Family assistants' living and working conditions and their interaction with patient and family caregiver variables: a study protocol

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Abstract. Background and aim: The progressive and constant aging of the global population together with the economy crises and the social variations within family contexts increasingly leads to the use of external resources (Home Care Workers, HCWs) for health care within one's own family of origin. Purpose of the study is to describe Italian Home Care Workers' (HCWs) living and working conditions and understand the interactions with outcomes of the patients and informal caregiver. *Methods:* Observational study with cross sectional design to evaluate the interaction of HCWs without specific training on patients and informal caregivers' outcomes. *Results:* understand Italian HCWs' condition and interaction between these conditions and outcomes of patients and informal caregiver. *Conclusions*: understanding how HCWs' conditions can affect outcome about patient and informal caregivers, represents a fundamental step in order to increase QoL of these families. (www.actabiomedica.it)

Key words: Family Assistant, Home Care Workers, QoL, dyadic outcomes, living condition, working condition

Background

Increased life expectancy and a decline in fertility rates are leading to progressive and constant ageing of the global population (1). Population ageing is associated with an increase in chronic degenerative diseases and disabilities (2), representing a challenge for health systems (3). It has been demonstrated that, given the exponential growth in healthcare spending, hospital admissions are reserved only for acute diseases (2). Therefore, community care, that not provided in hospitals but at the patient's home, is increasingly becoming the usual context of assistance and care for patients suffering from chronic-degenerative diseases and/or disabilities, especially in elderly population (4). In this context, within the family, an important role is provided by family assistants, who are also called "homecare workers" (HCWs). HCW is a non-health provider who, for a fee, takes the role of a formal caregiver, providing direct and basic assistance to the person. For example, the HCWs helps patient in their daily life activities – from washing to dressing, from preparing meals to feeding and from cleaning the house to helping the elderly person take medications. In some cases, the HCWs provides only keep company (5, 6).

As described by literature, the support of HCWs has positive impact on outcomes for both patients and families in different population, such as people with addiction (7), with physical and mental disabilities (5) and even without chronic pathologies (8). In addition,

HCWs, living in close contact with the patient, have the opportunity to observe and evaluate the symptoms' changes, to reduce the burden of informal caregivers (9-12), and to reduce a possible access to community services (13). However, becoming a HCW can be a burdensome experience in many cases (14). For example, high workload has been shown to be negatively associated with multiple health measurements (15), such as lower job satisfaction (16), worse mental wellbeing (17), worse job strain (18), higher depression (5), distress and fatigue, and physical symptoms (19). Several studies (18, 20) showed that HCWs reported a high level of on-the-job stress caring for ill, dying, aggressive, or disoriented clients, and prioritizing patients' emotional needs and happiness above their own.

However, although several studies have analysed the interaction between informal caregivers (such as family, friend or other significant) and patients, only few studies have described the interaction between HCWs and patients and families. This represents a gap, as patients are often assisted more by the HCWs rather than by the family member and this could lead to a form of interdependence. The interdependence in the patient and family dyad has been well documented in the literature (21, 22), while it appears to be a little known element in HCWs, which could establish a role of interdependence both with the patient and their family member. HCWs are an important resource that, if properly trained, could significantly improve the living conditions of elderly people and provide valuable support to their families. Understanding the main characteristics of HCW population and knowing their living and working conditions would allow us to highlight who it invisibly affects the well-being of elderly people and their family.

The study

Aims

The aim of this study is to describe the HCWs' living and working conditions within the southern and to assess the interaction between HCWs' living and working conditions and patients' and family caregiver outcomes.

Design

An observational design will be used for this study.

Sampling

A convenience sample through snowball technique of HCWs, patients and informal family caregivers living in southern Italy will be recruited. HCWs inclusion criteria are: 1) being a HCW for at least 6 months; 2) currently providing care to an elderly person with or without chronic disease; 3) understands the spoken and written Italian language; 4) consents to take part in the study. Patient inclusion criteria are: 1) elderly person with a chronic illness or over 70 years of age; 2) assisted by a HCW. Patient will be excluded if: 1) under the age of 70; 2) refuse to participate in the study; 3) their HCW refuse to participate in the study. Informal family caregiver inclusion criteria are: 1) family member or unpaid person who takes care of patient; 2) to be recognized by the patient as an informal caregiver; 3) consents to take part in the study. Informal family caregiver will be excluded if: 1) refuse to participate in the study; 2) their HCWs refuse to participate to the study.

Sample size

As this is a pilot study, we cannot pre-determine the sample size. We believe that a sample of 50 HCWs, 50 patients and 50 informal family caregivers is sufficient to have preliminary knowledge from the variables studied on which relationship hypotheses will be tested in future studies with a more accurate determination of sample size.

Data collection and settings

After we have explained to the HCWs, the patients and the informal family caregivers the purpose of the study and reassured potential participants about the confidentiality of the data, we will proceed with the signed informed consent. The data collection tools will then be administered, and the semi-structured interviews (only for the HCWs), which will be entirely audio-recorded, will be conducted. During the interview, the participants' privacy will be ensured.

Data collection

The following instruments will be used for HCWs (table 1), patients and informal family caregivers:

A socio-demographic questionnaire created ad hoc will be administered to collect HCWs', patients' and informal caregivers' data, such as age, gender, marital status, employment, education, income, living condition.

Short form-12 (SF-12) (23) will be administered to measure the quality of life. The SF-12 is a self-reported outcome measure assessing the impact of health on an individual's everyday life. It is often used as a quality of life measure. The SF-12 is a shortened version of its predecessor, the SF-36, which itself evolved from the Medical Outcomes Study. The SF-12 uses the same eight domains as the SF-36: (1) limitation in physical activities because of health problems; (2) Limitations in social activities because of physical and emotional problems; (3) limitations in usual role activities because of physical health problems; (4) bodily pain; (5) general mental health; (6) limitations in usual role activities because of emotional problems; (7) vitality; (8) general health perceptions. SF-12 has been tested in a range of disease populations, showing a good validity and reliability. This instrument will be administered to both HCWs, patients and informal family caregiver.

Patient Health Questionnaire-9 (PHQ-9) (24) is a tool for making criteria-based diagnoses of depressive and other mental disorders commonly encountered in primary care. It is a self-administered version of the PRIME-MD (Primary Care Evaluation of Mental Disorders) which it is used screening, diagnosing, monitoring and measuring the severity of depression symptoms using modified Diagnostic and Statistical Manual fourth edition criteria (DSM-IV) . The total scores categorized as follows: depression minimal/ no depression (0-4), mild depression (5-9), moderate depression (10-14), moderately severe (15-19) or severe depression (20-27). The internal reliability of the PHQ-9 was excellent, with a Cronbach's of 0.89 (24) and it was used in Italian population (25). This instrument will be administered to both HCWs, patients and informal family caregiver.

Caregiver Burden Inventory (CBI) (26) assesses

the caregiver's burden. It is a self-report tool, it consists of 24 items, which use a 5-point Likert scale from "Not at all" to "Very" for the answers. It is divided into 5 sections such as objective load, psychological load, physical load, social load and emotional load. Higher scores indicate a greater burden. Novak & Guest (26) reported Cronbach's alphas for subscales ranging from 0.76–0.96. The CBI has been also used on Italian caregivers (22, 27) and the psychometric characteristic was evaluated about Italian population (28). This instrument will be administered to both HCWs and informal family caregiver.

Caregiver Preparedness Scale (CPS) (29) measures the caregiver's preparation in coping with caregiving. The areas investigated concern preparation in physical assistance, emotional support, the ability to find support services and cope with the stress of caregiving. It consists of 8 items that use a 5-point Likert scale from 'not at all prepared' to 'very well prepared'. In addition, there is also an open question in which the caregiver is asked to identify further areas in which the caregiver would like to be prepared. The possible score ranges from 0 to 40: a high score means greater preparation of the caregiver in caregiving. In its initial validation, it presented reliability values of 0.86 . Subsequently, different versions of the scale were tested, which also demonstrated optimal internal consistency values of 0.90, 0.94 and 0.88 also it was tested in Italian population (30, 31). This instrument will be administered to both HCWs and informal family caregiver.

Positive Aspect of Caregiving (PAC) (32) 9-item PAC scale, consisting of 2-factors (Self Affirmation; six items); (Outlook on Life; three items) and an overall PAC score. This scale was developed by a PAC 11 item scale (33) to evaluate the positive aspects of caregiving. PAC 9-item scale scored on a 5-point Likert scale: disagree a lot (1), disagree a little (2), neither agree nor disagree (3), agree a little (4), and agree a lot (5). The overall PAC score, comprising all nine items, ranges from 9 to 45, a higher score reflects a more positive perception of the caregiving experience. The PAC scale showed acceptable content and constructs high validity (34). This scale was used in Italian population (35). This instrument will be administered to both HCWs and informal family caregiver.

	INDIVIDUAL MEASURES			
Operationalized as:	Measured by	HCW	Р	FC
Sociodemographic	socio-demographic questionnaire	Х	Х	Х
Living condition	socio-demographic questionnaire	Х	Х	Х
Work condition	socio-demographic questionnaire	Х		Х
Economic condition	socio-demographic questionnaire	Х	Х	
Quality of Life	SF-12	Х	Х	Х
Depression	PHQ-9	Х	Х	Х
Caregiver's Burden	Caregiver Burden Inventory	Х		Х
Preparedness to Caregiving	Caregiver Preparedness Scale	Х		Х
Positive Aspects of Caregiving	Positive Aspect of Caregiving	Х		Х
Daily Living Activities	Barthel Index		Х	
Lived Experience	semi-structured interviews	Х		
CW: Home Care Worker; P: Patient; FO	C: Family Caregiver			

Barthel Index (BI) (36), to evaluate the functionality in the execution of daily living activities. It is a 10-item that investigate of 10 common activities of daily living (ADL): "feeding", "bathing", "grooming", "dressing", "bowel" and "bladder control", "bathroom use", "Transfers (from bed to chair and back) "," mobility "and" climbing stairs ". Items are rated based on patients' ability to perform activities independently, assisted or totally dependent (10, 5, or 0, respectively, or 15 to 0 for transfers and mobility). The score ranges from 0 (worst mobility in activities of daily living) to 100 (full mobility in activities of daily living), where higher scores indicate greater independence. It used about a standard routine evaluation (27, 37). The BI score can be assessed orally by inquiring the patient or a family member (38). This instrument will be administered to both HCWs and informal family caregiver

The data will be collected with an ad hoc questionnaire and semi-structured audio-recorded interviews. The questionnaire will investigate the following areas: socio-demographic information, general perception of the work of family carers and specific characteristics of this work and perception of preparation to be an HCW. The interview will focus on the following topics: the lived experience of being an HCW, perception of one's role, negative experiences of being an HCW, positive experiences of being an FA and perceived preparation to be an HCW. Fully understanding what it means to be HCWs will help us to identify further aspects to be analysed in order to identify the areas of intervention aimed at protecting the health of these subjects and therefore the health of the assisted persons and the family nucleus that surrounds them.

Data analysis

The questionnaire data will be analysed with descriptive (e.g. mean, standard deviation and frequencies) and inferential statistical techniques. Pearson and Spearman correlations will be used to identify which variables will be correlated with HCWs', patients' and informal family caregivers' QOL. Multiple linear regression will also be used to identify predictors of the QOL for HCWs, patients and informal caregivers. The actor-partner interdependence model (APIM) will be used to analyse the dyadic data, as this approach allows investigators to evaluate the influence of partners on each other(39). In APIM, the actor effect is the influence of a person's emotions on himself or herself (e.g. the effect of depression on QOL). The partner effect is the impact of the person's emotions on his or her partner (e.g. the effect of depression in the person on the partner's QOL). The APIM will be used as the dyadic analytical procedure to test how some variables in HCWs (e.g. depression) will affect the same variables in their patients or informal family caregivers and vice versa. Multi-group analysis will be used to test the effect of moderators (40).

The semi-structured interviews will be fully transcribed and analysed with *content analysis*, an analysis technique that allows the researcher to evaluate the salient issues that emerged during the interviews.

Ethical considerations

The study was approved by the study institution's ethics committee of University of Roma Tor Vergata, in May 2020 and is in line with the Declaration of Helsinki. Participating subjects will be enrolled on a voluntary basis. Before data collection, all study participants will receive information on the study and accurate information about the confidentiality and archiving of their data. The signed informed consent will be obtained from all subjects before proceeding with data collection. Participants will be assured that study results will be published in aggregate form, not allowing identification of participants. Confidentiality and anonymity will be guaranteed through the assignment of a numerical code for each HCW, patient and informal family caregiver. During the transcription of the interviews, the researcher will eliminate any direct references that could compromise the privacy of the HCW, informal family caregiver and patient. All sensitive data will be treated according to the principles of Legislative Decree 30 June 2003 n. 196 and in compliance with the general regulation on data protection (European regulation no. 2016/679). Furthermore, all participating subjects will be informed that they will have the right to withdraw from the study whenever they wish. Research assistants will be trained to respect the enlisted subjects and the time required by them during data collection; therefore, if they see HCW, informal caregiver and patient getting tired during data collection, they will offer a break.

Validity and reliability/rigour

For this study, tools that have already been tested for validity and reliability will be used. For the tools developed by the research team, such as socio-demographic questionnaires for HCWs, for patient and informal family caregivers, the validity of their contents was assessed by a group of experts. For these tools, we will also test their inter-rater reliability.

Preliminary results

Our analysed sample includes 70 Home Care Workers with an average age of 45 years. The most prevalent sex is female (89%) The most important nationalities were: Italian 30%, Albanian 12.86%, Romanian 12.86%, and other nationalities for 47.14%.

Almost all of the sample found their current employment through word of mouth from acquaintances (92.45%). Half of the sample said they were doing this work for the first time and they does not have specific training in taking care of a person (55.71%) while assisting non self-sufficient people.

The main activities carried out are hygienic care, domestic assistance and, about half of the recruited subjects, admit to administering therapy and measuring vital parameters even though they "do not have a deep knowledge of what they are doing".

Discussion

This study will provide a first description of the living and working conditions of health workers present on the Italian territory.

The socio-demographic data collected with the study conducted are not consistent with those obtained from the literature regarding the nationalities most present in this work activity (41,42). However, it should be noted that the recent ISTAT reports show just how more and more Italians are approaching this "work" within our territory. The social and demographic changes of the Italian population, together with the economic crises and the failure to take off of community assistance, which have characterized the last few years, play their central role. This population is increasingly involved in caring for the elderly with or without chronic diseases, whether alone or within their own family. We have seen how healthcare professionals have had a positive impact on both the patients they care for and the patient's family. Their presence was associated with a reduction in the burden for informal caregivers, a better perception of QoL by the informal caregiver and also a possible reduction in improper access to local social services. Healthcare workers' health has also been correlated with their working conditions,

with negative implications for the performance of their jobs. To date, however, Italian health workers have not been studied much, much less the interaction between health workers, patients and informal caregivers. From the analysis of the data of this study, a possible interdependence between healthcare professionals and the patient and / or informal caregiver could emerge. The aim of the study is to evaluate the interaction between the living and working conditions of healthcare professionals and the outcomes of patients and informal caregivers. Healthcare professionals are often those who have long-term contact with elderly patients, with or without chronic diseases. They represent an important resource which, if properly trained, could positively influence the QoL of the elderly population and a valid support for their families. Knowing the real living and working conditions of Italian health workers would allow us to identify which variable linked to these conditions can influence the QoL of the elderly and their families. Professional Healthcare will be able to develop effective treatment plans that take into account the presence of health professionals. Finally, the results of our study will also provide important evidence to sensitize institutions to this reality and address specific training and regulation plans for this figure in the Italian territory.

Conclusions

The progressive and constant aging of the global population is proceeding at a high rate for what concerns Italy. At the same time, chronic degenerative diseases are increasing their prevalence, with a strong incidence in the elderly population. This segment of the population is destined to increase enormously over the next few years. The social and economic changes of Italian families favored the use of HCW as components dedicated to assistance to the elderly. Studying HCWs therefore represents a fundamental step; understanding their living and working conditions, and how these can affect the elderly and informal family caregivers, represents a fundamental first step in order to increase QoL of the elderly and their families.

This study will be conducted on a population often without a regular residence permit and a regular employment contract. This represents a first important difficulty linked to the sampling of HCQWs present in Italy. Furthermore, these HCWs are often migrant workers, not all from the same countries, and with cultures different from the Italian one. These probable cultural differences could represent a difficulty in generalizing the results.

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