

FAMILY CARERS

Becoming a caregiver: new family carers' experience during the transition from hospital to home

Angelika Plank, Valentina Mazzoni and Luisa Cavada

Aims and objectives. To explore and understand the experience of new informal caregivers in Italy during the transition from hospital to home.

Background. Frequent patient discharge into the home environment has led to a significant increase in postdischarge care being provided by family caregivers. The transition period in particular is seen as a period of great significance, as caregivers may be unprepared and concerned as to the amount of care required by the recipient.

Design. A qualitative phenomenological approach was used to gain a deeper understanding of caregivers' lived experiences.

Methods. Data were collected at two points in time using different methodologies: in-depth interviews were conducted to explore the caregivers' perspective of the pre-discharge period; focus groups obtained data after the patients' re-entry into the home environment and aimed to validate interview findings.

Results. Family caregivers reflected on three main themes during the transition period: (1) their newly acquired role; (2) the recipient's condition; and (3) the support they required. The core concept of 'being responsible for everything' seemed to be a recurring theme running through these three subject matters. Fulfilling numerous commitments and different social roles besides the caring activity itself seemed to weigh heavily on caregivers. Carers were referring particularly to their need for hope, confidence and safety during the transition from hospital to home.

Conclusions. It cannot be assumed a priori that families can cope with the demands of care-giving. Therefore, healthcare professionals should come to recognise caregivers as persons in need of emotional and practical support.

Relevance to clinical practice. The findings of this study can stimulate healthcare professionals to acquire effective communication skills and display an empathic attitude when assessing caregivers' needs in the particularly challenging phase of transition from hospital to home.

Key words: care responsibility, carer role, discharge process, informal caregiver, nurses, nursing, phenomenology, qualitative research

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Introduction

Over the last decades, both demographic and social factors have contributed to a rising need of informal caregivers. Estimates related to the growing percentage of the elderly

people in our societies, along with projections of increasing chronic and invalidating illnesses, are powerful reminders of the challenges lying ahead for the healthcare system. As in many other countries in the world, in Italy, the number of elderly people has increased rapidly: in 2009, individuals

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aged 65 years and older represented 20.2% of the population, as compared with 18.1% in 2000 (Marsili 2010). These demographic factors are coupled with the fact that patients are often being discharged earlier, sicker and more dependent from hospitals to redress rising inpatient costs and decreasing availability of beds (Grimmer *et al.* 2004, Shepperd *et al.* 2004, Bauer *et al.* 2009, Boughton & Halliday 2009). Moreover, because of important changes in family structures in recent times, the pool of people available to provide care is declining (Saiani *et al.* 2004). Despite these widespread social changes, elders and disabled persons in Italy are still usually cared for by their family: one Italian of four cares for a family member, a friend or a neighbour (Polverini *et al.* 2004).

Background

After acute illness patients are increasingly discharged into the home environment, a situation that leads to a significant rise in postdischarge care being provided by family caregivers. As a consequence, care-giving and the investigation into carers' needs as well as their perceived burden or strain are gaining importance as a field of research on an international level. Several studies reveal that discharging patients to home seems to have positive effects on their recovery and rehabilitation processes (Kerr & Smith 2001, Grimmer *et al.* 2004, Olofsson *et al.* 2005, Bauer *et al.* 2009), while, on the other hand, it puts an extreme burden on their caregivers (Dorsay & Vaca 1998, Boughton & Halliday 2009, Greenwood *et al.* 2009). Family caregivers frequently perceive the discharge planning process in a negative light, expressing frustration and poor trust and pointing to a lack of knowledge and education (Bowman *et al.* 1998, Bull *et al.* 2000). Patients are repeatedly being discharged into the care of family members who have not been assessed satisfactorily by healthcare professionals in terms of whether they can manage given their skill level, age and/or health status (McMurray *et al.* 2007). As a consequence, caregivers may be unprepared for the amount of care required by the recipient and concerned and overanxious about many aspects of caring (Kerr & Smith 2001, Bakas *et al.* 2002, Lane *et al.* 2003, Grimmer *et al.* 2004, Smith *et al.* 2004, Mackenzie *et al.* 2007). In fact, carers seem to cope better when they understand the disease process and have some knowledge of what to expect (Dorsay & Vaca 1998).

During the first months after patient discharge, caregivers are starting to grasp their new situation and realise changes to their quality of life (Grimmer *et al.* 2004, Smith *et al.* 2004, Pringle *et al.* 2008, Greenwood *et al.* 2009). In fact, many qualitative studies that focused on this particular period confirm that caregivers are feeling stressed and overwhelmed

(Han & Haley 1999, Turner *et al.* 2007). Furthermore, many caregivers express frustration at not knowing where to look for help and complain about a general lack of outpatient and community-based services available (Turner *et al.* 2007).

Especially in Italy, very little research so far has focused on the caregivers' lived experience regarding the pre-discharge period. Based on the literature and our personal experience, this period is to be considered as being a time of particular importance, not least because of the ever present sense of uncertainty. Fears and concerns about how to cope with the illness and/or the disability of the recipient and about how to organise the various aspects of caring are particularly frequent. White *et al.* (2007) indicate that hospital discharge for frail older people can be improved only if interventions are planned with an adequate assessment and with a clear understanding of caregivers' experiences, emotions and needs.

Aims

The purpose of this study is to explore and understand the experience of new informal caregivers in Italy in the time of transition from hospital to home, focusing on their thoughts and reflections. The experiences gained by carers provide important information allowing healthcare professionals to further improve the discharge process.

The questions that guided the research are the following:

- How is the discharge process experienced from the caregivers' perspective?
- What kind of thoughts and reflections do new informal carers associate with the phase of transition from hospital to home?
- How do these perceptions compare with their reported experiences in the early postdischarge period?

Methods

Research design

In accordance with the study's aim, a qualitative phenomenological approach was chosen, as it is considered a highly appropriate approach for examining the qualities of human experience (Wimpenny & Gass 2000, Balls 2009). Giorgi (2006) argues that the participant is the expert in relation to the phenomenon under investigation; the researcher may know theories and the literature, but he does not know the relevant dimensions of the concrete experience being reported by a participant. Indeed, phenomenological research is allowing the researcher to get into the participant's life-world to gain a deeper understanding of his or her experience (Mortari 2008, Balls 2009).

Participants

A purposive sample of primary caregivers was recruited from February to May 2010 in a general rehabilitation unit of a North Italian hospital. The primary caregiver was defined as a person providing informal (unpaid) support for an individual unable to complete all of the tasks of daily living after discharge into the home environment. Carers were included in the study if they were willing to participate and if they met the following criteria: (1) age 18 or older, (2) new to the carer role and (3) identified as the primary caregiver for patients discharged home, provided that patients were not dependent on a carer prior to hospital admission.

Data collection

Data were collected at two points in time using in-depth interview and focus group techniques. Interviews aimed at exploring the caregivers' lived experience and with the later focus group sessions researchers intended to validate the interview findings. The depth and type of topics disclosed during data collection may have been influenced in a positive way by the fact that all participants were known to the first author.

In-depth interviews

In-depth interviews were conducted with future caregivers prior to discharge to capture their experiences during this significant period. Data were not gathered in a retrospective manner like many other researchers did because, as Blane (1996) discusses, emotionally laden events are particularly likely to be remembered inaccurately. Caregivers who met the inclusion criteria for taking part in the interview were approached by researchers when time of discharge from hospital was known. If they agreed, an appointment for an interview was arranged. Each interview followed a set of open-ended questions, which were developed by the research team. Caregivers were asked to comment on their concerns about the imminent patient discharge and how they prepared themselves for it, their thoughts, expectations and feelings regarding their caring role and their needs in managing the care. Caregivers were recruited for interviews until no new information was being elicited. The mean duration of interviews was 50 minutes; they were carried out on average 11 days before discharging the patient into the home environment (range: 0–42 days).

Focus groups

Focus groups were held after the data analysis of individual interviews had been completed, and they aimed to validate

the interview findings by returning to new informal caregivers (Table 1, point 9). In fact, if focus group participants can see their own experience reflected in the findings and perhaps even recognise their own words, this lends credibility to the results (Mortari 2008, Balls 2009). Focus group methodology seemed appropriate because the interaction among care providers can facilitate the expression of ideas and experiences and illuminate the research participants' perspectives through the debate in the group (Kitzinger 1995, Morrison & Peoples 1999).

Potential participants who already were assisting the patient at home were contacted by letter and telephone, and a convenient time was chosen for all caregivers to hold the focus groups. The mean length of time since patient discharge was 35 days with a wide range from 4–133 days. Because of the small sample size of the first focus group session ($n = 3$), another one was conducted, including further caregivers who had not faced patient discharge yet. Indeed, as Kitzinger (1995) states, it can be advantageous to bring together a diverse group to maximise exploration of different perspectives in a group setting. The researchers based open-ended questions for focus groups on the data obtained through individual interviews. Both focus groups lasted about one and a half hours.

Both the individual interviews and focus groups were conducted in a room free from distractions at the rehabilitation unit. The participants completed a short demographic questionnaire before starting interviews or focus groups.

Table 1 The process of data analysis as followed in this study (Colaizzi 1978, Giorgi & Giorgi 2003, Mortari 2008)

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- (1) Close reading of each interview transcript for an overall understanding
 - (2) Re-reading of transcripts, highlighting of meaningful statements that are reflective of caregivers' experience
 - (3) Listing of meaningful statements in 'meaning units'
 - (4) Pooling of 'meaning units' into 'clusters of meanings'
 - (5) Writing of descriptions for each 'cluster of meanings' using a language relevant to the nursing profession
 - (6) Grouping of clusters of meanings into main themes
 - (7) Validation of the themes emerged by comparing them with the original transcripts confirming consistency between the researchers' emerging conclusions and the participants' original stories
 - (8) Integration of the main themes into an exhaustive description of the caregivers' lived experience during the transition from hospital to home
 - (9) Validating the interview findings by returning to some primary caregivers to ask how they compare with their experiences (using focus group technique)
 - (10) Incorporating any changes offered by the participants into the final description of the essence of the phenomenon
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Demographic data on the patients were obtained through medical records.

Ethical considerations

Approval for the study was obtained from hospital management administrators as well as from the head physician and the charge nurse of the rehabilitation unit. Each participant was explained the purpose and the procedure of the study by receiving an information sheet. Research participants were informed that they were under no obligation to participate, and explicit assurance was given about their right to withdraw from the study at any time. Written informed consent was obtained prior to data collection; all interviews and focus groups were audiotaped with participants' permission. Anonymity and confidentiality were protected.

Data analysis

The first author who conducted the individual interviews and focus groups transcribed them verbatim from the audiotapes and added field notes. The process of data analysis followed the phenomenological procedure described by Colaizzi (1978). As this procedure – and in particular the points 1–6 (Table 1) – is described also by Giorgi and Giorgi (2003) and Mortari (2008), some of their expressions were taken into consideration and integrated to Colaizzi's model. Table 1 shows the different stages of the systematic process set out by the three authors. The participants' most significant statements (see Table 1, point 3) were translated into English. Two members of the research team reviewed each transcript independently. Findings were compared and discussed in meetings until consensus was reached to limit the potential influence of researchers' preconceptions (Rochette *et al.* 2006).

Findings

The sample for this study consisted of eight carers taking part in individual interviews prior to discharge and ten carers participating in postdischarge focus groups. Three caregivers attended both the interview and the focus group. Table 2 summarises the demographic characteristics of the 18 research participants and the patients they are caring for. Patients' demographics show their degree of disability based on the Functional Independence Measure score (Granger *et al.* 1993) as this provides important contextual information.

The predischarge period as well as the early days and weeks at home following discharge are periods of significant emotional overload for caregivers, especially for those who are new to their role as they have to begin a new chapter in

their lives. The analysis of the individual interviews and the focus groups revealed that carers were reflecting on three main themes during the time of transition:

- 1 the newly acquired role as family caregivers
- 2 the recipient's condition and
- 3 the support they required to carry out the carer role.

In other words, caregivers experienced this period on an individual, an interpersonal and an organisational level. The care-giving role may vary with the recipient's age and the nature of his or her impairment but is likely to involve one core perception that turned out to be a leitmotif or, in other words, a recurring theme running through all three levels: being responsible for everything. Figure 1 intends to summarise the key themes to give a clearer understanding of the transition process from the caregivers' standpoint. The three main subject areas that emerged and the core concept linking them together will be discussed below.

Being responsible for everything

The feeling of 'being responsible for everything' represents the core feature of the caregivers' experience, running like a leitmotif through the three main themes arisen. Caregivers had to assist with the tasks that recipients were unable to do for themselves, such as personal hygiene and mobility. But caring for the recipient meant much more: ensuring an appropriate environment, providing constant supervision and emotional support, managing recipient's difficult behaviours, making decisions on his or her behalf, taking care of financial matters and paper work as well as taking charge of nursing and therapeutic tasks. Besides these specific care-giving responsibilities, carers had to continue completing those everyday tasks they had already been in charge of before (for example doing the housework), and frequently, they even had to carry out the role previously assigned to the recipient, because the recipient him or herself was no longer capable of it. It was consequently the need to 'try and juggle a multitude of tasks simultaneously' that weighed heavily on caregivers:

It's a continuing burden and stress...and you're always responsible for everything. [...] You have to prepare medication, you have to organise all kinds of formalities, you have to do a bit of everything...and in addition you should also be a wife...after some time you just can't manage anymore. (Carer no. 9)

I am increasingly worried and I'm sleeping less and less, because of all the problems regarding appropriate home environment, [...] shopping, cooking, washing...It seems absurd that now that she is doing better I'm sleeping less. [...] But now my thoughts are turning around the future. (Carer no. 7)

Table 2 Sample demographics

Carer's demographics		Patient's demographics
Individual interviews		
No. 1	Female, 50 years, patient's sibling, not living with the patient Married, no minor children, full time job	Male, 46 years, neurosurgical diagnosis, FIM score ^a = 49
No. 2	Female, 32 years, patient's adult child, not living with the patient Separated, two minor children, homemaker	Male, 63 years, neurological diagnosis, FIM score = 83
No. 3	Female, 76 years, patient's spouse, living with the patient Married, no minor children, retired	Male, 83 years, neurological diagnosis, FIM score = 76
No. 4	Female, 35 years, patient's adult child, not living with the patient Living with partner, two minor children, part time job	Male, 78 years, orthopaedic diagnosis, FIM score = 99
No. 5	Female, 35 years, patient's partner, living with the patient Living with partner, one minor child, full time job	Male, 40 years, neurological diagnosis, FIM score = 97
No. 6	Female, 43 years, patient's spouse, living with the patient Married, three minor children, part time job	Male, 49 years, neurological diagnosis, FIM score = 78
No. 7	Male, 55 years, patient's spouse, living with the patient Married, no minor children, full time job	Female, 54 years, neurological diagnosis, FIM score = 41
No. 8	Female, 69 years, patient's spouse, living with the patient Married, no minor children, retired	Male, 75 years, surgical diagnosis, FIM score = 89
Focus groups		
No. 9	Female, 43 years, patient's spouse, living with the patient Married, three minor children, part time job	Male, 49 years, neurological diagnosis, FIM score = 78
No. 10	Female, 64 years, patient's spouse, living with the patient Married, no minor children, retired	Male, 67 years, neurological diagnosis, FIM score = 72
No. 11	Male, 80 years, patient's spouse, living with the patient Married, no minor children, retired	Female, 77 years, orthopaedic diagnosis, FIM score = 91
No. 12	Female, 52 years, patient's adult child, living with the patient Widowed, no minor children, part time job	Female, 86 years, orthopaedic diagnosis, FIM score = 58
No. 13	Female, 54 years, patient's adult child, not living with the patient Married, no minor child, full time job	Female, 73 years, neurological diagnosis, FIM score = 101
No. 14	Female, 50 years, patient's sibling, not living with the patient Married, no minor children, unemployed	Male, 46 years, neurosurgical diagnosis, FIM score = 49
No. 15	Female, 74 years, patient's partner, living with the patient Widowed, no minor children, retired	Male, 74 years, neurological diagnosis, FIM score = 65
No. 16	Female, 46 years, patient's adult child, not living with the patient Living with partner, no minor children, part time job	Female, 68 years, neurosurgical diagnosis, FIM score = 21
No. 17	Male, 55 years, patient's spouse, living with the patient Married, no minor children, full time job	Female, 54 years, neurological diagnosis, FIM score = 41
No. 18	Female, 51 years, patient's partner, living with the patient Divorced, no minor children, part time job	Male, 50 years, neurological diagnosis, FIM score = 74

^aThe FIM-Score measures independent performance in self-care, sphincter control, transfers, locomotion, communication and social cognition. By adding the points for each item, the possible total score ranges from 18 (lowest) to 126 (highest level of independence). FIM, Functional Independence Measure.

Only in the postdischarge period, caregivers' concerns were moving away a bit from the recipient as they began seeking recognition for their own needs and appreciation for the care work provided. They increasingly perceived the need of having a break from care-giving responsibilities and to recharge their batteries:

I hope it's going to get better...even from a selfish point of view. You see, as long as I can go for a walk and get some fresh air, I think less about my worries. It's like relaxing the brain. (Carer no. 11)

Reflections on the newly acquired role as family caregiver (individual level)

Most caregivers seemed to provide care gladly and expressed positive feelings like hope, confidence, courage and willingness to enter the carer role:

I now have accepted this new situation and I feel I've got the strength to go on. I now have the strength I haven't had before. (Carer no. 1)

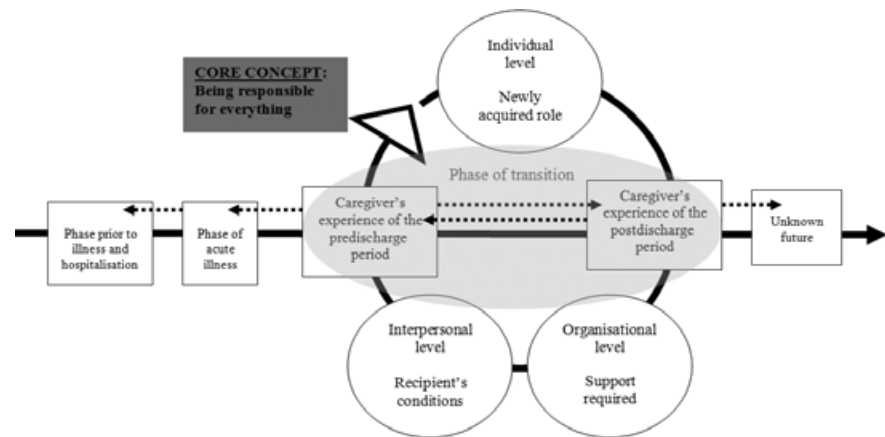


Figure 1 Conceptual framework: new informal carers' experience during the transition from hospital to home.

Caregivers' positive feelings were almost always opposed by negative ones, as they described recurrent feelings of worry, fear, doubt and uncertainty about their ability to provide the care required at home. However, it was striking that they reassured themselves by confirming and reconfirming their ability to manage ('Nonetheless, I'll make it'). This caused a continuing sense of ambiguity in caregivers when talking about the imminent patient discharge:

You see him sitting in the wheelchair, you see him lying in bed, you see him as a disabled person and then you have to face the situation to care for him at home. You're feeling joyful, but at the same time you feel anxious because you have to be prepared...and you don't know how to handle the situation. (Carer no. 6)

The omnipresent fear of the unknown was often increased by a perceived lack of information and preparation, especially in the pre-discharge period. Caregivers did not know what to expect and whether they possessed the emotional and physical strength to cope with the caring activity. Questions like 'How will it be', 'What's the likely extent of his recovery' or 'What should I do, when...' were common.

Information was needed during every step of the process, prior to patient discharge as well as in the early postdischarge period. What changed over time was just the focus of the questions. Information on financial support and organisational aspects, such as paper work or how to reconcile the caring activity with employment, was considered important only later on, when back into the home care setting. However, communication with healthcare professionals was a key issue for carers. They pointed out the importance of how information should have gone across in terms of quality and quantity rather than asking just for a simple exchange of information:

She [the speech therapist] didn't make illusory promises like 'He will be able to speak' but instead she said 'I hope he will be able to do a simple

conversation.' [...] It's a different way of saying things. It's a sensitive way that gives you hope. It's simply the way someone communicates with you that changes your interpretation of and reflections on things and that finally changes your way of facing them. (Carer no. 5)

Another caregiver complained that too much information had been given on one single occasion:

I have to be honest, this day was crucial. [...] perhaps [it would be better to] give only small bites [of information] at a time...in order to help people organising everything step by step...like building brick on brick [...] I knew that this moment would come, but I hadn't expected such an impact. It's like driving against a wall at 120 kilometres per hour... (Carer no. 7)

The postdischarge period entailed some new challenges as the patient was no longer cared for and protected by healthcare professionals. The unpredictability of every single day seemed to increase the carers' edginess and strain progressively. Indeed, it was now up to the caregiver to take full responsibility for the patient's well-being, a fact that often led to helplessness and fear of making mistakes:

I have to concentrate so much while preparing the oral medication in order not to commit any mistakes. [...] In fact, I am terribly worried about making mistakes. (Carer no. 10)

Reflections on the recipient's condition (interpersonal level)

Caregivers almost always drew a very specific picture of the care receiver. The patient was considered a frail and dependent human being, compared even with a small child. In fact, care-giving was perceived as an ordinary circumstance affecting carers' lives just like parenting does: education, surveillance 24 hours a day and protection from every possible risk or danger are only a few of the day-to-day challenges that were mentioned. Certainly, interpreting

spouses, parents or siblings as infants often resulted in unavoidable alterations in family relationships in terms of significant role transformations. The recipient, previously regarded as an important moral and physical support, by now became a person in need of permanent care and help:

In front of you there's a person that previously...let's say...was someone you could rely on. And now it's him who relies completely on me. You miss the person with whom you were able to share your fears and concerns. [...] And now I'm feeling a bit scared about the fact that I have to keep an eye on him...you have to look after him, but you aren't used to. So perhaps now I have two children instead of one? A small one and grown-up one? [...] And, indeed, this scares me. (Carer no. 5)

The care-giving relationship seemed to evolve in response to the recipient's behaviour towards the carer. The care receivers' character and their attitudes towards managing the illness influenced the caring needs and, as a consequence, facilitated or complicated the carer role:

He's a fighter. Maybe it's because of this that I feel more comfortable than others. Because of his strength of will! And this is an important benefit for me. (Carer no. 6)

Now that we are at home he's very nervous because he's too young to handle an illness like this. He's very nervous towards me and he's getting angry immediately over nothing. And I realise that this situation is starting to weigh heavily on me. [...] He rejects me, he feels even stressed by my presence...and I'm his wife... [cries] (Carer no. 9)

A positive previous relationship between the carer and the recipient seemed to reduce some of the strains of care-giving. Indeed, carers expressed the need of a relationship free from conflicts also when re-entering the home environment as they placed some expectations on their relative. They expected the recipient to adapt to the new situation as well as to be motivated and willing to recover:

It's not that easy. I tell him again and again: 'Look, I'll do everything for you, but you have to show some strength of will, too. Because if you let yourself go, I'm lacking the support I need.' (Carer no. 8)

Reflections on the support required to carry out the role of carer (organisational level)

When caregivers reflected on the support they required, nearly everyone named other family members as essential resources. Family gave important psychological and organisational assistance, and in some cases, close friends did so too. Caregivers felt being left alone and abandoned, when they missed this informal help completely. In some cases,

caregivers who needed some support were waiting for help to be offered to them rather than asking for it explicitly:

I think, his daughter could simply say 'Look, I'll take 10 days off to care for my dad. In the meantime you could get some rest.' I would even pay her...but...she never said anything. Neither for a day nor half a day [...] Everything is down to me. (Carer no. 8)

As literature suggests, hospital staff especially should adequately support caregivers during the transition period. In this research, caregivers reported different experiences related to formal support: some felt well prepared and involved in nursing and therapeutic procedures; others experienced little help as well as poor understanding and empathy:

I told them [the nursing staff] my doubts and my fears because I had always just known him as a healthy person. But despite this, no one understood me. I felt like they were not going to tell me anything else but 'Ah, you'll see, it's all going to work out'. I realised I had to manage on my own. It's best not to complain or speak about your doubts. And if you have any doubts, you better go and look for someone who you can really talk to. (Carer no. 6)

A noticeable aspect regarding the organisational level was that caregivers were often seeking information outside the hospital setting. The reasons for this phenomenon could be poor trust in and scepticism towards hospital staff, also related to previous experiences of bad care and bad medical support. Carers seemed to feel more comfortable and confident gathering information from qualified persons in their personal sphere as they showed better understanding of the caregivers' conditions. Also, individuals who were experiencing similar situations were considered highly credible and trustworthy:

I needed somebody to care for the whole organisational part as it is the very first time that I have to deal with it. It was a friend of mine, a nurse, who told me all those things and not a staff member. (Carer no. 9)

Discussion

The aim of this study was to gain an insight into caregivers' experience regarding the transition from hospital to home. Caregivers' statements as well as the field notes taken by the researcher revealed the emotional overload associated with this period. In fact, caregivers' thoughts and reflections prior to discharge and afterwards changed only slightly.

The decision to care for a patient at home was always associated with ambivalent feelings. Being at home allowed for the return of some daily routine and control, but at the same time this was connected with fears, doubts and

uncertainties. Previous studies support these findings (Grant *et al.* 2006, Turner *et al.* 2007, Boughton & Halliday 2009). During hospital stay, the patient's itinerary was organised, scheduled and outlined by healthcare professionals, in many instances without involving the carer at all. But when approaching the discharge process, the organisation of the caring activity and the responsibility for the patient's well-being was more and more left to one single relative making him or her feel unprepared and overanxious. As a consequence, one of the priority caregiver needs was to receive adequate information and preparation from hospital staff to provide good care after patient discharge. This mirrors other findings (Shyu 2000, Bakas *et al.* 2002, Grimmer *et al.* 2004, Goodwin & Happell 2006, Boughton & Halliday 2009), but what this research adds is that caregivers give clear suggestions on what respectful relationships and effective communication should look like. As communication processes are not only made up of the dimension of content but also of that of interpersonal relations, information should be transmitted in a direct, clear and competent manner using a humane, sensitive and honest attitude. Helping caregivers to draw new hope, instead of creating illusions, should be part of good communication. Also, Haesler *et al.* (2006, 2007) argue that promotion of positive communication strategies is essential for the development of an effective caregiver–staff relationship.

Perhaps, because of the sensation of being overlooked by healthcare professionals, caregivers mainly developed a strategy of looking for informal sources of information, attributing greater credibility and trustworthiness to those sources. Resorting to 'informal networking' in the absence of information from professionals is a finding described also by Brereton and Nolan (2002). According to Printz-Feddersen (1990), especially comparing carers' experiences and situations with others seemed to enable them to cope with the stresses of care-giving.

Regarding caregivers' reflections on the recipient's condition, role changes have been identified as a significant challenge families have to face when adapting to their new care-giving context. This finding is in line with previous studies (Hertzberg & Ekman 2000, Sandberg *et al.* 2002, Smith *et al.* 2004). However, coping with the problems of care-giving for a dependent person seemed to be easier in the context of a loving relationship and the recipient's positive behaviour and affective reward (Huang & Peng 2010).

The key finding of this study was that being responsible for everything seemed to weigh most heavily on caregivers. Findings regarding the relevance of other commitments in addition to the caring activity are well in accordance with other studies (Kerr & Smith 2001, Brereton & Nolan 2002, Grimmer *et al.* 2004, Mackenzie *et al.* 2007, Huang & Peng

2010), but they did not put such a great emphasis on it. This research highlights that the amount of responsibility required could lead to emotional overload and role strain in a short period of time. Carers have to concentrate their thoughts on the care receiver's needs and safety 24 hours a day and at the same time have to fulfil other social roles: they have to be spouses, parents, workforces and housekeepers and, in addition, they have to possess a certain amount of psychological, nursing and therapeutic skills. Those who cannot count on social and family support in these circumstances or are not able to take a break and detach themselves, increase the risk of experiencing the often cited caregiver's strain and burden (Lim & Zebrack 2004, Sit *et al.* 2004, Chow *et al.* 2007). However, it is important to state that the sense of responsibility gains a sour note only in the postdischarge period. Prior to discharge, responsibility seems to be rather associated with positive feelings, with carers expressing a maternal sense of caring for the recipient. It is only once home that caregivers become conscious about the full meaning of the recipient's impairment, gaining a more or less realistic picture of the situation. Considering that these relevant issues emerged quite clearly, it should be pointed out that caregivers appreciated the possibility of short weekend discharges before facing definite discharge of the patient. Trying out the carer role as well as testing the home environment for architectural barriers seemed to be very helpful.

Study limitations

The reported care-giving experiences may not be reflective of carers in other settings because the sample used in this study was purposive. It was not always possible to interview the caregivers alone. In a small number of instances ($n = 3$), caregivers could not leave the patient unaccompanied while participating in the interviews or focus groups and this fact may have constrained the carer's comments. As has already been discussed, the first month after arriving home is perceived as particularly dynamic and stressful. Ideally, this research should have been continued over a longer period providing a better understanding of how carers' experiences change over an extended time.

Conclusions

This study gave a rounded and deep insight into how caregivers experience the transition from hospital to home with the aim of facilitating a better understanding of their perspectives. Findings suggest that caregivers were not able to cope with some aspects of caring neither prior to patient discharge nor afterwards, and they often received little

professional support. Care-giving can be a demanding and even all-consuming task that takes a lot of time, psychological energy and physical stamina; therefore, it cannot be assumed that families can cope with the demands care-giving brings. Multi-professional healthcare teams should come to recognise the caregiver as the primary support for the recipient, as an important source of information, as a co-therapist in the home care setting and, last but not least, as a person in need of emotional and practical support.

Relevance to clinical practice

The study findings indicate that new informal caregivers' experience is still not receiving sufficient attention or remains even unnoticed by healthcare professionals. Consequently, the findings could guide hospital staff and especially nurses on how to deal with caregivers and on how to handle their needs, their emotions, their worries and their expectations. Indeed, caregivers gave important advice on actions they found supportive of their newly acquired role. Certainly not every challenge of care-giving can be addressed by healthcare professionals; nevertheless, hospital staff have to be encouraged to accompany caregivers in the process of adapting to their new role and provide education and support. To reach this goal, the following strategies could be effective:

- 1 acquiring effective communication skills and displaying an empathic attitude by:
 - encouraging caregivers to express their deep needs and feelings to tailor interventions in a more efficient manner;

References

- Bakas T, Austin JK, Okonkwo KF, Lewis RR & Chadwick L (2002) Needs, concerns, strategies and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing* 34, 242–251.
- Balls P (2009) Phenomenology in nursing research: methodology, interviewing and transcribing. *Nursing Times* 105, 30–33.
- Bauer M, Fitzgerald L, Haesler E & Manfrin M (2009) Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing* 18, 2539–2546.
- Blane D (1996) Collecting retrospective data: development of a reliable method and a pilot study of its use. *Society, Science and Medicine* 42, 751–757.
- Boughton M & Halliday L (2009) Home alone: patient and carer uncertainty surrounding discharge with continuing clinical care needs. *Contemporary Nurse* 33, 30–40.
- Bowman K, Rose J & Kresevic D (1998) Family care-giving of hospitalised patients: caregiver and nurse perceptions at admission and discharge. *Journal of Gerontological Nursing* 24, 8–16.
- Brereton L & Nolan M (2002) 'Seeking': a key activity for new family carers of stroke survivors. *Journal of Clinical Nursing* 11, 22–31.
- Bull MJ, Hansen HE & Gross CR (2000) Differences in family caregiver outcomes by their level of involvement in discharge planning. *Applied Nursing Research* 13, 76–82.
- Chow SK, Wong FK & Poon CY (2007) Coping and caring: support for family caregivers of stroke survivors. *Journal of Clinical Nursing* 16, 133–143.
- Colaizzi PF (1978) Psychological research as the phenomenologist views it. In *Existential Phenomenological Alternatives for Psychology* (Valle RS & King M eds). Plenum, New York, NY, pp. 48–71.
- Dorsay MK & Vaca KJ (1998) The stroke patient and assessment of caregiver needs. *Journal of Vascular Nursing* 3, 62–67.
- Giorgi A (2006) Concerning variations in the application of the phenomenological method. *The Humanistic Psychologist* 34, 305–319.

- valuing and appreciating caregivers' presence to make them feel more positive about their care-giving role;
- 2 satisfying carers' needs for hope, confidence and safety when re-entering the home environment by:
 - providing well-timed, individually targeted information, practical guidance and instructions;
 - carrying out a telephone follow-up in the first few days and weeks after discharge to monitor how caregivers are coping with the physical and emotional aspects of caring;
 - establishing self-help support groups for caregivers to enable them to socialise with others and to vent feelings;
- 3 removing a small piece of caregivers' responsibility by
 - assigning one health professional exclusively to the provision of information on organisational and bureaucratic matters to reduce the difficulties of searching for adequate information.

Contributions

Study design: AP, VM; data collection and analysis: AP, LC and manuscript preparation: AP, VM.

Conflict of interest

The authors have no conflict of interest.

- Giorgi AP & Giorgi BM (2003) The descriptive phenomenological psychological method. In *Qualitative Research in Psychology* (Camic P, Rhodes JE & Yardley L eds). American Psychological Association, Washington, DC, pp. 242–273.
- Goodwin V & Happell B (2006) Conflicting agendas between consumers and carers: the perspectives of carers and nurses. *International Journal of Mental Health Nursing* 15, 135–143.
- Granger CV, Hamilton BB, Linacre JM, Heinemann AW & Wright BD (1993) Performance profiles of the functional independence measure. *American Journal of Physical Medicine & Rehabilitation* 72, 84–89.
- Grant JS, Glandon GL, Elliott TR, Giger JN & Weaver M (2006) Problems and associated feelings experienced by family caregivers of stroke survivors the second and the third month postdischarge. *Topics in Stroke Rehabilitation* 13, 66–74.
- Greenwood N, Mackenzie A, Wilson N & Cloud G (2009) Managing uncertainty in life after stroke: a qualitative study of the experiences of established and new informal carers in the first three months after discharge. *International Journal of Nursing Studies* 46, 1122–1133.
- Grimmer K, Moss J & Falco J (2004) Becoming a carer for an elderly person after discharge from an acute hospital admission. *The Internet Journal of Allied Health Sciences and Practice* 2, 1–8. Available at: <http://ijahsp.nova.edu> (accessed 14 December 2009).
- Haesler E, Bauer M & Nay R (2006) Factors associated with constructive staff-family relationships in the care of older adults in the institutional setting. *International Journal of Evidence-Based Healthcare* 4, 288–336.
- Haesler E, Bauer M & Nay R (2007) Staff-family relationships in the care of older people: a report on a systematic review. *Research in Nursing and Health* 30, 385–398.
- Han B & Haley WE (1999) Family caregiving for patients with stroke. *Stroke* 30, 1478–1485.
- Hertzberg A & Ekman SL (2000) 'We, not them and us?' Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of Advanced Nursing* 31, 614–622.
- Huang TT & Peng JM (2010) Role adaptation of family caregivers for ventilator-dependent patients: transition from respiratory care ward to home. *Journal of Clinical Nursing* 19, 1686–1694.
- Kerr S & Smith LN (2001) Stroke: an exploration of the experience of informal care-giving. *Clinical Rehabilitation* 15, 428–436.
- Kitzinger J (1995) Qualitative research: introducing focus groups. *British Medical Journal* 311, 299–302.
- Lane P, McKenna H, Ryan A & Fleming P (2003) The experience of the family caregiver' role: a qualitative study. *Research and Theory for Nursing Practice: An International Journal* 17, 137–151.
- Lim JW & Zebrack B (2004) Caring for family members with chronic physical illness: a critical review of caregiver literature. *Health and Quality of Life Outcomes* 2, 50. Available at: <http://www.hqlo.com/content/2/1/50> (accessed 27 April 2010).
- Mackenzie A, Perry L, Lockhart E, Cottey M, Cloud G & Mann H (2007) Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation* 29, 111–121.
- Marsili M (2010) *ISTAT Demographic Indicators – 2009*. Available at: http://demo.istat.it/index_e.html (accessed 15 June 2010).
- McMurray A, Johnson P, Wallis M, Patterson E & Griffith S (2007) General surgical patients' perspectives of the adequacy and appropriateness of discharge planning to facilitate health decision making at home. *Journal of Clinical Nursing* 16, 1602–1609.
- Morrison RS & Peoples L (1999) Using focus group methodology in nursing. *The Journal of Continuing Education in Nursing* 30, 62–65.
- Mortari L (2008) *Cultura della ricerca e pedagogia*. Carocci, Roma [in Italian].
- Olofsson A, Andersson SO & Carlberg B (2005) 'If only I manage to get home I'll get better'-interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical Rehabilitation* 19, 433–440.
- Polverini F, Principi A, Balducci C, Melchiorre MG, Quattrini S, Gianelli MV & Lamura G (2004) *EUROFAMCARE – Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage*. National Background Report on Italy, INRCA Ancona. Available at: <http://www.uke.uni-hamburg.de/eurofamcare/> (accessed 11 June 2010).
- Pringle J, Hendry C & McLafferty E (2008) A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing* 17, 2384–2397.
- Printz-Feddersen V (1990) Group process effect on caregiver burden. *Journal of Neuroscience Nursing* 22, 164–168.
- Rochette A, Tribble D, Desrosiers J, Bravo G & Bourget A (2006) Adaptation and coping following a first stroke: a qualitative analysis of a phenomenological orientation. *International Journal of Rehabilitation Research* 29, 247–249.
- Saiani L, Palese A, Brugnolli A & Benaglio C (2004) Guida di autoapprendimento: La pianificazione delle dimissioni ospedaliere e il contributo degli infermieri. *Assistenza Infermieristica e Ricerca* 23, 233–249 [in Italian].
- Sandberg J, Nolan MR & Lundh U (2002) 'Entering a new world': empathic awareness as the key to positive family/staff relationships in care homes. *International Journal of Nursing Studies* 39, 507–515.
- Shepperd S, Parkes J, McClaran J & Phillips C (2004) Discharge planning from hospital to home. *Cochrane Database of Systematic Reviews*, Issue 1, Art. No.: CD000313. Doi: 10.1002/14651858.CD000313.pub3.
- Shyu YIL (2000) The needs of family caregivers of frail elders during the transition from hospital to home: a Taiwanese sample. *Journal of Advanced Nursing* 32, 619–625.
- Sit J, Wong T, Clinton M, Li L & Fong YM (2004) Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing* 13, 816–824.
- Smith L, Lawrence M, Kerr S, Langhorne P & Lees K (2004) Informal carers' experience of caring for stroke survivors. *Journal of Advanced Nursing* 46, 235–244.
- Turner B, Fleming J, Cornwell P, Worrall L, Ownsworth T, Haines T, Kendall M &

Chenoweth L (2007) A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury* 21, 1119–1130.

White CL, Korner-Bitensky N, Rodrigue N, Rosmus C, Sourial R, Lambert S & Wood-Dauphinee S (2007) Barriers and facilitators to caring for individuals with stroke in the community: the family's experience. *Canadian*

Journal of Neuroscience Nursing 29, 5–12.

Wimpenny P & Gass J (2000) Interviewing in phenomenology and grounded theory: is there a difference? *Journal of Advanced Nursing* 31, 1485–1492.

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