is strongly affected by this phenomenon because is the country with the highest percentage of older people and with a tradition of a "family" model of care [5].

To be effective, ageing in place and caring for older people in their homes, instead of use of residential care services, require remarkable joint efforts by families, public and private welfare organizations, and the voluntary sector [6]. Traditionally, informal caregivers are mainly represented by women aged 50 to 70 years, close relatives of the care recipients (e.g., partners or daughters), who are in charge of a wide range of activities, from health and personal care to financial and domestic management, mobility and emotional support [7]. Lack of homogeneous definitions and paucity of data have prevented reliable estimates of the size of this target group, which ranges, for the European Union only, from 19 to 100 million [8].

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Despite the growing amount of care and support activities informal caregivers provide every day to their family members in need, only few European countries started to recognize their pivotal role in the care process [9]. In Italy, the Central Government recently established the "Fund to support the caring role of informal caregivers", whereas some Regions adopted specific laws to recognize the role of caregivers and provide them improved support services. In this context, the analysis of the challenges caregivers are facing, but also the contribution they are providing to the society, are important to support the development of adequate policies in this field. Moreover, the Italian situation offers interesting insights on how social and political trends of the last decades have influenced elder care provision.

THE ITALIAN CONTEXT

The last available official figures show that in Italy there are about 3.3 millions of informal caregivers aged 15-64 years [10], a number that does not include the many over-65-years old who provide care to their partners or to other family members.

Although in Italy families have been traditionally the pillar of elderly care, demographic changes and the economic crisis contributed to gradually undermine this model [5]. On the one hand, the already low level of long-term care (LTC) public services was additionally reduced as an effect of fiscal austerity, except for the cash allowance provision - a universalistic measure targeted to completely dependent people – which increased of +3.1% in the period 2008-2014 [11], and then decreased of -0.5% in the period 2013-2015 [12]. On the other hand, Italian families – who started to use privately hired home care workers as a response to the increasing women's engagement in the labour market [11] – have been suffering in recent times from the economic difficulties brought by the recent international economic crisis, struggling to sustain these expenses [5]. Moreover, it is worth mentioning that, apart from cash allowances (granted to about 12% of older people), older Italians refer only to a limited extent to social and health care services, these being affected by a high fragmentation and variability across regions, low accessibility (i.e., only 5 and 2% of older people using home care and residential care, respectively) and low intensity (i.e., about 20 hours *per year* of home care on average) [13]. In Marche region, where this study has been carried out, recent data show that health homecare is used by 2.9% of older people for a yearly average of 27 hours, whereas social homecare services are used by 0.7% of people aged 65 years and over (1.2% in Italy) [12]. If residential care is considered, there are 2.2 beds every 100 persons aged 65 years and over. Finally, cash allowances are granted to 12.9% of older people, with a declining trend since 2010. These data suggest that Marche region has a mixed cash-for-care model, dominated by cash allowances and integrated with homecare [12].

When these services are not available, many families tend to seek help from privately hired migrant home care workers, estimated to reach about 830,000 in 2013 [14], even if most of them often do not have any specific training to carry out care activities, thus making it difficult to properly manage on a routine basis chronic illnesses like, for instance, Alzheimer's disease. The use of this solution is often not feasible for low-income people because the costs of a migrant care worker could be relatively high and the cash allowances, if received, usually cover only a part of it. As a consequence, the last decades have seen an increase of undeclared (and therefore cheaper) migrant care work [14]. These trends reflect, on the one hand, the efforts of Italian families to adjust their behaviours in the attempt to find the most suitable and sustainable solution to provide the best possible quality of care to their loved ones and, on the other hand, the still primary role of informal care.

IMPACT OF CAREGIVING

Informal caregiving could have positive benefits in terms of self-esteem and rewards, but also have a strong and negative impact on different aspects of life, such as health, family, work, and social inclusion. Becoming a caregiver means assuming the role of caring for a person in need, adapting and reinventing own life, with an uncertain future [15 16]. Research has extensively documented that caring affects both psychological and physical health, showing that caregivers often suffer from stress, anxiety, depression and burden [17], especially in the case of relatives suffering from Alzheimer's disease [18 19]. Moreover, they can be at risk of physical problems (i.e. injuries, worsening of chronic conditions) or of unhealthy life-styles [20], especially in the case of older spouses caring for their partners because they are also exposed to their own health decline associated with aging. Caregivers living with the care recipient or those providing intensive care could also face problems with their work duties, requiring a reduction of working hours or even to quit job [21 22]. In the same way, leisure time and family obligations are affected by the responsibilities associated with the role assumed. Thus, effects of caring are not only relevant for those providing care, but have a heavy impact also on the quality of care provided to the care recipients and on the society as a whole, with important implications in terms of costs and public expenditures.

It is not surprising, therefore, that in the last decades an increasing attention has been paid to the study of caregivers' needs and support services, although studies often focused on single aspects of caring [23 24] or used quantitative methods [25] [26]. A comprehensive view of the caregiver role should consider not only the different aspects of caregivers' life and the relationship among these aspects, but also the contextual aspects, such as the national organization of health and social service provision, and their impact on elder care. Availability of both individual and environmental resources and ability of the caregivers to use them are important elements to consider. For example, personal traits (e.g., optimism, self-esteem), presence of persons that can be called in case of need or that can be delegated to carry out some caring activities, assets, and accessible services, are all factors that can influence positively and significantly the perception of the caregiving experience [27]. Conversely, in other situations, caregivers could avoid telling other persons about their situation, preventing the search for help, or could have problems in the relationship with the care recipient, creating barriers and conflicts in the management of care and support [28].

In the light of these considerations, this study aims, in the first place, to provide additional insight on the experiences of a sample of Italian caregivers, trying to grasp and illustrate their perspectives, needs and problems using a qualitative methodology. In particular, the study attempts to answer the following questions: How and why has caregiving started? How are care and assistance activities organized in relation to private life, work and family commitments? What kind of support do caregivers search for, receive, and from whom? What kind of difficulties do caregivers encounter? What perspectives and expectations do they have for the future? How do they feel with regard to the way their role is perceived by their closer social network and by society?

Secondly, given the crucial role played by social relations in this field, the study takes into account the kind of relationship existing between the caregiver and the care recipient, as potentially influencing the motivations, feelings, needs and caring strategies implemented [29]. The relationship dynamics can be represented as an attempt of the caregiver to balance his/her needs and those of the care recipient, managing the changes occurring in the relationship, the motivations and the meanings of caregiving [30]. Willingness of the caregiver to maintain the relationship with the care recipient (e.g. love relationship) could have positive effects, but failure to do so could provoke conflicting feelings (e.g., love and anger) and disruption. Indeed, spouses could suffer from not being able to do things together with their partners, and children could have problems in accepting the reversal of the role with their parents. There are also other characteristics influencing differences in caregiving experiences by kind of relationship. For example, spouses assisting their partners are usually older people themselves and have more time to dedicate to caring as being retired, but have also reduced capabilities due to the health problems derived by the ageing process. On the contrary, children assisting a parent/grandfather are younger, but also likely to be employed and having other family commitments [22].

MATERIALS AND METHODS

In this study, we used a qualitative methodology in order to gain a more comprehensive view of informal caregivers' experiences and thoughts [31] [32].

SAMPLE

Participants were selected if they were family caregivers providing unpaid care – at least four hours per week of support, excluding financial support or companionship [33] – to a family member (adult or older people) with a chronic illness, disability or other long-lasting health or care need. The selection of participants was made in order to assure a certain degree of variation in terms of characteristics and conditions, thus providing a comprehensive view of caregivers' role, while looking at common patterns. Moreover, the sample was designed to include and be equally distributed between spouses/partners or sons/sons-in-law, in order to have some insights of the experiences and needs characterising the two groups. All participants lived in the Marche region (Central Italy) and were recruited in the facilities of the Italian National Institute of Health and Science on Ageing (IRCCS INRCA).

We interviewed six caregivers, 3 spouses (females) with an age ranging from 56 to 80 years, and 3 daughters/grandchildren (1 male and 2 females) from 46 to 54 years (Tab. I). Participants were the primary caregivers and in 4 out of 6 cases lived together with the care recipients. Duration of caring ranged from 8 to 22 years for the spouses, and from 5 to 10 years for daughters/grandchildren. Spouses were retired, except one still working full-time but going into early retirement within a year, whereas daughters/grandchildren were working part-time or full-time. Spouses were heavily committed to caring activities (e.g. 24 hours a day), mainly in surveillance and assistance with instrumental activities (e.g., shopping, transport, food preparation, medication) and, but to a lower extent, in assistance with basic activities (e.g., dressing, hygiene, walking). Although their partners were severely dependent, spouses tried to do things together and maintain as much as possible their autonomy. Daughters/grandchildren provided mainly assistance with instrumental activities, and to some extent surveillance, with variation among caregivers due to the presence of other persons taking care of the relative.

Table I. Characteristics of caregivers and care recipients.

Code	Caregivers[a]	Care recipients[b]
1	Female, 80 years, **spouse**, living with her husband, 3 children, retired, caring by 8 years	Male, 84 years, Alzheimer's disease, severely dependent
2	Female, 72 years, **spouse**, living with her husband, 2 children, retired, caring by 22 years	Male, 77 years, Parkinson's disease, severely dependent
3	Female, 56 years, **spouse**, living with her husband and 2 children, working full-time, caring by 9 years	Male, 56 years, Alzheimer's disease, moderately dependent
4	Male, 46 years, **grandchild**, living with his partner, working full-time, caring by 5 years	Female, 97 years, multimorbidity, moderately dependent
5	Female, 51 years, **daughter**, living with her husband and 1 child, working part-time, caring by 5 years	Female, 80 years, Parkinson's disease, severely dependent
6	Female, 54 years, **daughter**, living with her mother, working full-time, caring by 10 years	Female, 84 years, Alzheimer's disease, moderately dependent

[a]Gender, age, relationship with the care recipient, household condition, number of children (if any), working status, duration of caring; [b]Gender, age, health condition, level of dependency

Care recipients were moderately or almost fully dependent, based upon the stage and progression of the diseases they suffered from.

DATA COLLECTION

Data were collected by semi-structured face-to-face qualitative interviews between November and December 2017. Prior to the interview, participants were informed about objectives of the study, criteria for inclusion and methods used. Moreover, it was clarified that the participation was voluntary, and that the information collected would have been treated as confidential. Before the beginning of the interview, it was asked permission to record the interview for subsequent analysis, and it was used ice-breaking conversation to put the caregiver at ease and create a relaxed atmosphere. The interview guide (Appendix 1) was composed of 6 sections: 1) basic socio-demographic information about caregiver and care recipient; 2) history of caring; 3) information about care and support; 4) care network; 5) challenges and rewards; 6) recognition and expectations. Topics and questions were derived from the review of the literature in the field [34-36]. The flexible structure of the interview gave the possibility to the participants to express their opinions and emotions, while letting the interviewer exercise some control over the topic studied. Interviews were carried out in a quiet room at IRCCS INRCA's premises, and lasted between 50 minutes and one hour.

DATA ANALYSIS

Due to the small sample size, data analysis was carried out manually. To this purpose, we used the Framework Analysis technique [31 37], consisting of five steps such as familiarization, identification of a thematic framework, indexing, charting, mapping, and interpretation. Interviews were transcribed verbatim, read and re-read in order to become familiar with them. Main themes were then derived considering transcriptions and sections of the interview guide. One grid was used to analyse data of each theme, where columns represented participants and rows the sub-themes, analysing the transcripts of all participants both within and between cases.

The most meaningful statements, representing the main themes and describing the stories of the caregivers, were highlighted and translated. Quotes are reported in the text including the code of the caregiver (Tab. I); if relevant, it is also specified the degree of kinship with the care recipient.

RESULTS

Interviews provided rich material to understand caregivers' experiences and thoughts. Five themes emerged from the analysis, and results are presented following this structure: 1) the diseases and the need of information; 2) the caregiver role; 3) the organization of care; 4) the impact of caring; 5) the recognition of the role. Within each theme, several sub-themes were identified, as shown in Table II.

THE DISEASES AND THE NEED OF INFORMATION

Caregivers' histories began with the onset of the disease affecting the care recipients, which influenced their decisions, behaviours and assumption of the caregiver's role. For some of them the path to the diagnosis was easier, while for others it included a long list of visits and tests. Nevertheless, almost all participants described these moments with meticulous details. Some caregivers highlighted the difficulties encountered, often

Table II. Themes and sub-themes emerging from the interviews.

Themes	Sub-themes
Diseases and the need of information	• Disease's beginning and progression • The moment of the diagnosis • Need of information • Sources of information • Problems encountered
Caregiver role	• Reasons to provide care • Acceptance of the disease • Acceptance of the role • Changes of responsibilities
Organization of care	• Care plan • Care network • Time off from caring • Caregivers' support (spiritual aspects) • Caregiver style/coping strategies
Impact of caring	• Feelings and emotions • Relationship with the care recipient • Reconciliation with family and work commitments • Social isolation • Vision of the future • Positive aspects of caring
Recognition of the role	• Satisfaction with care provided • Possible improvements • Recognition of the role

related to the concomitant presence of other diseases/conditions affecting the care recipients, due to the ageing process.

The moment of the diagnosis was recalled by almost all participants as a crucial date, since it became for some of them the moment when they started realizing their situation:

The diagnosis a year ago... recently she begins to misfire and for me it's a stab, I'm crying, I'm venting by myself... these are small things you have to expect [from Alzheimer's disease], but for me the biggest sorrow is to accept the disease (P6).

From that moment onwards, an increasing need of information emerged, which was firstly addressed by the physician, followed by the reading of books, word-of-mouth with friends and other family members, and in few cases by on-line search. Different participants participated to ad hoc training courses for caregivers, which they evaluated as a positive experience:

There (caregiver's courses) they are always very nice… a relief valve and you find similar or opposite situations, you understand what kind of problems occur and you can find answers to your problems (P5).

However, caregivers struggled to find the right information about local services and voluntary associations, as well as about administrative procedures to get benefits and support:

The absurd thing is that with a diagnosis of Alzheimer's there isn't any standardized protocol… you have to tell me what I have to do, it cannot be that I'm at my wit's end (P3);

I have had enough of bureaucracy, those very complicated things… for some things the doctor told me, because otherwise I wouldn't have known it! (P4).

No differences emerged between spouses and daughters/grandchildren respect to the above issues.

Caregiver role

Spouses and daughters/grandchildren reported different reasons to provide care. The first ones talked about choices of love, while the second ones often mentioned the necessity to do it, with the care recipient or other family members taking for granted this role:

When I got married, 50 years ago, I asked myself 'what will be of my life'… anyway I will accept it… 50 years have passed and we are still together… I could not imagine myself without him (P2, spouse);

It was a forced choice due to increasing needs linked to physical decline… but it is absolutely not for me [doing the caregiver], I don't have the time to spend on this thing and I don't like it, but for the sake of my grandmother I do this and more (P4, grandchildren);

I live with my mother and so I charged myself with burdens and honours of a life with a parent, it was automatic... she did so much for me when I needed it, so now it's my turn (P6, daughter).

A common issue was represented by the drastic changes in responsibilities inside the relationships, causing suffering and frustration in caregivers, and felt as something for which there are no alternatives and that should be managed in some way. Spouses were used to share with the partners duties and pleasures of life, while children were used to receive support and help from their parents. In the new situation, these traditional roles and division of responsibilities were completely reversed:

My mother has always been alone and independent, so for me it has become complicated because I had to take care of everything that she used to do previously and I'm not familiar with doing these things even for me (my husband thinks about it)... and so it happens that then certain things are missed (P5, daughter);

I don't have a husband like a husband anymore… a support… all the things he used to care for, I'm from an era in which the husband did some things and the wife others, so I had to re-invent myself with difficulty, but that's it (P1, spouse).

Acceptance of the disease/condition of the care recipients was mentioned by all caregivers as an important point in the process of assumption of the caregiver role, and those who were not able or did not yet achieved it were exposed to a deep suffering:

For me, to deal with the disease has been difficult and it's still difficult… it's a process of acceptance still in progress… for some things (which he makes) he irritates me, I don't remember that there's the disease… My father-in-law [which assists his wife, with Alzheimer, too] is an extraordinary caregiver and the comparison with him is terrible… he lives for his wife and I tell myself that I would not be able to do the same… I have another style… (P3).

Organization of care

Due to the level of dependence of care recipients, caring activities were quite demanding for almost all caregivers, independent of the kind of relationship with the care recipient. The tasks included personal care, management of therapies, assistance with mobility and transportation, emotional support, and administrative issues. Caregivers slowly became responsible for everything, and described a typical day with a well-organized and strict schedule of tasks to be carried out alone or with their loved ones. The main challenge for all interviewed was to maintain as long as possible the autonomy of the care recipients, keeping them busy with different activities and stimulating them continuously. This task, for which caregivers felt unprepared in some occasions, was described as quite heavy and requiring a lot of patience, self-control and physical efforts:

We go out every morning to do the ordinary things… I've become very patient, he comes out of the car many times, he puts up and remove the belt… very slow times… he has a good behaviour if you go along with it (P1).

Those not living with the care recipient (i.e. daughters and grandchildren) or working full-time had to rely on external supports – often not meeting the caregiver's expectations – or had to be managed in some other ways, both alternatives being partly unsatisfactory:

It's hard because I understand that she is there [the migrant care worker] 24 hours a day, I imagine it's heavy… but she's often on skype or on the phone, at most they're both watching television or do some exercises but she should do more (P5);

I work all the day so she stays all day alone… I ask her to do small things but then I don't know if she will do them… in the past I had a person who helped me but I had to renounce to it because I had not enough money to pay her (P6).

The general picture provided by the caregivers suggested a strong need to cope with an instable and unpredictable situation composed of good and bad days. For this reason, caregivers avoided any long-term plan and rather focused their attention on the present, preferring to deal with problems or difficulties as they come up. Hence, different coping strategies emerged, which were heavily influenced by the acceptance of the disease and were aimed to maintain a serene relationship with the care recipients. For example, an experienced caregiver implemented the following approach:

It changed my life totally but I took it with simplicity… my Leitmotiv is: 'if I were in his shoes how would I have liked to be treated?'… this gives me the energy, the strength to go on, it is a continuous restart every day (P1).

The majority of caregivers admitted to be completely alone in their duties. Those receiving little support were helped by other family members, while 'strangers' were chosen if there were no alternatives. Although some care recipients were receiving cash allowances, caregivers preferred not to ask for external help. This argument was reported especially by the spouses, which were reluctant to ask help to their children because they didn't want to be a burden on them:

My children are busy, I can't pretend… of course if I call them they come, but I try to do so as little as possible (P2, spouse).

On the contrary, daughters expressed the need for support, but showed difficulties to involve their siblings in the care, especially if they were male:

My brother is completely absent, I live with her and the burden is mine… today he went on holiday and he told me just now… this makes me feel bad... (P6, daughter).

The burden of care produced stressful situations in caregivers, especially those in more demanding and longer caring situations such as the spouses, which felt to be like "prisoners". On the one hand, they all mentioned the need for some respite care to do some 'normal' activities, whereas on the other hand, they reported difficulties to create these occasions because these moments have to be taken away from care, causing in some cases a sense of guilt. The majority of caregivers reported feelings of loneliness and isolation, due to few psychological supports, and very few occasions to talk with some friends or other family members. In some cases, older caregivers mentioned the importance of the spiritual dimension:

We are religious people and we put everything on that level, in the trust of God that somehow will sustain ourselves (P2).

Impact of caregiving

Caring activities affected all areas of life, from psychological conditions to the reconciliation of work and private life. Different feelings emerged during the interviews, like distress, frustration, depression, anger, mental strain, burn-out and anxiety:

Two days ago, he read for half an hour with the intonation, I was astonished, then I asked him what he had read and he replied to me 'but I didn't read'… and then the world really crashes out on you (P1);

It's devastating, it's hard… the heavy thing is not showing that every time something happens it's a small knife to the heart (P3).

Sense of helplessness also emerged, causing sorrow and anger, because caregivers had to observe health decline of their loved ones without being able to do anything to avoid it:

For me it's a pain to not be able to get her out of this thing… every time she tells me that there is nothing to make her feel better, as if I had not been searching for… it's quite frustrating (P5).

The impact on private life was devastating, especially for those providing care 24 hours a day. Some differences emerged between spouses and daughters/grandchildren. Difficulties in reconciliating caring tasks with everyday life commitments were reported by daughters, which sometimes experienced anger towards the situation:

I'm always angry, as my mother says. When I go there at the end of the day I am full of many things, probably I don't have the patience and time to dedicate to her as I would like… (P5, daughter).

For the spouses, health conditions of their partners prevented even the simplest activities normally done with them before the onset of the disease, causing a long list of renunciations:

I am so sorry to not be able to do things together like travel… There are so many things that we have not been doing since so much, and now I have understood that I will not be able to do them anymore, and this is terrible (P3, spouse);

I would like to go here, there… but it's complicated, you have to limit yourself, you have to renounce… how many times I say 'I would like to take a walk, it's too long that I don't take a walk', I really miss it (P2, spouse).

Despite these thoughts, some caregivers affirmed that they should not complain so much about their situation because there are always other persons in a worse situation compared to them.

As regards the impact on the other family members, this was particularly heavy in the case of young children living with the care recipient. In another case, a caregiver living with her mother confessed to have had no opportunity to create her own family because of her situation:

… the love life that I don't have but I don't want to… I feel alone in dealing with this situation but at the same time I wouldn't be able to manage my own life because it wasn't born… however now I don't have head for this (P6).

Social life as well was heavily affected by caring duties. Isolation and loneliness, accompanied by a sense of hopelessness, were the feelings most strongly expressed by the spouses, who have friends in common with their partners who now find difficult to interact with them given their conditions:

Loneliness is the biggest problem… we are alone, we had many friends but people, as they love you, do not hold up the situation, they feel embarrassed (P1, spouse).

On the contrary, daughters and grandchildren, especially those not living with their parents, seemed not to be affected by this problem, because they had the possibility of carving out some space to keep friendships despite caring activities.

Working caregivers with part-time or a flexible working time reported to have no major problems with their work duties, while those working full-time highlighted problems in reconciliate work and care.

The difficulties associated with the caregiver role, together with the fear of the disease progression, produced in the caregivers the impossibility to think about the future. This feeling was reported by both spouses and daughters/grandchildren, and some were reluctant to speak about it:

I live day by day because I know that tomorrow will not be so good… I don't even want to think about it because otherwise I got chills… yesterday it passed and it was good, today we live in the present, tomorrow we don't know what to expect… what shall we do? (P2).

Moreover, older caregivers expressed the additional worry to not be able to continue providing care to their spouses, in case of a worsening of their own health conditions:

… then because I'm fairly well, because if I will feel poorly then yes, these is a big problem! (P2).

Despite the difficulties encountered, some positive feelings appeared to the mind of spouses as a part of their love relationship, while daughters/grandchildren were not able to identify any issue:

Days ago, he [the husband] said he was confused and I was suffering for that… so I told him 'Do you know that today are 55 years we are married and we are still together?'… in that moment he took my hand and kissed my wedding ring (P1, spouse)

At night, when I close the windows and it's just us I say 'how wonderful it is' (P2, spouse).

Recognition of the caregiving role

Caregivers – both spouses and daughters/grandchildren – showed a moderate satisfaction with the care they were providing, mentioning the need to increase time for both caring and respite care, as well as to have someone with whom sharing the caring tasks. One caregiver highlighted the need to reduce and simplify the administrative procedures, in order to be able to have more time to enjoy the relationship with his relative.

The social recognition and acknowledgement of the caregiver role were poorly evaluated by all interviewed. Only in some cases other family members showed comprehension about the activities performed, while friends showed often to not be able to understand the situation:

Friends tell me 'I'd never do what you do (for your husband)' and I'm used to answer 'I hope you never need' (P1).

Caregivers felt to be invisible for both society and institutions, and made a desperate cry for help due to the inadequate support and lack of information they felt. Both spouses and daughters/grandchildren explained that society is not aware of what they have to manage every day:

One who is not living the situation does not understand it, in my opinion they do not see them [people with Alzheimer's disease] as being sick, as it is a common thing and therefore there are no problems (P6, daughter);

We are far behind, but not only for this issue… I don't hide my situation, on the contrary I tell my story to others but it does not generate so much feelings, people are admired but it ends up there (P1, spouse).

DISCUSSION

This study, thanks to its qualitative methodology, offers a unique opportunity to gain an in-depth original insight into the experiences, feelings and thoughts of Italian family caregivers. The collected material allowed a twofold analysis. Firstly, the themes emerged covered all main aspects caregivers have to deal with while caring for a family member and, while largely consistent with previous studies in the field, provided additional insights on the specific Italian situation and the existing contextual aspects. Secondly, the stories of the caregivers revealed different perspectives and difficulties between spouses and daughters/grandchildren.

Caregivers described in detail their stories and the circumstances that lead to the assumption of caregiver role. From that moment, they were responsible for a variety of activities and put efforts in maintaining the independence of their loved ones, through a constant level of assistance [23 25 36]. These tasks required specific competencies, not always owned and in some cases developed by means of training courses and self-help groups, which are proved to enhance sense of confidence of caregivers about their role and skills [35 38]. Moreover, management of the health conditions of the care recipients could be improved by the use of new technologies and e-health tools, especially in case of chronic conditions and multimorbidity [39 40]. However, these solutions are not widely used in Italy, a country which performs in this regard quite poorly compared with most European countries [11].

Consistent with other studies [15 17 24], care burden was reported as increasing as long as the health conditions of the family member were getting worse, producing psychological and physical distress, anxiety and depression, especially for caregivers of patients with Alzheimer's disease. These feelings were related not only to the demanding and mentally-exhausting nature of caring, but also to the close relationship with the family member, which often produced negative emotions like compassion and fear of loss [17 23]. As showed by Gilhooly et al. [38], a common coping strategy, emerged also in this study, was that caregivers tended to deal with a problem when it arose, increasing in this way their knowledge base for subsequent similar situations. As expected, acceptance of the disease played an important role [18 35 41] and followed a different path for each caregiver, based on their resilience and coping strategies adopted [23 36 38 42]. Some caregivers referred also to have found comfort in spirituality and religious beliefs, which are positively associated with well-being, and with a better relationship with the care recipients [42 43].

The need of information and the difficulties in find them emerged clearly from the interviews, producing a sense of isolation and frustration in caregivers. Information are usually sparse and scattered, difficult to find and not equally accessible to everyone [19 33 35 36]. This phenomenon is particularly relevant in Italy because of its fragmented organization of services, on the one hand, and the digital divide and low health literacy of older people, on the other hand, which could be reduced by improving the integration among different services [44].

As regards support received by others, our results showed, in line with other studies [19 25 35 44], that the majority of caregivers were women and were alone in this role, with a very limited support from family members or other persons. Moreover, although the severe level of dependence of the care recipients would require huge amount of care and support, only few were receiving cash allowances. In Italy cash benefits are accessible only to fully disabled people who are not able to perform autonomously any activities of daily living, and other kind of social and care services are accessible only to a small portion of people in need [9 11]. Hence, those not receiving any allowance have to provide themselves for care and support – with all the limits they have due to work or other family commitments – because in many cases their economic situation does not allow them to pay for an external help. As a consequence, occasions of respite care and comfort from friends and support groups, essential to perform some 'normal' or leisure activity or to contain stress [24 25 35 42], were also limited.

In general, caring for a loved person led to a radical change of life and a deviation from what had been considered 'normal' before the onset of the disease [16 24 45]. Caregivers complained that they were missing very simple activities, like going out for a walk, visiting friends, going to the cinema or on holiday. Moreover, care recipients and their spouses, due to their common social network, experienced a gradual and slow exclusion from society. Nevertheless, in an attempt to render the 'unmanageable situation manageable' [46], they tried sometimes to justify this behaviour as being a normal consequence of their situation, or saying that they knew people who were worse off. These themes are recurrent in literature, especially when co-residency caregivers are considered [18 20 26 29]. Many of these micro-level difficulties reverberate often in a wider circle of consequences at a both meso level (i.e. within the caregivers' social networks) and macro level (i.e. within the wider society), that have to be managed in addition to the specific support and care provided to the ill person, undermining the sustainability of the whole system.

Invisibility and lack of recognition of the role by institutions and society represented additional burdens for caregivers, who explained to feel abandoned and not understood by service providers and close people [25 47 48]. Older spouses appeared as the most vulnerable because they were affected also by their own health problems [17 19 24], which found difficult to manage, posing at risk the sustainability of their role and, as a consequence, of the quality of care granted to their loved ones.

The second objective of the study was to take into account kind of relationship between caregivers and care recipients in the analysis of the interviews. Spouses and children/grandchildren showed similarities in some aspects of their stories, such as the difficulties encountered in the first phases of the role assumption, the need of information, the burden of care activities, the expectations for the future and the recognition of their role by the society. However, also some differences emerged from the interviews. For example, they reported different reasons prompting family members to provide care. Older spouses were less likely to recognize themselves as caregivers, because they tended to see their role as a part of their marital commitment and *a choice of love* [48], whereas daughters/grandchildren explained to have started caring as an obligation or a necessity [15 26]. As a consequence, the former ones were less likely to ask for help, assuming the complete supervision role, often 24 hours a day, whereas the latter had to reconcile caring activities with their own work and family duties, looking for the support of others or being forced to reduce the number of worked hours [21-23]. Those in employment used to benefit from the paid leave to assist relatives in need, which in Italy foresees 3 days per month – for covering emergency situations or for small tasks (e.g., carrying the loved one to medical appointments) – and up to 24 months. In line with other studies, spouses appeared more affected by the caring tasks compared with children, due to the high level of responsibilities, the older age and the spousal relationship [17 20 29 48]. Notwithstanding, satisfaction for the care provided and moments of rewards were mentioned mainly by spouses [29], who tried to maintain as long as possible the love relationship with their partners and to do things together, even if their roles deeply changed [18 23]. These results are in line with those of Bull [42], who reported that, despite the burden produced by dementia, spouses were not able to imagine their life without their partners. On the contrary, daughters and grandchildren were more likely to suffer from this role, and often did not have the capacity to assist their loved ones in a successful way.

Finally, it should be underlined that, although the results obtained by this study are in line with previous research, confirming most of the evidence highlighted by the international literature also for the Italian context for the first time in such a detail, this investigation presents some limitations. Firstly, since it used a qualitative methodology, the small sample does not allow a generalization of the results to other contexts. Moreover, the recruitment of respondents was carried out by personal contacts and support groups, a strategy that does not permit to control for additional variables. Thirdly, it did not involve the perspective of service providers' representative who are daily in contact with informal caregivers, as their opinions might have contributed to better understand and contextualise the perspective of caregivers investigated here. Despite these limitations, we believe that our findings offer a useful, updated insight into the struggles and strengths of a core component of Italy's long-term care system.

CONCLUSIONS

The impact of caregiving is enormous and affects all aspects of one's life and society as a whole. When a person becomes a caregiver, he/she is at risk of high psychological distress and of social isolation, with heavy consequences also on the capacity to actively participate in the society. Our results confirm that caregivers are not a homogeneous group, with different needs and experiences that vary according to both caregiver's and care recipient's characteristics. Although these results cannot be generalized due to the small sample size, they provide important elements to be further explored as well as some suggestions for implementation in the clinical practice and for the planning of political and economic interventions. Hence, supporting caregivers in their tasks is a big societal challenge, requiring a holistic approach and specific tools. Moreover, as formal care is expensive and governments report increasing difficulties in providing adequate financing, supporting informal care could represent an essential strategy to save costs and delay institutionalization [22]. Despite the high number of studies in this field, some critical issues remain and should be regarded as priorities by policy makers and researchers. These include an urgent need to reorganize health and social services in order to provide caregivers with more effective counselling and guidance, complete and accessible information, as well as psychological support and respite care services. More systematic and improved interventions in these areas would contribute to alleviate the burden of care and, as a consequence, increase the quality of care provided to the care recipients. Policy makers should therefore consider to further develop specific programmes to better recognize the role of caregivers and reduce their still remarkable social invisibility. In particular, they should promote measures to help caregivers in better reconciliating caring activities with their private life and work in order to allow them to provide the best care for their family members, if they wish to do so, without having to stop being and feeling a member of the wider society. Although some steps in this direction have been already made by the Italian government, our findings clearly show that a lot still needs to be achieved in this country to set up a true partnership between citizens and institutions to protect the dignity of frail older people and of their family caregivers.

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CONFLICT OF INTEREST

The Authors declare to have no conflict of interest.

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Appendix. Interview guide

1) Basic socio-demographic information about caregiver and care recipient:
    a. Caregiver: gender; age; marital status; living arrangements; presence of children; working status (if retired, last work done); educational level; hobbies/interests;
    b. Care recipient: gender; age; relationship with the caregiver; living arrangements (if in different household); health conditions; level of dependency (severely dependent, moderately dependent, slightly dependent, independent).
2) History of caregiving:
    a. How and when did you start caring for your family member?
    b. What were the reasons?
    c. Now think about a typical day during which you provide assistance to your family member. Could you tell me about it? What activities do you do, how do these activities intertwine with your private life and your work? How many hours a week do you provide care to him/her? Do you provide care to other persons?
3) Information about care and support:
    a. Now let's talk about information on health of your loved one, how it should be managed, useful contacts etc. Where do you get this information and how?
    b. What are the main difficulties encountered, if any?
4) Care network:
    a. Now think about all the people who are involved with you in caring to your family member, considering both other family members and external people like doctors, health workers, associations, friends, etc. Who are these people? What activities do they do and how?
    b. Do you receive (or have recently requested and are awaiting a response) other external aids (e.g. economic) from social or health services, associations, other people outside the family? If yes, what are they?
    c. Is there someone who supports you to deal with this situation? If yes, who and how?
5) Challenges and rewards:
    a. How do you feel in the role of caregiver?
    b. Did you have or do you currently have difficulty in reconciling your care activities with your private life / work etc.? If so, which ones? How do you deal with them?
    c. Have you had or are you currently having difficulty managing your loved one's assistance activities? If so, which ones? How do you deal with them?
    d. Did you have or do you currently have difficulty managing relationships with other people involved in caregiving activities? If so, which ones? How do you deal with them?
    e. On the other hand, are there any positive aspect or things that make you satisfied? If yes, what are they?
6) Recognition and expectations:
    a. Are you satisfied with the assistance you provide to your loved one?
    b. Do you think your family understands your role and what you are doing for your family member?
    c. And your employer and colleagues?
    d. And society as a whole?
    e. Given all that we have said so far, could you tell me what would you change / add to improve your quality of life and the care you provide to your loved one?
    f. What are your wishes for the future?

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