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Caregiver's psychological well-being and quality of relationship with cardiac amyloidosis patients

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ABSTRACT

Caregivers' psychological well-being is linked to the quality of care provided for familiar with chronic illness. Despite caregivers of cardiac patients present an impaired psychological well-being, less investigated is the psychological well-being of caregivers of individuals with a rare disease such as the Transthyretin Cardiac Amyloidosis (ATTR-CA). Specifically, given that no study explored the well-being of the caregiver and the caregiver-patient relationship, this study aimed to analyze the prevalence of anxiety and depression in ATTR-CA caregivers and if these disorders were associated with patient's and caregiver's characteristics. Fifty-eight dyad caregiver-ATTR-CA patients completed the Hospital Anxiety and Depression Scale and the Network of Relationships Inventory. Moreover, ATTR-CA patients completed the Kansas City Cardiomyopathy Questionnaire, while caregivers completed the Multidimensional Scale of Social Support. Results showed that anxious caregivers (44%) reported higher conflict with patients. They had ATTR-CA relatives with a worse perception of cardiac symptoms and higher anxiety and depression. Depressed caregivers (39%) reported higher conflict with ATTR-CA relatives and lower perceived social support. Caregiver reported a high prevalence of anxiety and depression associated with worse personal relational well-being and to patient's psycho-physical condition. The care of ATTR-CA patient should consider the caregiver well-being.

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Introduction

Informal caregivers provide significant unpaid care to a family member or friend with a chronic illness or disability (Adelman et al., 2014). In Italy, about 7.3 millions of adults are estimated to be caregivers, and most of them is woman, aged between 55 and 64 (ISTAT, 2022). In general, literature has highlighted that the condition of caregiver is

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linked to an increase of psychological burden and distress (Garlo et al., 2010; Strawbridge et al., 1997). Despite this, in Italy the caregiver is still poorly supported from a social welfare point of view compared to other European Union countries, which provide specific protections for informal caregivers (Petrini et al., 2019).

The role of the caregiver has been studied in many chronic condition including heart failure (HF) and cardiomyopathies (Stromberg, 2013). Caregivers may support cardiac patients in several activities including maintaining self-care, supporting activities of daily living and providing psychosocial support (Buck et al., 2015; Clark et al., 2014) depending by the patient's symptoms and comorbidities.

Given the multiple roles and tasks, they handles at the same time (Dionne-Odom et al., 2017), it is not surprising that also caregiver of cardiac patients often report mental stress, anxious and depressive symptoms (Hooley et al., 2005; Hu et al., 2017; Stewart et al., 2018) related to the time and effort spent on the caregiving experience (Graven et al., 2020; Saunders, 2008). However, given that the well-being of the caregiver is one of the most important factors in keeping a patient out of a hospital (Bidwell et al., 2017; Girardi Paskulin et al., 2017; Hooley et al., 2005), understanding factors associated with increased anxiety and depression seem to be relevant in order to develop interventions aimed at improving the caregiver and patient experience (website Family Caregiver Alliance).

Most of the literature in this area, focusing on individual factors related to caregiver anxiety and depression showed that caregiver depressive symptoms have been related to cardiac patients' functioning. Specifically, depression in the caregiver correlates with aspects related to the patient's quality of life (Hooley et al., 2005), state of health and severity of disease in terms of hospitalizations and comorbidities (Hu et al., 2017). Moreover, longer caregiving enhanced the depressive symptoms (Grant et al., 2020).

Less investigated are the relationship between caregiver well-being (in terms of anxious and depressive symptoms) and social interactions in the context of heart failure and cardiomyopathies. On the contrary, this topic has been more investigated in other pathologies, such as cancer (García-Torres et al., 2020), Alzheimer's Disease (Hellis & Mukaetova-Ladinska, 2022) or Parkinson's disease (Yang et al., 2019) in which literature showed anxious and depressive symptoms in caregivers, especially related to the lack of social support.

One study showed that caregiver social isolation or a reduced perception of social support were related to higher level of depressive and anxious symptoms in caregiver of cardiac patients (Noonan et al., 2018). Moreover, the desire for more help reported by caregiver was positively associated with higher level of depressive and anxious symptoms (Burton et al., 2012; Graven et al., 2020; Saunders, 2008). These data suggest that the quality of social relationships may be highly protective in buffering the negative effects of the stresses (Hooker et al., 2015).

Yet, literature is currently very limited about the quality of the relationship between caregiver and patient in heart disease. On the other hand, also the nature of the caregiver-patient relationship may impact on the caregiver well-being (Drentea & Goldner, 2006). At this regard, Yeh and Bull (2012) showed that, when caregivers perceive a better quality of relationship with the patient, they also perceive a lower level of burden.

Despite the role of caregiver has been studied in different cardiomyopathies, the latter represents a heterogeneous group of diseases with different age of onset, natural history, inheritance and penetrance. Till now, few attention has been paid

in literature to the caregiver of patient affected by Transthyretin Cardiac Amyloidosis (ATTR-CA). ATTR-CA is a rare disease due to the abnormal folding of proteins that tend to form amyloid fibrils, which can accumulate in various tissues or organs, especially in the myocardium. There are two different forms of ATTR-CA: hereditary (ATTRv) and Wild Type (ATTRwt). The first condition (ATTRv) is genetic with an autosomic dominant inheritance, incomplete penetrance and derives from mutations on the gene coding for the TTR protein, while in ATTRwt, the amyloid deposit is linked to the aging of the non-mutated TTR protein (Perfetto et al., 2013). Generally, the patient with ATTRv amyloidosis experiences an involvement that can be mainly neurological, mainly cardiac or with a mixed phenotype, while patients with ATTRwt show an almost exclusively cardiac phenotype. Symptoms are often nonspecific and insidious, and this frequently leads to several medical contacts before reaching the correct diagnosis that is subsequently delayed. Despite the significant improvements, in the last decade, regarding non-invasive and more accurate diagnostic methods and the establishment of new therapies and disease management strategies, the path of the patient with amyloidosis remains difficult and frustrating for a large part of the population (Gertz & Dispenzieri, 2020).

Furthermore, amyloidosis is currently considered a rare disease meaning that the diagnosis process is still tortuous and long, the centers for diagnosis and management are few and are not always close to the patient's residence; this makes the management of this disease more complicated than other cardiac disease (Gertz & Dispenzieri, 2020) with a negative impact on patient's psychological (Smorti et al., 2023) and relational (Fumagalli et al., 2023) and physical well-being (Ponti et al., 2023).

Research on psychological aspects and impact of ATTR-CA is still at a very early stage. To our knowledge, few studies analyzed the anxious and depressive symptoms in the caregivers of patients with heart disease due to ATTR-CA (Rintell et al., 2021; Stewart et al., 2018). Moreover, no study explored the well-being of the caregiver and the caregiver-patient relationship.

The few studies available have been mainly conducted in ATTRv form and shows that amyloidosis is perceived as a very stressful condition for both patients and family members; patients and caregivers are often emotionally overwhelmed and, considering fears and anxiety perceived by the dyads, they mostly regard the inheritance of the disease, fear of developing symptoms in caregivers and of genetically transmit the disease to their children by patients (Rintell et al., 2021). Moreover, caregivers of patient with ATTR-CA report unfavorable perceptions, as well as mild-to-moderate levels of anxiety and depression (Stewart et al., 2018). Starting from these considerations, the aim of this study is to analyze the prevalence of anxiety and depression in the caregivers of patients with ATTR-CA and explore how these psychopathological aspects are linked to the physical and psychological characteristics of the patient and to sociodemographic and relational aspects of the caregiver. We hypothesize that greater levels of anxiety and depression in caregivers are linked to greater levels of anxiety and depression in patients, to a greater severity of cardiac symptoms, and finally to a lower one caregivers' perception of social support. Regarding the relationship between the caregiver's possible symptoms and the quality of the relationship with the patient, we do not formulate hypotheses given the absence of literature in the field.

Materials and methods

Participants and procedures

Patients and caregivers were recruited at the Regional Amyloidosis Centre in Tuscany, Italy, between January and August 2022 during a routine cardiologic assessment by a trained psychologist who administered the questionnaires in a private room at the end of routine cardiologic assessment, separately for patients and caregivers. The study was approved by the local Ethical Committee. Participation to the study was voluntary, and written informed consent was obtained from patients and caregivers during recruitment time. Inclusion criteria for patients were diagnosis of ATTR-CA according to standard international criteria (Garcia-Pavia et al., 2021), absence of cognitive impairment, able to understand Italian language, and the caregiver was the partner or child. Inclusion criteria for caregivers were to be the partner or child of the patient and be the person providing care to her/him, absence of cognitive impairment, and able to understand Italian language.

A total of 64 dyads of consecutive patients and caregivers were invited to participate. Of them, six patients (9.4%) refused for the lack of time to wait for the meeting with the psychologist trained for data collection. The rest of the invited dyads (90.6%) agreed to participate in the study. So, the final sample was composed by 58 patients aged between 62 and 90 years (83.1% males) and 58 caregivers aged between 32 and 84 years (86.4% females).

Measures

The following sociodemographic information were recorded for all patients and caregivers: age, gender, marital status, living condition, and employment status. Moreover, caregivers were asked what relationship they had with the patient. Finally, physician recorded the subsequent clinical data of patients: type of ATTR and months since diagnosis.

The Italian version of the Kansas City Cardiomyopathy Questionnaire (KCCQ) (Miani et al., 2003) was employed to assess the subjective perception of symptom severity in patients. The KCCQ is composed of 23 items and allows to measure the impact of HF symptoms. Example of items are ‘Please indicate how much you have been limited by HF in Showering/Bathing’; ‘Please indicate how your HF may have limited your participation in hobbies, recreational activities’. The KCCQ has demonstrated its validity and reliability in numerous etiologies of heart failure (Spertus et al., 2020). The total score ranges from 0 to 100, with higher scores meaning better health perception. In the present sample, KCCQ Cronbach’s alpha was 0.93.

The Italian version of the Hospital Anxiety and Depression Scale (HADS) (Iani et al., 2014) was used to assess the level of anxious and depressive symptoms both in patients and caregivers. The HADS is composed by 14 items (7 assessing anxiety and 7 assessing depression) asking to range the frequency of feelings in the past week on a 4-point Likert scale from 0 to 3. Example of item assessing anxiety is ‘I feel tense or ‘wound up’ ‘and example of item assessing depression is ‘I have lost interest in my appearance’. Higher scores on the subscales mean higher levels of psychological symptomatology. HADS scores 8–10 indicate mild; 11–14 moderate; 15–21 severe symptomatology. HADS

demonstrated significant internal consistency and concurrent validity in various populations (Brennan et al., 2010). In the present sample, the Cronbach's alpha was 0.89 and 0.87 for the anxiety and depression subscales, respectively.

The Italian version of the Network of Relationships Inventory (NRI; Guarnieri & Tani, 2011) was used to assess the quality of relationship that caregivers reported towards patients. The NRI is composed by 36 items asking how much a relationship quality occurred with patient. Responses are given on a 5-point Likert scale that allows to measure both positive and negative interactions within close relationships. The positive interactions, named 'Social Support', include aspects such as the level of satisfaction, companionship, instrumental aid, intimacy, nurturance, affection, admiration, and support. Example of items is 'How much free time do you spend with this person?' or 'How much do you turn to this person for support with personal problems?'. The negative interactions, named 'Conflict', includes aspects such as the perceived level of punishment, conflict, antagonism, and dominance. Example of conflict item is 'How much do you and this person get upset with or mad at each other?'. Higher scores on these dimensions mean higher levels of qualities. NRI demonstrated significant internal consistency with Alpha ranged from .78 and .83 (Tani & Smorti, 2013). For the present study, the Cronbach's alphas were .91 and .80 for Social support and Conflict, respectively.

Finally, the Italian version of the Multidimensional Scale of Social Support (MSPSS; Di Fabio & Busoni, 2008) was used to assess the amount of social support that caregiver perceives from three sources: friends, family and significant other/special person. MSPSS is composed of 12 items on a 7-point Likert scale, with higher the score, the greater the amount of perceived social support. Example of item is 'I can talk of my problems with my family'. The Italian validation of MSPSS in the healthcare settings showed good reliability and validity in reference to chronic diseases and satisfying internal consistency (De Maria et al., 2018). The Cronbach's alphas for the present sample were .96, .89, and .93 for friends, family and significant other/special person respectively.

Data analysis

All data were analyzed using SPSS version 23.0 (IBM, Armonk, NY, U.S.A.), and $p < .05$ was considered significant. The HADS cut-off points of 8 (Zigmond & Snaith, 1983) were used to assess the prevalence of anxiety and depression and identify caregivers with a clinical level of psychopathological symptomatology. In order to compare caregivers with clinical level of anxiety and depression and caregiver without clinically relevant psychopathological symptoms a series of student's t-test and chi-square analysis were performed, depending on the continuous or dichotomous nature of variables.

Results

Characteristics of patients and caregivers

Patients aged 62–90 years ($M = 78.92$; $SD = 6.63$); 49 of them (83.1%) were males; 47 (79.7%) were married, 1 (1.7%) divorced, 2 (3.4%) unmarried celibate, and 9 (5.3%) widowers; 9 (15.3%) lived alone, 41 (69.5%) lived with spouses/partners and 9 (15.3%) with spouses/partners and children; 56 (94.9%) were retired, 2 (3.4%) were employed, 1

(1.7%) housewife. Moreover, 55 (88.1%) had ATTRwt and the months since diagnosis range from 6 to 72 ($M = 27.12$; $SD = 16.68$).

Caregivers aged 32 to 84 ($M = 64.68$; $SD = 12.83$); 51 of them (86.4%) were females; 50 (84.7%) were married, 5 (8.5%) divorced, 4 (6.8%) unmarried celibates; 39 (66.1%) lived with spouses/partners and 20 (33.9%) with spouses/partners and children; 22 (37.3%) were employed, 6 (10.2%) housewife, 31 (52.5%) were retired; 34 (57.6%) were partner and 25 (42.4%) were daughters/sons. Of the 58 caregivers, 26 (44.1%) presented significant levels of anxiety and 23 (39%) of depression.

Characteristics linked to anxious caregivers

Caregivers with clinical levels of anxiety symptoms did not differ from other caregivers on their sociodemographic characteristics: age, gender, marital status, living condition, employment status, and relationship type with the patient. Moreover, referring to the quality of relationship with patients, no significant differences by group emerged on the level of NRI Social support; however, a significant difference was found for NRI Conflict where caregivers with higher levels of anxiety reported higher levels of conflict in their relationship with the patients ($p < .05$). Referring to the level of perceived social support, results showed no significant difference by group on the level of social support perceived from friends, family, and significant other/special person.

Finally, caregivers with and without anxious symptomatology did not differ on the subsequent characteristics of patients: age, gender, type of ATTR, and months since diagnosis. However, significant differences were found on KCCQ and HADS scores. In particular, caregivers with clinical level of anxiety have relative with ATTR with a worse perception of symptom severity ($p < .05$) and higher levels of anxiety ($p < .001$) and depression ($p < .01$). All these results are reported in [Table 1](#).

Characteristics linked to depressive caregivers

Similar to anxious symptoms, caregivers with and without clinical levels of depressive symptoms did not differ on their sociodemographic characteristics: age, gender, marital status, living condition, employment status, and relationship type with the patient. Moreover, the two groups did not differ on the NRI social support, but they differed on NRI Conflict ($p < .01$). In particular, caregivers with higher levels of depression reported higher levels of negative interaction in their relationship with the patients than caregivers without significant depressive symptomatology did. Referring to the level of perceived social support, results showed that the two groups were not different on social support from family or significant other/special person, but caregivers with significant depressive symptomatology perceived a lower social support from friends ($p < .05$).

Moreover, caregivers with and without depressive symptomatology did not differ referring to the subsequent characteristics of patients: age, gender, type of ATTR, and months since diagnosis, patients' perception of symptom severity and the levels of anxiety, and depression. All these results are reported in [Table 2](#).

Table 1. Descriptive statistics of socio-demographic, clinical and psychosocial characteristics by anxious groups, and analysis results.

	Anxious caregivers (n = 26)	Not anxious caregivers (n = 33)	χ^2 (df)	t(57)	p
Age in years, mean (SD)	63.73 (13.10)	65.42 (12.75)		.50	.619
Gender, n (%)			$\chi^2(1) = .132$.716
Females	22 (84.6)	29 (87.9)			
Males	4 (15.4)	4 (12.1)			
Marital status, n (%)			$\chi^2(2) = .091$.956
Married	22 (84.6)	28 (84.8)			
Unmarried	2 (7.7)	3 (9.1)			
Widower	2 (7.7)	2 (6.1)			
Living condition n (%)			$\chi^2(1) = .203$.652
Lives with partner	18 (69.2)	21 (63.6)			
Lives with partner and children	8 (30.8)	12 (36.4)			
Employment status, n (%)			$\chi^2(2) = .313$.855
Employed	10 (38.5)	12 (36.4)			
Housewife	2 (7.7)	4 (12.1)			
Retired	14 (53.8)	17 (51.5)			
Type of relationship, n (%)			$\chi^2(1) = .272$.602
Partner	12 (46.2)	13 (39.4)			
Son/daughter	14 (53.8)	20 (60.6)			
NRI_social support	3.96 (.60)	4.15 (.52)		1.37	.177
NRI_conflict	2.48 (.84)	2.05 (.55)		-2.36	.022
MSPSS_friends	4.31 (1.72)	4.93 (1.27)		1.60	.115
MSPSS_family	5.26 (1.33)	5.73 (1.05)		1.53	.131
MSPSS_other/special person	5.43 (1.36)	5.99 (.91)		1.89	.064
Patient's age in years, mean (SD)	79.23 (7.61)	78.67 (5.86)		-3.22	.749
Patient's gender, n (%)			$\chi^2(1) = 1.24$.265
Males	20 (76.9)	29 (87.9)			
Females	6 (23.1)	4 (12.1)			
Type of ATTR			$\chi^2(1) = .774$.379
WT n (%)	24 (92.3)	28 (84.8)			
Variant n (%)	2 (7.7)	5 (15.2)			
Months since diagnosis, mean (SD)	30.19 (16.83)	24.70 (16.41)		-1.26	.212
KCCQ score of patients	54.83 (21.98)	66.42 (15.40)		2.38	.021
HADS_depression score of patients	9.58 (5.08)	5.73 (4.49)		-3.09	.003
HADS_anxiety score of patients	8.88 (5.15)	5.03 (3.56)		-3.40	.001

Note: NRI: Network of Relationships Inventory; MSPSS: Multidimensional Scale of Social Support; KCCQ: Kansas City Cardiomyopathy Questionnaire; and HADS: Hospital Anxiety and Depression Scale.

Discussion

Caregivers of relatives with chronic illnesses are at risk to develop a relevant psychological burden linked to their caregiving activities (Reinhard et al., 2008) but few studies were available about the caregivers of patients with ATTR-CA. This study investigated if the presence of clinical levels of anxiety and depression in caregivers was associated with different sociodemographic, clinical, psychological and relational characteristics related both to caregivers themselves and their ATTR-CA relatives.

In line with previous studies on other chronic illness (Rintell et al., 2021; Stewart et al., 2018), our results showed that the profile of ATTR-CA patients' caregivers mostly correspond with a woman, in her 60s married, daughter or wife of the patient. ATTR-CA caregivers reported high level of anxiety (44%) and depression (39%) similarly to caregivers of patients with other cardiomyopathies (Hooley et al., 2005; Hu et al., 2017; Stewart et al., 2018).

However, the presence of these psychopathological symptoms does not seem to be linked to the socio-demographic characteristics of the caregivers, such as age, gender, marital status, living condition, employment status or the relationship type in terms of

Table 2. Descriptive statistics of socio-demographic, clinical and psychosocial characteristics by depressive groups, and analysis results.

	Depressive caregivers (n = 26)	Not depressive caregivers (n = 33)	χ^2 (df)	t(57)	p
Age in years, mean (SD)	66.17 (13.22)	63.72 (12.66)		-.71	.479
Gender, n (%)			χ^2 (1) = .472		.492
Females	19 (82.6)	32 (88.9)			
Males	4 (17.4)	4 (11.1)			
Marital status, n (%)			χ^2 (2) = .227		.893
Married	19 (82.6)	31 (86.1)			
Unmarried	2 (8.7)	2 (5.6)			
Divorced	2 (8.7)	3 (8.3)			
Living condition n (%)			χ^2 (1) = 1.03		.311
Lives with partner	17 (73.9)	22 (61.1)			
Lives with partner and children	6 (26.1)	14 (38.9)			
Employment status, n (%)			χ^2 (2) = 1.05		.591
Employed	7 (30.4)	15 (41.7)			
Housewife	2 (8.7)	4 (11.1)			
Retired	14 (60.9)	17 (47.2)			
Type of relationship, n (%)			χ^2 (1) = .162		.687
Partner	14 (60.9)	20 (55.6)			
Son/daughter	9 (39.1)	16 (44.4)			
NRI_social support	3.95 (.60)	4.14 (.50)		2.23	.024
NRI_conflict	2.55 (.96)	2.04 (.54)		1.72	.091
MSPSS_friends	4.11 (1.71)	5.01 (1.23)		1.37	.175
MSPSS_family	5.20 (1.39)	5.74 (1.02)		.002	.998
MSPSS_other/special person	5.49 (1.43)	5.91 (.93)			
Patient's age in years, mean (SD)	78.91 (8.13)	78.92 (5.60)			
Patient's gender, n (%)			χ^2 (1) = .408		.523
Males	20 (87)	29 (80.6)			
Females	3 (13)	7 (19.4)			
Type of ATTR			χ^2 (1) = .362		.547
WT n (%)	21 (91.3)	31 (86.1)			
Variant n (%)	2 (8.7)	5 (13.9)			
Months since diagnosis, mean (SD)	31.17 (17.35)	24.53 (15.94)		-1.51	.137
KCCQ score of patients	58.19 (22.97)	63.31 (16.60)		.994	.325
HADS_depression score of patients	8.96 (5.05)	6.44 (4.95)		-1.89	.064
HADS_anxiety score of patients	8.09 (5.26)	5.86 (4.16)		-1.81	.076

Note: NRI: Network of Relationships Inventory; MSPSS: Multidimensional Scale of Social Support; KCCQ: Kansas City Cardiomyopathy Questionnaire; and HADS: Hospital Anxiety and Depression Scale.

being partner or child of the patient. Despite this, it is interesting to note that more than 80% of the caregivers in the present sample are women. This is a fact that agrees with what emerges from the literature on heart disease (Stromberg, 2013). Furthermore, it emerges that female caregivers reported more psychiatric symptoms than male caregivers. Comparisons with no caregiving community samples suggest that female caregivers experience excess psychiatric morbidity attributable to caregiving (Yee & Schulz, 2000). It would be interesting to delve deeper into this aspect in the Italian context, investigating the relationship between gender differences and symptomatology, given that the literature on the matter is still limited.

No significant differences emerged even in relation to the duration of the disease (in terms of time since diagnosis). This data may seem difficultly interpretable, based on the literature on caregiver well-being in other cardiomyopathies (Grant et al., 2020). However, ATTR-CA has often nonspecific symptoms, and its diagnosis is sometimes delayed. It is therefore possible that the physical condition of the patient may play a predominant role compared to the mere disease duration.

In fact, anxious caregivers, compared to non-anxious ones, have relatives with a worse perception of cardiac symptoms severity and higher levels of anxiety and depression. These data suggest that a more severe psychological and medical condition of the patient is linked to the likelihood that caregiver suffer of clinical anxiety. So, it is possible to affirm that the caregiver's anxiety is linked both to the patient's physical and psychological health.

Referring to depressive caregivers, these aspects seemed not relevant. Caregiver depression was instead linked to a lower perceived social support, especially from friends.

Finally, this study also explored the relationship between caregiver-patient and if the relationship quality is associated with the caregivers' well-being. In this regard, anxious and depressive caregivers reported a more conflictual relationship with the patient than caregivers without psychopathological symptoms. Given the cross-sectional design of the study, it is difficult to understand the direction of these results. It is possible that a more conflictual relationship with own ATTR-CA relatives increases the level of anxiety and depression of the caregivers; otherwise it is possible that the presence of anxious and depressive symptoms could lead caregivers to perceive their relationship as more conflictual.

Overall, these results highlighted how anxiety and depression reported by caregivers are associated with different aspects. Caregivers' anxious symptomatology is linked to the well-being of relatives patients: having own family member with a worse disease and psychological condition could therefore be associated with greater concerns which results in higher levels of anxiety. On the other hand, caregiver depressive symptoms appear more linked to a lack of social support external to the family. A sense of social isolation and low support has already been highlighted as a risk factor for the well-being of caregivers of cardiac patients (Noonan et al., 2018).

Despite the interest of these results, the study has a number of limitations. Firstly, the sample is small, and this could hinder the correct identification of the presence of psychological symptoms in caregivers. Moreover, this is a monocentric study, and this could run into biases of the reference center. Finally, both patient and caregiver groups are heterogeneous on some aspect, such as gender or type of ATTR-CA, and this could make the results obtained less reliable. However, although these limitations and the need to expand the results with larger samples, the present study has important clinical and social implications. The healthcare personnel should pay attention to the well-being of caregivers, especially their own levels of anxiety and depression. Healthcare personnel are made up of those people who more than each other are in contact with the patients' families, and who have the tools necessary to provide help and assistance: for example, they can guarantee adequate information with respect to the disease, its management and prognosis, or even being able to intercept the possible manifestations of malaise in such a way as to be able to guide the person, if necessary, in the direction of a path of help from a psychological point of view. The identification of the aspects most associated with forms of psychological distress among caregivers could make it possible to prevent or reduce their discomfort, with positive repercussions on the care and management of patients.

It also seems important to act in this direction also from a social welfare point of view: often the attention and interest of the individual doctor or healthcare professional can be useful, but not sufficient to limit the caregiver's psychological distress. In addition to training to learn or strengthen the skills of informal caregivers, some States provide specific projects for psychological support, such as Australia, Denmark, Latvia and Norway (Petrini et al., 2019). On the contrary, there are still no specific

directives regarding the implementation of psychological support projects in Italy. In light of what emerged in this research work, it could be useful to implement welfare policies aimed at improving these aspects.

As regards future lines of research, it could be useful to investigate the relationship from a longitudinal point of view. For example, it could be interesting to investigate the symptomatic evolution of the caregivers in relation to the development of the patient's pathology. Furthermore, it could be useful to further investigate the influence of the quality of the relationship on the well-being of the members of the dyad.

Conclusion

In conclusion, ATTR-CA caregivers reported relevant psychopathological diseases. In particular, an anxious symptomatology seems linked to a worse clinical and psychological condition of the relatives, while a depressive symptomatology seems to be linked to the quality of caregivers' social network. Moreover, anxious and depressed caregivers perceived a more conflictual relationship with their ATTR-CA relatives. Considering all these results, in the management and care of patients with ATTR-CA, physicians should pay attention to the well-being of caregivers, especially to their levels of anxiety and depression. Attenuation of caregivers' psychological distress could be very important in the care of the ATTR-CA patient and on their relational well-being.

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