

The characteristics of caregivers attending adult and paediatric patients in a Milan hospital

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Parole chiave: Caregiver, ospedale, pazienti adulti, pazienti pediatrici

Abstract

Background. The role of the caregiver has received increasing attention in recent years. This is due in part to today's longer life expectancy, which has resulted in a larger population affected by chronic pathologies. But it is also due to the lack of suitable solutions provided by the social and health structures. This research aims to investigate in depth the characteristics and the needs of caregivers involved with adult and paediatric patients who are receiving treatment for acute pathologies in hospitals.

Study Design. Questionnaire

Methods. A questionnaire was used that was validated in a previous study. It was administered in the period from March 2014 to January 2015 at the Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico di Milano in six wards. The questionnaire was anonymous.

Results. We administered 364 questionnaires which enabled us to identify the characteristics of adult and paediatric patients' caregivers. Those in hospitals are prevalently women. Adult patients' caregivers tend to be from 40 to 79 years of age, those of paediatric patients from 20 to 59.

Adult patients' caregivers may often be the husband/wife (35%), or a son/daughter (32%). Paediatric patients' caregivers for paediatric patients are almost always parents (97%).

The states of mind and the sensations felt by caregivers are anxiety and tension.

Conclusions. The increasing number and severity of the conditions of people needing care, the changing family composition and the economic crisis have compelled caregivers to perform tasks requiring technical skills that should not be expected from them, but which the circumstances do not allow them to evade. It emerges from an analysis of the data provided by this research that a more complete use could be made of caregivers' potentials by involving them to a greater extent in the care process by the healthcare providers.

Introduction

A caregiver is “a non-professional person who provides assistance, principally, wholly or partly, to a non-self-sufficient individual who depends on those around him/her for the activities of their daily life. This ongoing assistance may be dispensed more or less continuously and may take various forms: in particular, nursing, medical or personal care, support in education and socialization activities,

administrative formalities, coordination, ongoing supervision, psychological support and domestic activities” (1).

Attention towards the caregiver as a provider of “informal” care has increased, to the extent that it has become the object of studies and assessments by numerous welfare and healthcare organizations and research groups in many countries.

This growing attention is due to the rising number of individuals needing care and assistance on account of the increased

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life expectancy, often combined with higher levels of chronic pathologies, disabilities and non-self-sufficiency. Society has therefore had to take stock of those who contribute to the “service system” by dedicating time and effort to the “invisible care” of these patients (2).

In Italy, where a greater ageing of the population has been reported than in other countries, the increase in the need of elderly people for care and assistance has been so rapid as to have hindered a cultural and practical adjustment to this new trend (3).

This new situation has gone hand in hand with a constant reduction in hospital beds, with the adoption of different provision levels of social-healthcare assistance, with payment methods for hospital stays, with the need to keep healthcare costs within the available funds and with the impossibility to provide dedicated, multidimensional solutions to emerging new needs. As a result, the place of care and assistance for fragile individuals with challenged autonomy has more and more frequently become the person’s own home. In short, caregivers have increasingly become the individual’s family (4).

The family, as the WHO has already observed, has always been, and remains, the main provider of long-term care, but social, economic, demographic and epidemiological factors are reducing its resources and its capacity to respond, which should, therefore, be adequately supported (5).

The 46th CENSIS report on the social situation in the country (2) confirms the role played by families in Italy as substitute caregivers. Caregivers, in this country, are prevalently women, amounting to over 80% in severe phases of illness, reinforcing the eternal female role as the dispenser of care (6).

In 72% of cases, in fact, women are those who deal with care and assistance, with escorting patients to and from hospital and with organizing and attending medical

examinations. They are daughters or wives, almost all (87.4%) aged over 40, almost half (40.2%) being over 60 (6,7).

On average, seven hours per week are dedicated to direct assistance. This leaves around 15 hours per week of free time in the initial phases, but this drops to 4 hours as the pathologies reach an advanced phase. There is consequently a significant impact on caregivers’ health as well as on their psychological and relational conditions. They are frequently driven to the use of tranquillizers and anti-depressants (7).

Caregivers subjected to the stress of looking after family members with severe pathologies have a life expectancy reduced by 9 to 17 years. Furthermore, the perception of inadequate social support can lead to pathologies depressing the immune system (8, 9).

Certain social-environmental and economic conditions, as well as the state of health and the personality features of the caregiver and the conflictual nature inherent in the family system, affect the level of stress suffered by caregivers dealing with individuals with chronic and/or terminal diseases (10, 11).

The level of stress suffered by caregivers seems also directly correlated to the number of hours they dedicate to assistance, rather than to the severity of the patient’s disease. Nevertheless, the development and worsening of the sick relative’s pathology tends to induce in caregivers a sense of disorientation, guilt, fragility and impotence. This impacts negatively on the assistance (12).

There are other repercussions which have previously been underestimated and which are becoming the subject of study only now. 8% of those assisting a sick person suffer a decreased income, especially if they are free-lance workers, 5.5% lose their jobs and 2% apply for early retirement (1).

Therefore, the extra expenses they have to meet, directly or indirectly, should be added to caregivers’ health problems(6).

More difficult to assess are the organizational problems met when attempting to obtain flexible and/or reduced working hours, or paid or unpaid leaves.

Medical literature has always concentrated primarily on the domestic context, which is considered to be the caregiver's normal place of action. Those who look after a non-self-sufficient relative at home, however, often continue in their role as caregivers during hospital stays required by worsening health conditions. It is important, therefore, to study and collect information on the roles these caregivers play within the healthcare structure, since they are resources that can be exploited as part of the hospital assistance programmes (1, 13).

Medical literature does not offer many studies covering this aspect. Those few available confirm that, in Italy too, caregivers are prevalently women (81.4%), usually the spouse, with an average age of 57 and an average of ten years' school education. Seventy percent are working women (14, 15).

Caregivers are mainly present in healthcare facilities during the afternoon (75.6%). They are least present during the night (26.7%) (16). They assist the patient in washing (50%), eating (48.8%), mobility (19.8%), going to the bathroom (30.2%) and in diagnostic examinations (19.8%). They act as supervisors to the sick person (19.8%) and, above all, as companions (93%) (13, 16).

Caregivers' participation in looking after patients while in hospital is basically limited to ensuring that the healthcare personnel respond to patients' needs (13). Many caregivers present in a ward complain of a lack of communication between them and the healthcare staff, and the nurses in particular, who tend to underestimate their need of information and training (17, 20, 21).

Nursing personnel nevertheless solicit and consider indispensable the presence of a caregiver, especially when hospitalization

periods lengthen, when patients' needs for assistance increase or when these latter are children (1, 22).

Hospitalized non-self-sufficient patients require higher attention levels, but economic evaluations have often ignored the incidence of caregivers on such costs (16). In the United States it has been estimated that the economic value of the services provided by caregivers amounts to many billions of dollars. It can be seen, therefore, that this type of assistance also represents a significant saving in personnel costs and resources in hospital facilities (23).

Other data show that caregivers express a need for help in providing assistance, as well as the necessity for psychological support, both for themselves and for the patient (14, 15, 24).

The "caregiver burden" has been described as the "burden of the assistance as perceived by the caregiver". It translates into a psychological state characterized by anxiety, depression and physical ill-being, arising from the impact that the provision of care has on the individual's social and economic situation. It impacts globally on the caregiver's quality of life (24, 25).

The presence of a psychologist is frequent in hospital wards associated with high emotive impact, for example those dedicated to oncology, paediatrics or gynaecology. It is much less frequent in other wards, such as the geriatric wards, which contain patients attended by their caregivers (24).

International medical literature has investigated the role of the caregiver in the hospital context with reference to the specific psychological aspects affecting caregivers involved with particular types of patients, such as paediatric patients (26, 27), patients suffering from dementia (28, 29), patients with oncological pathologies (30-34), patients who are terminally ill or who are suffering from a degenerative disease (35-37), or those with chronic illnesses (25, 29, 34, 38, 39).

Medical literature provides very few data on the caregivers of elderly or paediatric patients hospitalized in Italy. Such data have analysed, in particular, the need to receive information on the health conditions of the patient. They shed little light on the healthcare activities performed by caregivers in hospitals, the possibility of including them in healthcare programmes and of their benefiting from services that would lessen the burden of their caregiving activities during the patient's stay in hospital (1).

The questionnaire of which we give the results aims to examine the features of caregivers of elderly and paediatric patients in a city hospital in Northern Italy.

Methods

This investigation was carried out between January and September 2015 in six wards of the Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico: three internal medicine wards and those of geriatrics, dermatology and paediatric surgery.

The patients hospitalized in the internal medicine, geriatrics and dermatology wards all belonged to the same area. The types of patients were therefore similar and they had for the most part arrived via the emergency ward.

The investigative tool was a questionnaire answered anonymously and consisting of either closed questions with a single answer or multiple choice questions for which more than one answer could be given. The questionnaire was subdivided into 5 sections, with a total of 34 questions.

The questionnaire used was drawn up in 2013 by a workgroup of the Società Italiana di Igiene Medicina Preventiva e Sanità Pubblica (Italian Society of Hygiene, Preventive Medicine and Public Health, SItI), which validated it and used it for a similar survey on caregivers carried out in

other hospitals, including also rehabilitation centres (40).

Together with the questionnaire, caregivers were provided with an information sheet which briefly described the study and offered useful suggestions for its completion. It was intended to explain to the caregivers the reasons for the research and to obtain their cooperation.

The survey was approved by the Ethical Committee (41).

The information obtained was processed using Excel software.

Results

A total of 364 questionnaires were completed, of which 246 in the Internal Medicine wards, 35 in the Geriatrics ward, 12 in the Dermatology ward and 71 in the Paediatric Surgery ward.

Forty-seven percent of assisted hospitalized individuals were female, 53% male. Adult patients were prevalently elderly: 44% were aged over 80, 39% were between 60 and 79. Paediatric patients were mainly aged 6-14 (49%).

Most of adult patients (57%) had been hospitalized for fewer than 10 days, while 25% had been hospitalized for 11-20 days. Almost all paediatric patients (96%) had been hospitalized for fewer than 10 days.

In the case of adult patients, 86% had been hospitalized, through the Emergency Ward, 87% had not undergone, nor were expected to undergo, surgery, 80% did not know how long their hospitalization was likely to last. In 47% of the cases, it was foreseen that ongoing assistance would be needed after their return home. For paediatric patients, on the other hand, 69% of cases had passed through the Emergency Ward, while 31% were present for planned treatment. Eighty percent had undergone or were to undergo surgery. They were generally aware (66%) of the presumed length of their stay in

hospital. Thirty percent of the patients might be in need of ongoing assistance after their return home.

Thirty-five percent of caregivers to adult patients were retired people, 37% were employees while 15% had no employment. Of the employees, only 19% made use of the leave of absence allowed by Law 104/1992 (42). 5% of workers requested unpaid leaves while 95% reduced their working hours.

In the case of paediatric patients, 54% were employees, 18% were free-lance workers and 28% had no employment. Of the employees, only 18% made use of leaves allowed by Law 104/1992 (42). 3% of workers requested unpaid leaves while 97% reduced their working hours.

Eighteen percent of adult patients' caregivers lived at less than 3 km from the hospital while 62% lived at a distance of 3 to 15 km. Seven percent of paediatric patients' caregivers lived at less than 3 km, 41% at 3 to 15 km.

The survey showed that caregivers of both adult and paediatric patients are prevalently women – 89% and 75% respectively. Adult patients' caregivers were mainly aged 40-79 (82%), while those of paediatric patients were aged between 20 and 59.

Twenty-six percent of adult patients' caregivers had a degree or a diploma, 45% had the higher school diploma. For paediatric patients' caregivers, the figures were 30% and 44%.

Thirty-five percent of adult patients' caregivers were the husband or wife, 35% were a son or daughter. Paediatric patients' caregivers were almost all one of the parents (97%).

Eighty-seven percent of adult patients' caregivers stated that the assistance they provided was not requested by the ward staff, though in 97% of cases they had been providing this assistance since the beginning of the hospitalization period. Fifty-seven percent of caregivers stated that they dedicated less than 4 hours per day to

care provision and were present in the ward mainly in the afternoon.

Seventy-six percent of paediatric patients' caregivers stated that the assistance they provided had been explicitly requested by the ward personnel. Moreover, they had been providing this assistance since the beginning of the hospitalization period throughout the entire day.

Fifteen percent of adult patients' caregivers were alone in their assistance activities and had no other support. Where they were joined by others, they generally collaborated with other family members (70%), acquaintances, neighbours or a paid carer. The situation was very different in the case of paediatric patients' caregivers. Only 11% were alone in their assistance activities. Eighty-four percent collaborated with other family members and just 5% with neighbours or acquaintances.

The activities carried out by patients' caregivers are reported in Table 1. The most frequently used simple piece of equipment was the aerosol nebulizer.

The states of mind and the sensations most frequently felt by patients' caregivers during assistance activities are shown in Table 2.

Forty-nine percent of adult patients' caregivers and 59% of paediatric patients' caregivers replied, however, that none of the aspects proposed needed to be altered to make assistance activities more effective (Table 3).

Caregivers were then asked to indicate on a scale from 1 to 4 (1 equals "little", 4 equals "a lot") the extent to which they felt their assistance activities were recognized and appreciated by the ward personnel (Table 4).

Twenty-eight percent of adult patients' caregivers and 55% of paediatric patients' caregivers stated that they were aware of the regulations of the hospital in which the person they assisted was hospitalized and that they had become aware of it through notices placed at the entrance to

Table 1 - Assistance activities carried out by caregivers. With which aspects of assistance do you deal?

	Paediatric patients	Adult patients	Total
Relations with healthcare personnel	70 (99%)	272 (93%)	342 (94%)
Assistance with personal hygiene	39 (55%)	36 (12%)	75 (21%)
Use of simple equipment	2 (3%)	8 (3%)	10 (3%)
Giving meals	44 (62%)	93 (32%)	137 (38%)
Physiotherapy	0	1	1
Interpreting	0	1	1
Acting as companion	70 (99%)	279 (95%)	349 (96%)
Total	71 (100%)	293 (100%)	364 (100%)

(it was possible to provide more than one answer)

the ward. However, 96% of adult patients' caregivers and 99% of paediatric patients' caregivers stated that they were unaware of the existence of an Assistance Plan for the patient they were assisting.

Only a minority (16%) of adult patients' caregivers declared that they had been provided with information sheets at the moment of hospitalization, describing the services available to patients (57%) and their

family members (15%), the programming of activities in the ward (39%) and rules of conduct (17%). The percentage rose to 28% for paediatric patients' caregivers and the information concerned the services available to patients (95%) and family members (30%), the schedule of activities in the ward (90%) and rules of conduct (95%).

No meal service was envisaged for adult patients' caregivers. An easy chair was

Table 2 - Describe the states of mind/sensations that you most frequently feel during assistance activities

	Paediatric patients	Adult patients	Total
Anxiety	35 (49%)	72 (25%)	107 (29%)
Anguish	10 (14%)	36 (12%)	46 (13%)
Tension/ nervousness	26 (37%)	47 (16%)	73 (20%)
Tranquillity	28 (39%)	110 (38%)	138 (38%)
Utility	34 (48%)	184 (63%)	218 (60%)
Loneliness	6 (8%)	19 (6%)	25 (7%)
Fear of making mistakes	14 (20%)	37 (13%)	51 (14%)
Tiredness	12 (17%)	69 (24%)	81 (22%)
Security	22 (31%)	120 (41%)	142 (39%)
Impotence	0	1	1
Anger	0	1	1
Sadness	0	3 (1%)	3 (1%)
Worry	1 (1%)	2 (1%)	3 (1%)
TOTAL	71 (100%)	293 (100%)	364 (100%)

(it was possible to provide more than one answer)

Table 3 - Identify which aspects you feel should be improved to make your assistance activities more effective

	Paediatric patients	Adult patients	Total
none	42 (59%)	144 (49%)	186 (51%)
Relating with the doctor	5 (7%)	44 (15%)	49 (13%)
Relating with nursing and healthcare personnel	8 (11%)	46 (16%)	54 (15%)
Information on handling emergencies	0	11 (4%)	11 (3%)
Availability of booklets	0	8 (3%)	8 (2%)
Relating with head nurse	0	4 (1%)	4 (1%)
Old structure with little respect for no. of patients	0	20 (7%)	20 (5%)
Hygiene of ward	2 (3%)	5 (2%)	7 (2%)
Organization of ward	7 (10%)	4 (1%)	11 (3%)
Allowing the eg. to eat in the room	4 (6%)	0	4 (1%)
Improving pain management	4 (6%)	0	4 (1%)
Lack of privacy in medical interviews	0	2 (1%)	2 (1%)
Lack of personnel	2 (3%)	38 (13%)	40 (11%)
Quality of food	2 (3%)	2 (1%)	4 (1%)
Dermatology should be separate from geriatrics	0	4 (1%)	4 (1%)
Few and inadequate bathrooms	0	16 (5%)	16 (4%)
Total	71 (100%)	293 (100%)	364 (100%)

(it was possible to provide more than one answer)

available to rest during the night for only half of the interviewees. In the Paediatric Surgery ward, however, all caregivers had a bed available for the night and the ward envisaged a meal service for them.

Ninety-eight percent of caregivers, both of paediatric and of adult patients, were unaware of the existence of special agreements with hotels near the hospital.

Caregivers were asked to report on a scale from 1 to 4 (1 equals "poorer than expected", 4 equals "better than expected") an opinion on the services provided (Table 5).

Discussion

In line with medical literature, our study confirmed that the majority of caregivers are

Table 4 - Do you feel that your assistance activities are recognized/appreciated by ward personnel?

	Paediatric patients	Adult patients	Total
1 = little	2 (3%)	20 (7%)	22 (6%)
2	3 (4%)	131 (45%)	134 (37%)
3	32 (45%)	88 (30%)	120 (33%)
4 = a lot	34 (48%)	54 (18%)	88 (24%)
	71 (100%)	293 (100%)	364 (100%)

Table 5 - Information on hospital structure/caregiver relations. How far did the services provided meet your expectations?

	Paediatric patients	Adult patients	Total
1 = poorer than expected	0	21 (7%)	21 (6%)
2	6 (8%)	59 (20%)	65 (18%)
3	31 (44%)	115 (39%)	146 (40%)
4 = better than expected	34 (48%)	98 (33%)	132 (36%)
	71 (100%)	293 (100%)	364 (100%)

female, with around 12 years of education. Thirty percent are retired. Those who are workers find themselves compelled, in the vast majority of cases, to reduce their working hours. Other family members often collaborate with them in their assistance activities.

Adult patients' caregivers are aged 40 to 79. In particular, 44% are between 60 and 79. Adult patients' caregivers are therefore elderly people in their turn. In most cases it is the husband or wife or the children who look after the assisted person. In a few cases the presence was noted of a paid carer to whom the family had entrusted the care of the hospitalized person when they were unable to attend as often as they would have wished. In view of their age, most caregivers are retirees. Only 20% of those who are employees make use of the provisions of Law 104/92 (42). Paediatric patients' caregivers, on the other hand, are fairly young people, aged 20 to 59. This is because, apart from rare exceptions, it is always the parents who look after the young patient. Most caregivers are employees (54%). Only 16% make use of the provisions of Law 104/92 (42). This low percentage may be explained by the acute phase in which the paediatric patient arrives in hospital, unlike the situation of the elderly patient.

Most caregivers live in Milan.

The best time for administering the questionnaires in the Internal Medicine, Geriatrics and Dermatology wards was in the late afternoon. Mornings proved less

suitable, since this was the time when the doctors of the ward were mainly present, with the result that the caregivers were anxious to receive information and updates on their patients' state of health. The situation was different in the Paediatric Surgery ward since the caregivers, with few exceptions, were present all the time.

Also in line with medical literature, the assistance aspects with which the caregivers dealt were mainly those of providing company for the hospitalized person and holding relations with the healthcare staff. When the patient needed it, they also helped the assisted person in eating meals and in personal hygiene, especially in the case of paediatric patients.

In the vast majority of cases, caregivers attended to the patient from the beginning of the hospitalization period. This emphasises the fact that it is always the same person who gives care, generally the patient's spouse.

Once again in line with medical literature, adult patients' caregivers are present above all in the afternoon. On average, the time spent per day on providing care for elderly hospitalized persons is less than 4 hours per day (57%). In 25% of cases it is between 5 and 8 hours. With paediatric patients, where the assistance personnel have explicitly requested the presence of a caregiver, this latter is present in 76% of cases. No one declared that they dedicated less than 4 hours a day to providing care for a paediatric patient.

Ninety-seven percent of caregivers stated that they were unaware of the existence of an Assistance Plan for the hospitalized patient. They therefore did not know if the activities they performed had been attributed to them. This certainly points to a failure on the part of healthcare professionals and Assistance Plan managers to involve and support the caregivers.

Regarding this, 45% of adult patients' caregivers declared that they feel their activities are poorly recognized and appreciated, whereas almost all paediatric patients' caregivers declared that they felt their assistance activities were appreciated by the healthcare personnel.

The states of mind and the sensations most frequently felt by adult patients' caregivers were generally positive, such as utility, security or tranquillity. A lower percentage also perceived negative sensations such as anxiety, anguish, loneliness, sadness and worry. The sensations felt by paediatric patients' caregivers, on the other hand, were mixed, even within the same person. For example, anxiety and utility had the same percentage scores, as did tension/nervousness and tranquillity, security and the fear of making mistakes. From this point of view, it would be useful both to caregivers themselves and to the healthcare structures, as other studies have already pointed out, to make available a professional figure who provides psychological support.

Our study is furthermore in line with medical literature in finding that 50% of caregivers feel it necessary to improve relations and communications with healthcare personnel, nurses and assistants as well as doctors. In particular, adult patients' caregivers emphasized the need to count on the presence of a larger number of assistance personnel. In particular, paediatric patients' caregivers would like to be able to consume their meals in the room so as to remain constantly at the side of their children.

Seventy-two percent of adult patients' caregivers and 92% of paediatric patients' caregivers declared that, overall, the services provided were better than they had expected.

The increasing number and severity of the conditions of people needing care, the changing family structures and the economic crisis have compelled caregivers to perform tasks requiring technical skills that should not be expected of them, but which the circumstances do not allow them to evade (3). It is becoming ever more necessary, therefore, to create structured systems in which the work they provide is recognized and proper support is given to these figures of assistants/organizers/nurses/psychologists at their various levels of need. These needs may be practical/technical, they may be relational, they may concern time-organization or they may even involve regulations, health insurance and economic questions (7). In view of this, the Azienda Sanitaria di Brescia has drawn up a Manifesto for caregivers. This has the strategic aim of including the caregiving system within the "official" organized caregiving structure, and it lays down the necessary measures for bringing this about (3).

Society needs caregivers. As well as providing indispensable assistance to their loved ones, caregivers are major contributors to the sustainability of our healthcare systems. The complexity of the care needed, the constant commitment made all the more difficult by a still inadequate network of services, the implications on the relational and emotional level, as well as the direct and indirect costs, tests the caregiver's psychophysical wellbeing (6). If we wish caregivers to continue providing quality assistance, their needs and requests should be made an integral part of the development of healthcare and social policies and their contribution should be properly recognized.

Directly assisting elderly non-self-sufficient individuals, and indeed those of all age groups, is a difficult task on the

human level and a complex one in terms of organization. It calls for skill, physical and psychological “strength”, availability of time, and, in many cases, availability of economic resources (3). Non-self-sufficient individuals and their caregivers are the foremost experts of their own needs and of the responses best able to meet them (1). Caregivers should therefore receive greater attention in hospitals. They should be considered a precious resource for the healthcare personnel, rather than an obstacle to the smooth working rhythm (unpublished data). An analysis of these research data shows that better use could be made of caregivers’ potentials. Caregivers could be more fully involved by the healthcare personnel; they could play a more proactive role in relation to patients’ needs. At the same time, they could be a resource for the ward, if carefully instructed and prepared by means of an initial training. Healthcare personnel should be able to recognize the type of caregiver with which they are dealing, and act accordingly, in order to reduce caretakers’ burdens, improve their quality of life and make best use of their presence in the ward.

Involving caregivers could facilitate communication with healthcare professionals. Hospitalization could become an opportunity for caregivers, enabling them to acquire new and improved assistance strategies and so enhance the quality of their care after the patient’s discharge from hospital (17, 43). Healthcare personnel should also provide specific advice to support caregivers and encourage them not to neglect care of themselves while they are assisting their loved ones in hospital (13). The therapeutic team should not forget to “support those who support” during the long, problematic progress of the pathology (1). It would be fundamental, therefore, to set aside areas and rooms in the hospital structures dedicated to caregivers (16).

The sample of paediatric patients’ caregivers investigated was too small to

provide satisfactory results. However, the aim of this study was to gather preliminary data. These will enable us to set up a further study intended to confirm or otherwise investigate the results obtained. It would also be useful to assess the inclusion of caregivers in healthcare structures’ Assistance Plans. Wards should be encouraged to provide services that would reduce the burden of caregivers’ activities during the time spent in hospital by the patient they assist. A real and effective match should be sought between caregivers’ needs and potentials and the social opportunities and services that could be provided for them. This would enable the creation of programmes that could be implemented by institutions and associations and adopted as part of national and local healthcare policies.

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SC contributed for the conception and design of the study, NC for the acquisition of data and the drafting of the article, ML for the analysis and interpretation of the data; SC, NC and ML reviewed it critically and approved the final version to be submitted.

The study was approved by the Ethical Committee, Milan area B, n. 109/2014

Riassunto

Le caratteristiche del caregiver del paziente adulto e pediatrico ricoverato in un ospedale di Milano

Introduzione. La figura del caregiver sta ricevendo, negli ultimi anni, molta attenzione. Questo è dovuto in parte all’allungamento della speranza di vita che porta ad un aumento della numerosità della popolazione affetta da patologie croniche ed in parte alla mancanza di soluzioni fornite dai servizi sociosanitari. Questa ricerca vuole indagare le caratteristiche ed i bisogni dei caregivers di pazienti pediatrici ed adulti ricoverati con patologie acute in ospedale.

Study Design. Indagine questionario

Materiali e Metodi. Un questionario anonimo, validato in un’indagine precedente, è stato distribuito a 364 caregivers di ricoverati adulti e pediatrici in sei degenze

della Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico di Milano.

Risultati. Sono stati raccolti 364 questionari la cui elaborazione ci ha permesso di individuare le caratteristiche dei caregivers dei pazienti adulti e pediatrici ricoverati. Il caregiver è prevalentemente donna con una età compresa tra 40 e 79 anni per i pazienti adulti e 20 e 59 per i pazienti pediatrici.

Il caregiver del paziente adulto è spesso la moglie/marito (35%), o il figlio/a (32%). Per i pazienti pediatrici il caregiver è quasi sempre un genitore (97%). Il sentimento più frequentemente provato dal caregiver è l'ansia.

Conclusioni. Il numero crescente e la severità delle condizioni dei pazienti non autosufficienti, la mutata struttura della famiglia e la crisi economica hanno spinto i caregivers a svolgere compiti a cui non sono preparati ma a cui non si possono sottrarre. Dall'indagine emerge che i caregivers devono essere considerati una risorsa da parte del personale di assistenza in ospedale che li deve formare e coinvolgere nel percorso di cura.

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