# Social capital in chronic disease: an ethnographic study

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#### **Abstract**

Chronically ill conditions are particularly difficult to manage because of their impact both on the social and on the corporal sphere that negatively alter the quality of life. Chronicity has also a considerable effect on social capital. Chronic Venous Disease (CVD) includes several pathological alterations of the venous system of the lower limbs. The aim of this study is to explore the dynamics of social capital within people's experience of CVD and describe the roles of family and friends and the health care system. The method used based on face-to-face semistructured interviews, following Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist. Sixteen patients were included: eleven women and five men. The results show a certain difficulty in terms of daily activities, pain management; work problems; non-coverage of healthcare costs for medications and drugs prescribed. Moreover, the bonding social capital of the patients interviewed was more positively perceived in the role of CVD management than by the patients' families. The total absence of knowledge of patient associations with CVD was also detected. Thus, alongside the biographical destruction that CVD entails, there is evidence of the scarce relevance and presence of health policies that cause several related issues.

**Keywords:** social capital; chronic venous disease; chronicity; qualitative study; ethnographic study; biographical disruption.<sup>††</sup>

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# 1. Introduction

Chronically ill conditions are particularly difficult to manage (Verbrugge et al.1989) because they impact both the social and corporal sphere (Swain 2000) to such an extent as to involve a series of problems that negatively alter the quality of life of patients suffering from chronic disease (Cocksedge et al. 2014, Theeke et al. 2013), in terms of higher health costs, reduction of primary and secondary networks, as well as pain, difficulty in carrying out daily activities and negative feelings such as anxiety, despair, frustration, etc. (Gerontoukou et al. 2015).

Furthermore, chronic disease is an important and costly social problem. The burden is most marked at the community level with significant rates of chronicity (Cravey et al. 2001). Thus, 'Chronic disease requires long-term and comprehensive management by affected individuals, their families and support networks, and the healthcare system providing services to those individuals' (Cravey et al., 2001:1763). Thus, chronicity has a considerable effect on social capital.

In the current literature, it is known that social capital may contribute to a range of advantages on people's health. In this regard, 'different types of social capital are relevant to different economic and social outcomes, e.g., bonding social capital is most important to health in early childhood and frail old age, whereas bridging social capital is most important in adult life when looking for employment' (Aldridge at al. 2002:5).

From a methodological point of view, social capital is a complex topic that can be studied both with qualitative and quantitative approaches. While strongly advocating for integrated research methods, this article focuses specifically on a qualitative approach (Dudwick et al. 2006). For these reasons, we used a qualitative approach because 'Qualitative research thus has great potential to illuminate some of the ongoing debates regarding the definition, utility, applicability, and impact of social capital in relation to public health' (Kawachi et al. 2008:96).

Several chronic diseases have been analyzed from a sociological point of view, such as diabetes (Cravey et al. 2001), obesity (Kim et al. 2006), drug addiction (Jonas et al. 2012), etc. While there are still no research articles on chronic venous disease despite the fact that it is a pathology that affects a very large number of subjects worldwide with disabling symptoms.

# 2. Chronicity and sociology

With a sociological approach, a chronic disease is considered a biographical disruption (Bury 1982). In particular, "chronic illness it is an experience in which, as Bury suggests, the structures of everyday life, it's taken for granted features, and the tacit stocks of knowledge upon which they rest are profoundly disrupted.

Chronic illness, that is to say, `involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others. It

is in this sense that Bury conceptualizes chronic illness as a major kind of disruptive experience, or, in Giddens's term, a critical situation" (Williams, 2000: 43).

According to Bury (1982), there are three dimensions of biographical destruction typical of chronic diseases: 1) the loss of daily attitudes and actions so much that in this phase the attention is directed to the bodily aspects of the disease, from which the need for help arises; in particular 'Bury suggests, involves attention to bodily states not usually brought into consciousness, and decisions about seeking help.

Chronic pain and suffering, effects a transition from our normal phenomenological modes of bodily `disappearance'. a body which `passes us by in silence' in Sartre's terms a state of corporeal `dysappearance' (i.e. a dysfunctional appearance). Pain, in this sense, becomes a form of `bodily alienation' or `betrayal' (Williams 1996b, Bendelow and Williams 1995) which, whilst physical and emotional through and through, may nonetheless be depicted as the experience of `psychophysical dualism' (Vrancken 1989)' (Williams 2000:43); 2) in the second dimension, people affected by a chronic disease, thinking about it, begin to become aware of the change in their biography by asking themselves questions such as 'why me?, why now? nature: questions which, given the `clinical reduction' of modern medicine and the absence of any overarching explanatory or metaphysical frame of reference, prove hard to answer.

It is here, as we shall see below, that work concerning the narrative reconstruction of illness and the symbolic attempt to repair ruptures between the body, self and society, has provided new insights into the meaning and experience of chronic illness' (Williams 2000:43); 3) in the third dimension, practical actions are implemented with respect to the chronic condition, therefore resources are used, one acts on the social and natural environment in which the subject is inserted, so this phase 'suggests that meaning and context cannot be easily separated' (Bury 1991: 543).

Thus, Bury (1982) also underlines another aspect, namely, that according to chronic disease biographical destruction acts negatively on the social relations of individuals, i.e., it involves a considerable reduction of social capital.

# 3. Social capital and health

A significant relationship has been found between social capital and health in the sociological literature, and not only. In fact, a high level of social capital is associated with health and a better response to disease (Moore and Kawachi 2017, Villalonga-Olives and Kawachi 2015), while a low level of social capital tends to aggravate the state of health (Villalonga-Olive and Kawachi 2017).

There are various definitions of social capital, but for the purposes of this paper, the 'social capital consists of networks, norms, relationships, values, and informal sanctions that shape the quantity and cooperative quality of a society's social interactions' (Aldridge et al. 2002: 5).

Briefly, Pierre Bourdieu and Robert Putnam are the two best known theorists in the area of social capital. For Bourdieu (1986), social capital can be traced back to the

individual sphere 'that is an aggregate of an individual's actual or potential ability to accumulate and access scarce social advantages and resources. He posited that individual biography (e.g. education) and networks (e.g., friends in high places) combined to give holders a credential which entitles them to credit in various senses of the word' (Kawachi et al. 2008:95). According to Putnam, however, social capital consists of a set of 'features of social organizations, such as networks, norms, and trust that facilitate action and cooperation for mutual benefit' (Putnam, 1993: 95). Thus, 'Putnam's "communitarian" approach has some overlap and some discrepancies with Bourdieu's "network" approach. Both see benefit in group membership and activity' (Kawachi et al., 2008:97). Bourdieu attributes positive elements to social capital related to the size and impact that social networks have on an individual. The opposite is Putnam's position, which attributes centrality to civic and associative involvement. Furthermore, Putnam supports the beneficial impact of social capital also from a geographical point of view and therefore spreadable among nearby localities. Conversely, Bourdieu ascribes benefits to social capital spreading from individuals to their family contexts.

In particular, for Banfield (1958), the family is generally defined as a form of bonding social capital, i.e., social capital that hinders the diffusion of knowledge and the socialization of trust (Gittel and Vidal 1998), and is associated with lower levels of development (Putnam 1994). Studies on what we could call "family social capital" aim, above all, to evaluate the impact of family ties on the accumulation of human capital and on the well-being of young people. The best-known contribution is that of Coleman (1988), who measures the strength of family ties through the ratio between the number of parents and that of children.

In the case of bridging capital, Putnam (1994) identified good neighborly relationships as a factor in the accumulation of social capital, as opposed to the habit of bowling alone, considered a sign of the deterioration of the relational dimension of individuals' lives.

Sociology recognizes the role of "bridges" in the weak ties between friends and acquaintances, which favor the circulation of information and the diffusion of trust between different socio-economic environments, which otherwise would never enter into contact (Granovetter 1973,1985).

Alongside these dimensions, the density of voluntary organizations is used as the main indicator of a community's social capital. The basic hypothesis, advanced by Putnam (1994) in the study of the Italian regions, is that associations can function as schools of democracy, whose activity favors the diffusion of rules of trust and reciprocity in the surrounding social environment; thus, members of voluntary organizations show greater civic sense and higher levels of political participation (Almond and Verba 1963, Brehm and Rahn 1997, Hooghe 2003).

Another element of social capital is trust. According to one of the most famous definitions, social capital is made up of a set of characteristics of the social structure – networks, rules, and trust – which favor collective action and the pursuit of shared objectives (Putnam 1995).

From a methodological point of view, social capital has been studied both with quantitative approaches, and therefore using surveys, and with qualitative approaches. The latter, according to the current literature 'Qualitative research, can explore and elucidate the relative influence of individual networks, access to resources, collective norms, and individual/ ecological trust on diverse aspects of health and well-being. Through its bottom-up epistemological orientation, qualitative research can explore social processes and mechanisms that are health-enhancing (or health-damaging) without being beholden to a particular paradigm of social capital' (Kawachi et al. 2008:97).

## 4. Chronic venous disease: an overview

Chronic Venous Disease (CVD) includes several pathological alterations of the venous system of the lower limbs that cause a wide range of symptoms and signs, ranging from mild clinical manifestations such as telangiectasia (small, widened blood vessels on the skin), reticular veins (visible veins below the skin that appear blue-purple in color, without bulging out), and varicose veins (VV) (swollen and enlarged veins bulging or twisted in appearance) to more severe forms such as skin changes and chronic venous leg ulcers (CVLUs) (wounds on the skin due to CVD). CVD has a prevalence with a prevalence of up to 57% and 77% in men and women, respectively, in the adult general population, considering the presence of any of the aforementioned clinical signs (Serra et al. 2016).

In particular, CVD clinical manifestations are described in the clinical, etiological, anatomical, and pathophysiological (CEAP) classification, which defines the following clinical classes (Fig. 1), C0 includes no visible or palpable signs of venous disease; C1 includes teleangectasia and reticular veins; C2 includes trunk VV of variable origin; C2r includes recurrent varicose veins; C3 includes lower limbs edema; C4a includes pigmentation or eczema; C4b includes lipodermatosclerosis or atrophie blanche; C4c includes corona phlebectatica; C5 includes healed ulcer; C6 includes active ulcer; C6r includes recurrent active ulcer (Costa et al., 2023) Moreover, each clinical class may be subcharacterized by a subscript indicating the presence (symptomatic, s) or absence (asymptomatic, a) of symptoms attributable to venous disease, such as leg heaviness, achy or tired legs, cramping, restless legs. (Serra et al. a, 2015; Serra et al. b, 2016; Lurie et al., 2020).

The most severe form of CVD is defined Chronic Venous Insufficiency (CVI) and corresponds to C3-C6 class of CEAP (Serra et al. , 2015; Serra et al. b, 2016). CVD may affect all types of working people, and in particular health professionals. In fact, considering the functional level, 42% of patients reported that CVLUs interfered significantly with work activity. Moreover, among working adults, 10.4% missed days of work as a result of CVD-related symptoms. For example, in the United States (US), this amounts to 2 million work-days missed each year. Furthermore, due to miss work hours and medical disability, patients with CVD are further burdened with high expenses related

to drugs, elastic stockings, and medications related to CVD treatment (Costa et al., 2023; Kim et al., 2021).

US and European countries have also reported that CVI accounts for 1% to 2% of health care spending with an annual expenditure of \$1 billion and £400 million in the United Kingdom and US, respectively (Kim et al., 2021).



Figure 1. Clinical classes of CEAP classification

Thus, the evidence therefore suggests that social capital is an integral part in the health and disease of individuals, but there are not many studies in this regard concerning CVD, so more research is needed to explore which components of social capital are more important and how they act, to understand what social capital is for patients suffering from CVD. The objectives of this study intend to explore, with a qualitative approach, the dynamics of social capital within people's experience of CVD, and describe the roles of family and friends and the health care system.

# 5. Materials and methods

Study design

A qualitative study based on face-to-face semistructured interviews was performed, following the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Additional file 1) (O'Brien et al., 2014). The study was approved by the Institutional Review Board of the Interuniversity Center of Phlebolymphology (CIFL)

International Research and Educational Program in Clinical and Experimental Biotechnology (ER.ALL.2018.54A.) and all patients gave written informed consent.

#### Study participants

The study participants were adults ( $\geq$  18 years) who were clinically diagnosed CVD ( $\geq$  6 months). They should not have any other important comorbidities such as cardiac problems, arterial problems, malignancy, autoimmune diseases, and hematological diseases. To understand how chronicity impacts social capital, subjects from all CEAP classes (0-6) were included.

#### Recruitment of participants

Purposive sampling was used to obtain a wide variety of patients' characteristics and hence to ensure a broad range of experiences and thoughts. This technique is widely used in qualitative research in order to identify information-rich cases (Patton 2002).

Consecutive patients with CVD were referred to the Vascular Surgery Units of two hospitals (Mater Domini University Hospital of Catanzaro and the Federico II University Hospital of Naples).

Patients were invited to participate in the study by the physician of the vascular unit with the sociologist of medicine, who explained the aims and implications of the study and obtained written informed consent.

Demographic information and medical history were collected. In particular, the vascular surgeons involved had the task of classifying the patients according to the CEAP classification.

Recruitment continued until data saturation, thus, when no new information or additional perspectives were observed in the data when adding more participants (Guest et al. 2006) was achieved, which was checked after each interview.

#### Data collection

Data disclosure was accomplished through semistructured face-to-face interviews. After the literature study, an interview guide (Table 1) with open-ended questions was created in advance and evaluated by researchers experienced in applying qualitative approaches.

The duration of each interview was approximately 100 min and was conducted by the principal researcher (DC), who had specific training on interview techniques. The interviews occurred at the vascular surgery clinic of the Magna Graecia University of Catanzaro and the Federico II University of Naples. The interviews were audio-recorded and transcribed verbatim.

Six interviews were conducted online due to the COVID-19 pandemic. All interviews were conducted in Italian and occurred between January 2019 and December 2022.

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Topics	Main questions
Living with CVD	Can you tell me something about your
	chronic condition?
	How do you experience your chronic
	condition?
	What does your condition mean to you?
	How does your condition affect your life?
	What has changed in your life since your
	diagnosis?
	Does this illness involve many healthcare and
	treatment costs?
Bonding social capital	How many people are in your family?
	How far away are the homes of some
	members of his family?
	Since you were diagnosed with the disease,
	what has been the frequency of contact with
	your family members on any type of
	occasion?
	Are you satisfied with your relationship with
	your family in relation to the disease?
	In the event of economic difficulties and not
	only related to your illness, did your family
	members help you?
Bridging social capital	Since you were diagnosed with the disease,
	what has been the frequency of contact with
	your friends for any type of occasion?
	Are you satisfied with your relationship with
	your friends in relation to the disease?  In the event of economic difficulties and not
	only related to your illness, did your friends
	help you?
Associationism	Are you a member of any association for
Associationism	patients with CVD?
	Are you a member of other types of
	associations?
Trust	Do you trust institutions in general?
2,000	Do you trust institutions that can help you
	manage your illness?
	Do you trust the health institution or the
	National Health Service?
	Do you trust vascular surgery specialists?
	Do you trust only physicians or also other
	health professionals (pharmacists, nurses,
	etc.)?
L	1 /

Table 1 Interview guide used for semistructured interviews with CVD patients

#### Data analysis

The data analysis process was performed using NVivo software version 12 (Bazeley and Jackson 2013). The approach used was constant and a comparative method was used between and within interviews with an orientation aimed at identifying, analyzing, and interpreting models by means of data coding with an inductive approach (Glaser 1965). The transcripts were open-coded by the principal researcher (DC).

After analyzing each interview, the various codes were compared in such a way as to structure categories and subcategories with an iterative and inductive approach. The findings were noted as major themes and represent the starting point for understanding the disease experience of CVD patients.

Through meetings on a regular basis (every week), the principal researcher (DC) and four experts with different backgrounds and experiences (MA, NI, UMB, RS) argued codes, concepts, relationships of them, and about the preliminary results, with the ultimate aim of achieving investigator triangulation, i.e. the technique that involves the presence of two or more scholars involved in the same research activity, in order to make various considerations, evaluations and conclusions(Craig et al. 2021).

## 7. Results

Sixteen patients were included: 11 women and 5 men. The middle age was 50.1 years (range 33-84 years). In Table 2, there are summarized socio-demographic data and the synthetic characteristics of the participants' disease status. Five majors' themes emerged from the analysis: living with CVD, the role of the family in CVD, friendship and CVD, the relationship with associations, and the relationship of trust with the health care system (Table 3). The findings are presented with some excerpts from the interviews.

Partecipant number	Age	Sex	Gender	Relationship status	Number of family	Education	Employment status	CEAP
					members			
P1	58	Male	Man	Single	1	Low	Employed	C <sub>3</sub>
P2	49	Female	Woman	Married	3	Low	Unemployed	$C_2$
P3	39	Female	Woman	Single	1	Medium	Employed	$C_2$
P4	76	Male	Man	Married	4	Low	Retired	C <sub>4</sub>
P5	47	Male	Man	Divorced	1	High	Employed	$C_2$
P6	46	Female	Woman	Married	2	Medium	Unemployed	$C_2$
P7	42	Female	Woman	Married	3	Medium	Unemployed	$C_2$
P8	71	Female	Woman	Single	1	Low	Retired	$C_3$
P9	56	Female	Woman	Married	4	Low	Employed	$C_2$
P10	37	Female	Woman	Divorced	3	High	Unemployed	$C_1$
P11	84	Female	Woman	Single	1	Low	Retired	$C_6$
P12	78	Female	Woman	Married	3	Low	Retired	$C_5$
P13	44	Male	Man	Divorced	4	Medium	Unemployed	C <sub>1</sub>
P14	42	Female	Woman	Married	4	Medium	Unemployed	$C_1$
P15	33	Female	Woman	Single	1	High	Unemployed	C <sub>0s</sub>
P16	81	Male	Man	Married	6	Low	Retired	$C_6$

Table 2 Socio-demographic data and CEAP classification of the participants.

Theme	Subtheme
1.Living with CVD	1a): Personal life in relation to CVD
	1b): CVD difficulties and high cost
2.The role of the family in CVD	2a) The family and its presence in life in general
	2b) The role of family members since CVD was
	diagnosed
	2C) Satisfaction and family relations
3.Friendship and CVD	3a) Friends and their Presence
	3b) The power of friendship since the diagnosis of
	CVD
4.Relationship with associations	4a) Doubts and uncertainty associations
5. The relationship of trust with the health care system	5a) The experience of CVD and the role of the national
·	health system
	5b) CVD and health professionals

Table 3. Main themes and subthemes identified.

#### 7.1 Living with CVD

#### 7.1.1 Personal life in relation with CVD

All patients with CVD described a difficult quality of life for many causes.

My life is very complicated. This disease is little known, but it limits all my activities, from the daily ones to the more particular ones (P1).

In particular, above all classes of patients from C2 to C6, describe limitations, and many problems, psychological and physical.

Pain, heaviness, cramps often torment me to the point that I am very worried about my health. This is because daily living activities such as housework or personal care are particularly limited. In this way I am frequently nervous and anxious because I don't feel able to live life fully. I don't like the sense of dependence on others very much(P6).

The complicated life with CVD is about the perception and impact of appearance.

I have a lot of concern about my appearance because I am afraid of arousing feelings of disgust and embarrassment (P2).

Appearance turns out to be important for both men and women with a negative impact on interaction with others.

I can't wear shorts or skirts because I'm afraid that others will feel the same disgust as I feel at these tangles of veins (P7).

For some time now, if I go walking in the summer, I choose times when there aren't a few people around to be able to wear shorts or I avoid going out because in the heat I wouldn't feel comfortable in long trousers (P5).

Another theme in this regard has emerged, namely, how much CVD causes difficulties at the working level.

In terms of work, this disease is very annoying. I'm a worker so I have to stand for many hours, and this causes me to feel pain to the point that I'm often distracted and not always efficient. Moreover, because of the checks and visits, I have to ask for days off from work. This affects my work and psychological serenity (P1).

Being a promoter, I spend many hours on my feet, and not only do I have physical discomfort, but I also have difficulty wearing a uniform with a skirt, due to the varicose veins being visible or due to the use of therapeutic stockings if they are unsightly. I often think I want to change jobs because of these issues(P3).

#### 7.1.2 CVD between difficulties and high costs

A common element that characterized all patients concerned the costs of both preventive and therapeutic treatments, regardless of whether they were employed or not.

When preventive stockings were prescribed to me, I didn't imagine they had a high cost, as happens with other diseases, it would be ideal to have a form of exemption, even if partial (P15).

Even if it doesn't seem like it, CVD is a disease that comes with many costs: the prescribed drugs or supplements are totally at our expense. I also suffer from diabetes, yet metformin is paid for by the state. Something should be done about it (P10).

Costly are above all, for the patients interviewed, are advanced wound care therapies.

Because of my ulcers, I have to buy expensive dressings which are not provided by the health system. This leads me to have to make sacrifices, depriving myself of other basic necessities (P4).

For advanced medications, my sons have to call a home a nurse, living in a place that is difficult to reach, the cost of this service is particularly heavy for me. If a form of exemption were foreseen, I would certainly have less expenses to bear and less inconvenience caused to my sons (P16).

#### 7.2 The role of the family in CVD

The bridging the social capital of the interviewed patients is relatively relevant in life in general but particularly lacking in regard to CVD.

#### 7.2.1 The family and its presence in life in general

Patients interviewed about the presence of their families in their lives, in general, showed a certain homogeneity in their response to hematological diseases, which indicates a relatively stable presence.

My family members are present to the extent of their possibilities. Between the rush and the various commitments, it is not easy to always have them with me, but they try to make sure that I am never alone(P12).

On the physical proximity of family members, a certain variety was found as some patients spoke of family members who live either nearby or even in the same house, others, instead, have their family members very distant, even if a form of advantageous presence mediated by telephones and social networks is underlined.

*Luckily, I see my family everyday living in the same neighborhood*(P9).

My family members live in another country, and unfortunately, I see them very little. Luck is the cell phones that allow me to hear them every day. So even if they are not physically present, they are virtually(P4).

#### 7.2.2 The role of family members since CVD was diagnosed

Regarding the role of family members in CVD, there is evidence of a generic underestimation of the disease on their part, to the point of making patients frustrated and with negative feelings towards their family members.

When I complain about my concern for the presence of varicose veins, my children tell me "Mom, I searched the internet, it's not an aneurysm!" (P11).

I don't feel very understood by my husband. He often tells me I'm exaggerating, making comparisons with other diseases that he says are more serious. This makes me suffer a lot because I'm not an imaginary patient. In fact, I feel comforted when I find blogs on the internet with people describing the same symptoms as me... Well in that case I feel less alone and heartened (P6).

I don't feel understood at all, this leads me to argue very often with my family. They consider me exaggerated and too anxious. It's actually the physical pain associated with misunderstandings that make me even more nervous and frustrated (P9).

Another problem with the role of the family in relation to the disease, encountered above all by elderly subjects, concerned the limited availability of time, which led patients to delay either the first visit or postpone check-ups for a long time.

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I don't want to be too critical, but my children don't have much time for me because they work all day. So much so that today I had a check-up two months later than when it was prescribed for me. At a certain age you become a burden....(P12).

My son don't have much time, moreover the waiting lists are very long and this means that the dates that are provided often do not coincide with my children's free days, and this has caused the fact that only today, after I don't know plus how long, she managed to come to the hospital for the visit. It will seem strange, but the more children you have, the less chance there is that any of them will be available. In fact, I often go with a neighbor who is always available (P16).

#### 7.2.3 Satisfaction and family relations

The patients interviewed, in general, demonstrated sufficient satisfaction with family relationships but little satisfaction in relation to the relationship with these and CVD.

Well, in general I am satisfied with my family, but I would like to be, as already said, more understood because I am seriously ill(P13).

#### 7.3 Friendship and CVD

The bonding social capital of the patients interviewed was particularly interesting, synthetically, it would seem much more positively perceived in the role of CVD management than by the patients' families.

#### 7.3.1 Friends and their presence

The patients interviewed not only showed good satisfaction with friendship in general, but also a certain relevance and much higher presence than family members.

My friends are always there on social media, and especially in my daily life. Without offending any of my family members, I can certainly say that my friends are much more present and helpful! For example? During the lockdown it was they, being my neighbors, who took care of me, and I can't forget this! (P12)

In my daily life I am everything! They are not only friends, but also my family. If I have a problem, even the most trivial, they come and help me. They are my guardian angels(P15).

#### 7.3.2 The power of friendship since the diagnosis of CVD

Regarding the role of friends in patients' management of CVD, they are considered a real source of physical and moral support for some patients.

In the beginning, when I was diagnosed with CVD, I was worried, so much so that I didn't even go to the beach for fear that my friends might stare at me with concern or

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disgust. Instead, right from the start, not only did they support me, but they began to document themselves so that they could always be operational in case something should happen (P5).

My neighbours are often the ones who accompany me for check-ups, being more available than my children, making it easier for them to have to leave work for a day (P12).

This way, friends become real substitutes for family members, also as regards the economic needs related to CVD.

My health problems started right around the time I lost my job. If I hadn't had my best friend, who paid for my meds. If I didn't have her, I would be lost. (P10).

My friends give me a big hand with CVD, especially for the various visits, paying me, I say it without shame, the petrol for the trip since I don't work, and my family members live outside the region (P14).

#### 7.4 The relationship with associations

#### 7.4.1 Doubts and uncertainties about associations

On the issue of involving patients in associations of various types and in particular in associations of patients with CVD, the response was unequivocal: they are not involved in any activity nor are they aware of associations other than patients with CVD. All this is regardless of the age of the interviewees, however, the importance of the collective involvement of other subjects with the same pathology is recognized by all patients.

I do not belong to any association, nor am I aware of any CVD patient associations. I know of other types but never heard of my disease. It wouldn't hurt if there was, and I'd like to be involved. It could make a difference to be able to carry on our testimony of chronically ill people(P2).

I know of no association of any kind. I would like it if there were, maybe I could find comfort with other people my age with the same problems(P16).

#### 7.5 The relationship of trust with the health care system

The results with respect to the perception of trust and protection on the part of the health system appear particular.

#### 7.5.1 The experience of CVD and the role of the national health system

The patients described a series of difficulties with respect to the national healthcare system, which concern lengthy reservations, the cost of treatment, the difficulty of reaching hospital facilities, because they are very distant from their homes, and therefore a significant lack of infrastructure emerges. Thus, the sense of distrust in health care institutions, quite homogeneously, is very high.

I'm not referring to vascular surgeons or nurses, but I don't have much faith in the hospital from an administrative point of view. To book the first visit, after the onset of symptoms, it took me 2 months! (P10).

I live in a small mountain village in Calabria, at my age reaching the hospital was not easy, I was forced to take the car despite the pain, because there are not enough bus connections, which can coincide with the timetable of visits. I am discouraged towards Italy in general! (P4).

The fact that everything concerning the treatment of this disease is totally the responsibility of the patient is inconceivable! From elastic stockings on various drugs, there is not a single treatment that can be even partially paid for by the state. It's as if CVD weren't a disease on our health services! I am very disheartened! (P1).

#### 7.5.2 CVD and health professionals

The relationship with health professionals is particularly interesting, because the analysis revealed a great deal of trust in vascular surgeons, general practitioners, pharmacists, nurses, etc.

My relationship with the vascular surgeon who is following me is exceptional! It is available at any time. I have the possibility to contact him by phone without any kind of obstacle. I feel reassured and followed! He explained my condition in detail, what the risks are, the complications and above all he invited me not to contact "Doctor Google", due to the wrong information I had learned on the internet and exposed to the surgeon (P10).

All health professionals are important, but the vascular surgeon who treats me is the figure I trust the most. My general practitioner provided me with non-specific information on the onset of symptoms, as did the pharmacist I had contacted to get a natural supplement (P14).

Everyone is good to me from the home nurse to the vascular surgeon. They treat me sweetly; I've become their granny...(P11).

## 8. Discussion

This study examined the relation of social capital and a chronic disease such as CVD. First of all, regarding the quality of life of patients with CVD, the results obtained are completely in line with the current literature which shows a certain difficulty in terms of daily activities, pain management and work-related difficulties (Davies, 2019; De Maeseneer et al., 2022; Costa, 2023).

Our study showed that social capital was associated with CVD and the problems related to it. Particularly, the bonding social capital of the patients interviewed was more positively perceived in the role of CVD management than by the patients' families. This is an interesting result because the family has always been considered an important tool for protecting the health and managing the disease of its members (Foster et al., 2007; Rosland and Piette, 2010; Leaviss et al., 2020). In our study, however, social capital bonding is most helpful in managing CVD, probably due to the fact that family members are engaged and often far more distant than friends of CVD patients (Labropoulos et al., 2009). Thus, the bonding social capital could be further studied and analyzed with respect to its role on health and disease.

Overall, the findings highlight the value of emotional support in CVD. Thus, family, and in the specific case of this study, friends and neighbours not only provide the emotional support necessary to cope with the disease on a social and psychological level, but also provide material support (Martínez, and Rodríguez-Brito, 2020) such as: medicine, taking the patient to specialist visits, giving financial support for the payment of visits or medicines.

Another interesting result concerns the role of patient associations. From the responses provided, none of the patients knew of a specific association with CVD. In this regard, it must be emphasized that in Italy the most important patient association is the AMA-Vas(Associazione contro le malattie vascolari) (Association against Vascular Diseases) (http://www.amavas.it/15-home/12-benvenuti-in-amavas.html)in which searching the word CVD on the site, no results are found, this means that to date CVD has not had the right attention from the patients themselves. At the same time, the fact that there is no form of protection association for people with CVD means that one of the main factors of social capital is missing, being the "community school" associations in which feelings of trust and reciprocity towards the social environment in which one is inserted (Putnam, 1995; Leonardi et al., 2001).

A relevant issue concerns the relationship between CVD and work activity: on the one hand, it appears particularly limited due to the symptoms that this disease entails; and because it causes loss of working days and above all, as already mentioned, it affects the economic dimension of the patients (Allegra, 2003; Kim et al., 2021).

The results obtained reveal a major problem for patients with CVD, i.e., the non-coverage of healthcare costs for medications and drugs prescribed for the treatment of this disease. To date, in fact, in Italy, unlike what happens for pathologies such as diabetes, heart attack, etc., the national health system does not provide any type of support for the purchase of drugs or devices such as elastic stockings, which, they have a high cost(Allegra, 2003). This is an essential aspect since, being a chronic disease, there is no possibility of resolution, therefore, these patients must resort to pharmacological and containment treatment throughout their lives. The high costs, in fact, have a high negative effect on access to CVD diagnosis and treatment services, as patients unable to bear the costs of the treatments prefer to avoid being examined (Allegra, 2003).

There are limitations to this study. The results obtained cannot be generalized to the entire Italian population since a qualitative approach was used.

The questions included may not be exhaustive, but for reasons of time and the average cultural level of the patients included, they have been deemed the most appropriate to the context.

Although the sample cannot be taken into consideration as representative, the selection of the interviewees considered the heterogeneity and diversity of the socio-economic, cultural, and geospatial aspects of the participants in order to improve the learning possibilities and the reliability of the results. In this regard, the coding procedure used allowed the incorporation of emerging nuances and interpretations, which contributed to the consistency of the results. Despite these limitations, the qualitative approach used in our research, it may be appropriate in different contexts.

### 9. Conclusions

Living with a chronic disease such as CVD means having many social and relational needs and requirements, which is why social capital, especially represented by the support of friendship networks, has proved to be much more effective and fundamental in this disease.

Thus, alongside the biographical destruction that CVD entails, there is the scarce relevance and presence of health policies capable of improving the quality of life of these people not only from a social and medical point of view but also from an economic point of view.

Future research should expand on these aspects and try to provide suggestions for providers (Costa et al. 2023).

## **Author contributions**

Conceptualization, D.C. and R.S.; methodology, D.C.; validation, D.C., M.A., N.I., U.M.B., and R.S.; formal analysis, D.C., and R.S.; investigation, D.C., M.A., N.I., U.M.B., and R.S.; data curation, D.C., M.A., N.I., U.M.B., and R.S.; writing—original draft preparation, D.C., M.A., N.I., U.M.B., and R.S.; writing—review and editing, D.C. and R.S; visualization, D.C., M.A., N.I., U.M.B., and R.S.; software, D.C.; supervision, R.S.; All authors have read and agreed to the published version of the manuscript.

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