



The impact of stroke on lay carers

The Science Shop

The impact of stroke on lay carers.
A qualitative study with 8 carers of stroke patients.

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On request from:

Northern Ireland Chest Heart and Stroke Association.

(NICHSA)

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Foreword.

In the summer of 2000 I started thinking about doing the second research project of my course in Biology abroad. But after my first experience with research I realised that fundamental research wasn't my thing. I felt the need to do something practical, more useful in my eyes. Therefore I turned to the Science Shop for Biology, at the Utrecht University. They were surprised at my request, because they had never sent a student abroad for a project. And I in return I was surprised that this had never happened. But my timing couldn't have been better, because the Science Shop had just started a project on international cooperation and exchange. So the contacts were there and we agreed to give it a go. A few months later I booked my flight to Belfast, Northern Ireland.

What was supposed to be a six-month stay became a nine-month stay, and the project itself took over a year, instead of six months. I ran into some problems, being the first student to go abroad on a Science Shop project; not having a student card and therefore not having access to the computers in the library; not having an official supervisor here, so that she had to do the supervising in her own time, and so on. But it was definitely worth it.

I find myself back in Belfast again, even though there's no need for me to be here. I fell in love with the country, (it's pubs) and it's people. A great experience.

I'd like to thank the Science Shop for Biology (UU) and in particular Caspar de Bok for giving me this chance and supporting me from afar. I would also like to thank the QUB Science Shop, especially Eileen Martin, for having me and trying to make things easier for me. Many thanks to Hazel McFadden of the School of Nursing (QUB) as well for advising and guiding me in her own time.

Further, my thanks go to my parents, for supporting me financially and in many other ways; my brother and sister, for sending me articles I needed and keeping me up to date about the home front; Sean, for letting me live with him, showing me the best of Belfast, winning me a Mediterranean cruise, and for being a great friend; Lynette and Paul for letting me use their computers, and all my friends back home and here for making sure I've had a great time.

Anke Jongen

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Abstract.

Northern Ireland has one of the highest rates of stroke and heart attack in Europe. The Northern Ireland Chest Heart and Stroke Association (NICHSA) has been trying to improve its services for lay carers.

In this research the following questions were answered:

- What are the issues carers have to deal with in caring for a stroke patient?
- What are carers' needs with regards to services and support?
- How can NICHSA meet these needs?

A literature review was done and a semi-structured interview was designed. Eight lay carers were interviewed about their problems and needs.

The results showed that the more severe the stroke had been, the more often carers felt down in mood, felt their role in life had changed, and the less guilty they felt asking others for help. Some carers felt frustrated with the patient from time to time as a result of the patient's physical and cognitive disabilities.

The most important factor in the support network of carers was their family. But even though most carers felt they received great support from their families, they felt guilty sometimes to ask them for help. They felt the patient is their own responsibility.

The opinions on professional support were divided, though most carers were not very satisfied with the information and support received in hospital. Especially the preparation for the time directly after discharge and on the longer term was unsatisfactory. They also felt professionals didn't consider carers enough and therefore felt forgotten about. They didn't know whom to turn to for practical help, support and benefits. More information about this is necessary.

Carers felt down in mood from time to time as a result of the caring role. Often this was a result of being bound to the house because of the patient's physical disabilities. They expressed a need for a break from caring, to relieve stress. Some of the carers that expressed a need for a break didn't know how to realise this. More information about services available to them should be provided.

The changed character of patients had an effect both on the relationship between carer and patient, and on the carer's social life. It led some carers to get frustrated with the patient. The relationship between carer and patient had an effect on how the caring was perceived by the carer.

Carers felt uncertain about the future. Carers mentioned feeling worried about becoming less able to cope with caring, either because of deterioration of the patient, or of their own health.

Recommendations for NICHSA are made.

1. Introduction.

In Northern Ireland there are approximately 4000 new cases of stroke every year¹. It is the third leading cause of death in the United Kingdom, accounting for 10-12 per cent of all deaths². Of the survivors, over a third are left with some degree of permanent disability². A stroke therefore often has a great impact on the lives of both patient and carer*. In “Living with stroke”³ the reaction to stroke is likened to bereavement. Like bereavement a stroke often means significant loss for those involved. For the victim there is the sudden loss of physical functions and therefore of the life he or she was used to. For the carer it may feel as if something of the person has been lost, either in physical terms or in changes in their personality.

After the first shock both patient and carer start focusing on rehabilitation. Most authorities agree that recovery is greatest during the first three to six months following stroke⁴. After that recovery is slow and minimal. This might result in disappointment, as full recovery might not occur. Patient and carer then find their lives turned upside down overnight. The patient may have to give up working because of his disabilities. The carer may have to start doing the things the partner used to do. Their social life might not be the same since the stroke. They start to realise that their lives will never be the same again. Appendix 1 gives a striking example of this.

Northern Ireland has one of the highest rates of stroke and heart attack in Europe. There is an organization that’s trying to do something about this, the Northern Ireland Chest Heart and Stroke Association (NICHSA), which was established in 1946. Its mission is to prevent and alleviate chest, heart and stroke illnesses through programmes of research, information, advice, Stroke Clubs, at which patients can meet each other, relax, and learn to cope with the consequences of their stroke, and Family Support Schemes, to support families of people who have had a stroke.

NICHSA appreciates the fact that a stroke influences not just the life of the person who suffered the stroke, but that it brings along quite some changes for the carer as well. NICHSA has been looking to improve it’s services for carers. After listening to carers’ stories NICHSA realised there was a need for support regarding the mental problems faced by carers. With this aim NICHSA turned to the Queen’s University Belfast (QUB) Science Shop.

* The term ‘carer’/‘caregiver’ refers to lay carer/caregiver throughout the document.

Though a lot of research has been done into the impact of stroke on the lives of carers, most of these have been quantitative studies. These studies have given an insight in the impact of stroke, but they haven't taught us a lot about the 'lived experience' of caring for someone who has had a stroke. In quantitative studies carers might not be able to express all their concerns and all aspects of caring. In qualitative research carers are given a better chance to do so.

There have been qualitative studies over the years, but these have focused on one specific aspect of caring. McLean⁵ examined areas of perceived need amongst carers, Thompson⁶ focused on depression in carers, Wiles⁷ identified information needs of carers, Pound⁸ and Wellwood⁹ both studied carers' satisfaction with services.

None of these studies was done in Northern Ireland. So there was a need for a qualitative study into the overall impact of stroke on the lives of carers in Northern Ireland.

In this research I tried to answer the following questions:

- What are the issues carers deal with in caring for a stroke patient?
- What are carers' needs with regards to services and support?
- How can NICHSA meet these needs?

The research was carried out at the Queen's University of Belfast (QUB) Science Shop in close association with the Science Shop for biology of the Utrecht University in The Netherlands. The total duration of the research was 6 months and it was supervised at the School of Nursing (QUB).

2. Methods.

This research consisted of two parts. First, a literature review was done to find out more about the needs of lay carers.

Second, a semi-structured interview was designed. A qualitative approach was used, because this focuses on the “lived experience” and the interpretations and meaning which people attach to it¹⁰. The goal of qualitative research is the development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants¹¹. This approach was specifically suited for this research, because I was interested in what the problems are that carers face and what their needs are. In other words; “What is X and how does X vary in different circumstances, and why?”, rather than “how many X’s are there?”, which is the focus of quantitative research¹¹. After identifying the “X” in this qualitative study, the next step could be determining “how many X’s there are”, in a follow-up quantitative study.

Several books on qualitative research were used as guidelines for the interview^{10,12-14}, which was designed to find out what issues carers deal with and if and how they think stroke services don’t measure up.

2.1. Literature review

The search engines used to find literature on the subject were Medline and Psychlit. Search terms used were: stroke, care(r)(s), caring, caregiver(s), well-being, coping, chronic illness, distress, impact, recovery, bad/sudden news, respite, intervention, service(s), support, stroke clubs. Articles both in English and in Dutch were reviewed. For unpublished literature about caring in Northern Ireland I looked at the collection of unpublished material in the Medical Library of QUB in the Royal Hospital, Belfast. This resulted in a total of 66 articles. I chose not to give a complete survey of what has been written on the subject of caring for a stroke patient, because this would be too time consuming. Instead I focused on the topics that would help me in discussing the results of my own research and that would help me make recommendations for NICHSA.

2.2. Subjects

Initially, the goal was to get a total of 15 participants. This number was chosen, because of a time factor. It was the largest number of interviews and transcriptions I thought possible as part of a 6 month research. Subjects were recruited in two ways. In order to get carers to participate voluntarily, I wanted to place an advert in the local paper. This turned out to be too costly. Therefore, the PR-consultant of NICHSA interviewed me over the phone and sent the press release resulting from that to 6 local papers. Unfortunately not all papers printed this in full. NICHSA tried to rectify this. Six carers responded to the article. They were sent letters in which the research was explained once more. After a few days they were phoned, given the opportunity to ask questions and again asked if they wanted to participate. Participants had a choice of time and venue of the interview. At each of those interviews carers were encouraged to ask others to join in the research, but no more responses came from that.

Further, letters were then sent out to 6 different Stroke Clubs and a Carers Group, all organised by NICHSA. In this way, I would be able to reach a lot of carers at the same time, which would increase the chances of reaching the target of 15 participants. It also meant that all participants to come had already been in contact with NICHSA. Although this meant a restriction in the way that subjects would be more part of a selection than I wanted them to be, it would also give me the opportunity to compare the two different groups, since none of the 6 carers recruited via the papers had been in contact with NICHSA.

In response to the letters two more carers decided to participate, bringing the total to 8 subjects. Two other carers let me know by letter that they really appreciated the initiative, but weren't able to participate. Although the initial target was 15 subjects, there was no time to try and recruit more carers in yet another way.

2.3. Measures

The interview consisted of 4 multiple-choice questions and 6 open questions to cover demographic details. The second part of the interview consisted of 12 multiple-choice questions. These allowed comparison of answers given by participants. The answers to the multiple-choice questions in the second part of the interview had to be explained by the participant.

The interview also consisted of 8 open questions, allowing the participants to answer as briefly or as extensively as they want. The advantage of open questions is that the answers you'll get will reflect what is important to the respondent¹² (for full interview, see appendix 2).

Six of the eight interviews were done at the participants' homes. The other two were done in small local lunchrooms. These venues were the participants' choices. Duration of the interviews ranged from 25 to 90 minutes. At two interviews the patients were present as well. These two carers both stressed that they had already spoken to their spouses about the problems they faced. The presence of the patient therefore didn't influence the interview, as both participants spoke freely.

Before the interview participants signed an informed consent. Participants were offered to receive a summary of the results, and all took that offer.

At four of the eight meetings with participants, I had a conversation with the carer after the interview, in which some more themes were mentioned, or themes were mentioned again. These were written down as soon as possible and analysed the same way as the interviews. The reason for this is that the respondent's construction of their experience often only begins to emerge after lengthy in-depth dialogues¹⁴. Since most interviews took no longer than 40 minutes, the information given after that time was a valuable addition to the interview. Carers repeated what was important to them or added new information to it spontaneously.

2.4. Analysis

The data were analysed using *content analysis*, which is defined as the systematic examination of text (field notes) by identifying and grouping themes and coding, classifying, and developing categories¹⁴. For the analysis of the data 7 steps were taken. These steps were taken to bring structure into the collection of statements that each interview was¹². To study the impact of stroke on the lives of carers it was necessary to find out which themes came up for discussion. The 7 steps mentioned below enabled me to distinguish and categorise the different themes.

- 1) Transcribing interviews into computer (example of transcription: appendix 3).
- 2) Dividing each interview into fragments.
- 3) Giving each fragment a theme, no more than 4 themes per fragment.
- 4) Categorising each theme in one or more of the following 8 main categories (for complete list of themes see appendix 4):
 - Complexities of the carer role
 - Unpredictable nature of support network
 - Emotional demands of caring
 - Need for carer education and support
 - Personal and social impact on carer
 - Need for planned respite service
 - Emotional impact of changed relationship on life carer
 - Coping with caring
- 5) Counting frequencies of the different themes in each interview separately and all the interviews together. (list of all themes + frequencies: appendix 5)
- 6) Looking for a possible correlation between occurring frequencies.
- 7) Looking at each interview for occurring combinations of themes (within fragments, or in adjacent fragments) and compare combinations of different interviews.

Although with only 8 subjects there isn't much point in statistically analysing data, because all your findings are going to be based on coincidence¹⁵, I did look at occurring combinations of themes and correlations between answers to the multiple choice questions. The reason for this is the fact that though those results do not carry any statistical significance (and therefore weren't analysed in that way), they carry a lot of information that should not be ignored. These combinations and correlations could give an insight into the reasons behind carers' problems.

2.5. Discussion.

In the discussion the findings of this research were compared to findings from earlier studies to confirm or question their importance. Because the sample of this study was small, this was an important step. It

enabled me to look critically at the findings of this study and pinpoint the contingent weaknesses of the research.

2.6. Recommendations.

These were derived from the discussion. Therefore the recommendations were the result of both findings from this study, as well as findings from previous studies.

3. Literature review.

The purpose of this review was not to give a complete oversight of the research that has been done into caring for a stroke patient and caring in general. It was simply meant as background information for the second part of the research. In this review I have taken a closer look at the following subjects:

- 1) The influence of the carer on the recovery of the patient.
- 2) Carers' needs with regards to information.
- 3) Carers' needs with regards to services and support.
- 4) Support actions and their results.
- 5) Comparison of stroke carers to carers for patients with other illnesses.
- 6) Caring in Northern Ireland.

These subjects were chosen because they would complement the findings of this research. Before finding out the impact of caring on carers, it is important to establish the effect carers have on the patients (subject 1). Will improving their mental health also improve the patient's health?

Further, it was essential to find out what other studies had found out about carer's needs and problems (subject 2-4), to enable comparison with the results of this study.

Also, in trying to improve their services, Stroke Associations might benefit from research into other illnesses, if there are similarities between the problems these carers face and the problems stroke carers face (subject 5).

Finally, since this research will include recommendations for an organisation in Northern Ireland, it seemed useful to look at carers in Northern Ireland specifically (subject 6).

3.1. The influence of the carer on the recovery of the patient.

During the last 20 years there has been a growing interest in the effect of stroke on the carer. One reason for that might be the fact that the carer has a great influence on the recovery of the patient¹⁶⁻¹⁹.

Or, as Anderson puts it: caregivers influence rehabilitation of the patient through their willingness and ability to support²⁰. They influence the amount that patients do for themselves and their subsequent progress in rehabilitation^{16,21}.

A patient's morale has an important influence on his recovery. In general, carers are a lot less optimistic about the patient's recovery than the patients themselves²². Purk and Richardson²³ tried to find out

whether the morale of stroke patients and their spouses were related. After assessing 44 couples they found that this was indeed the case. Overall morale of caregivers and care receivers were positively related. The researchers conclude from this that the morale of care receivers may have a positive effect on caregivers morale and vice versa. Since there seems to be such an influence, it would be a good idea for support services to consider the carers as well as the patients. Purk and Richardson²³ advise: "Spouses of patients should be included in any program of physical rehabilitation and counselling, for both the patient's and the spouse's benefit."

Carnwath and Johnson²⁴ looked into depression among spouses of stroke patients. They state that after a year little physical improvement can be expected in patients with stroke. The difference between successful and unsuccessful rehabilitation depends on the degree to which social interests, activities, and occupations are taken up again. Their study showed that depression in the spouse might be an important factor militating against such rehabilitation. If the spouse does not feel like seeing anybody it is very hard for the patient to take the initiative and organise it himself. Helping spouses overcome their own depression may play an important part in the rehabilitation of patients at this stage.

Williams²⁵ states: "Because the patient's family can either enhance or undermine the success of a rehabilitation program, rehabilitation professionals and families must work together to provide a solid support base for the disabled person."

3.2. Carers' needs with regards to information.

One of the problems carers face when a loved one has a stroke is that they often have no previous experience in caring, or knowledge about stroke. Quite a few carers will be shocked by what has happened and researchers have questioned whether they are able to take information in shortly after the stroke, wondering if maybe it is pointless to inform carers when they are very emotional. This definitely seems to be the stereotype by which nurses and other medical staff make their judgements. When asked to give an opinion on how emotional they considered six hypothetical wives of stroke patients to be and how much information they thought each wife would be able to absorb, nurses and the general public were more pessimistic than caregivers in their assessment of the amount of information that could be absorbed, even though these two groups did not differ in their assessment of

the emotionality of the wives²⁶. The existence of this stereotype provides an explanation for why caregivers sometimes feel neglected in medical settings.

In a follow-up study Braithwaite and McGown²⁷ aimed to explore the capacity of emotional caregivers to learn about stroke. In this research the knowledge of 37 stroke carers was assessed before and after a 2-hour seminar. Results showed that emotionally unstable carers were as capable of learning about stroke as stable carers. The researchers note that this does not discount the fact that emotional carers might be too shocked to take in information from hospital staff at the time of admission. In a study by Greveson and James²⁸ most of the interviewed patients and carers stated that they felt they couldn't assimilate the information presented to them in the few days after the stroke when they were still in a state of shock. This is not just typical for relatives of stroke patients. Research shows that information given when breaking bad news does not permeate the sense of shock²⁹. Carers have a need for sympathy and consideration, rather than information at that time. They need their feelings to be acknowledged and respected, rather than ignored by overwhelming them with information³⁰.

From this we can conclude that the moment of admission might not be the best moment to provide carers and patients with information. This could be one of the reasons why research has consistently shown that patients are frequently dissatisfied with the quality and quantity of information provided by nurses and other health professionals³¹. It could also explain why in a study about the knowledge of stroke⁹ among patients and carers 22 % of the patients and 15 % of the carers did not differentiate between a stroke and a heart attack. They were probably still too shocked to take in the information given to them at the time of the stroke and drew the wrong conclusions later on.

Wiles et al.⁷ tried to identify the information needs of patients and carers at three different phases post-stroke: during hospitalisation, up to 1 month post-discharge, and 2 months to 1 year post-stroke, through in-depth interviews. The results showed that there were information needs in three main areas: clinical information, practical information and information on continuing care and resources in the community.

Almost all interviewees wanted more information about recovery than they had received. At all three phases there was a need for information about what stroke is, what the causes of stroke are and how a stroke can be prevented. On discharge, carers in particular were distressed at the lack of information given about the effects the stroke had had on the patient. Immediately after discharge and up to a year

after discharge both patients and carers expressed a need for practical information relating to coping with day-to-day care. At every phase patients and carers had a need for information about what would happen to them once they were discharged from the hospital, what benefits and resources were available in the community and how these could be assessed.

The study has shown that there's a desire for general information (e.g. resources available in the community), but also for individualised information (e.g. recovery, effects of the stroke, services available).

Other studies also found a need for better support, services and information after hospital discharge^{8,28}. A lot of these sources are actually available, but patients and carers are unaware of them²⁸. Morrison concludes in her review that in terms of improving the quality of care to carers, having information about the stroke and available services can reduce carer distress and increase control and informed choice³². Though it might not be easy to meet every individual carer's needs, it's important to try and do so. The importance of this was also pointed out by Wellwood et al.⁹ and Wiles et al.⁷. The latter attempted to set up a database of information needs, to provide individualised information packages. Though time consuming, this would be a very effective way of meeting carers' needs.

Some more recommendations are given by other studies. Wellwood et al.⁹ suggest increasing the available literature to patients and carers, organising group meetings and compiling audio-visual information packages. Greveson and James³³ recommend that hospitals should have an agreed policy for providing information about stroke illness and available resources to all stroke patients and carers. They also think professionals should work more closely with agencies such as the Chest Heart and Stroke Association, to ensure better support to patients and carers.

3.3. Carers' needs with regards to services and support.

Stroke is a 'family' illness; it presents challenges and dilemmas to those who live with or support patients²². There is no time to prepare for the changes they have to make because of the suddenness of the stroke. What do these changes involve?

According to James³⁴ there are three essential components of caring. Firstly physical work, which encompasses aspects such as help with personal care or shopping, secondly emotional work, which refers to the way carers support and reassure the care recipient, and finally managerial, which involves taking responsibility for organising the care receiver's life in an acceptable way to the individual concerned. This is quite a job to handle for an (in a lot of cases) elderly person. For a lot of carers it's too much. A common phenomenon among carers of stroke patients is depression^{24,35,36}, though numbers vary from 18 to 61 % of the carers³². It is important to tackle this problem, not just for the carer's sake, but also because the social rehabilitation of patients has been found to be less successful if their spouse was depressed²⁴. Support and services for carers have become an important issue.

In April 1996, the Carer (Recognition and Services) Act³⁷ came into force and as a result of this, each local authority is obliged on request to recognise and assess the needs of carers³⁸. But what are the support needs of carers? McLean et al.⁵ asked 20 stroke survivors and 20 main informal carers about their needs in semi-structured interviews. This resulted in six areas of need:

- 1) Physical care (assistance with activities of daily living).
- 2) Affective needs (poor communication with health professionals, uncertainty about how to handle the patient's emotionalism).
- 3) Physical health (health problems resulting from caring: poor sleeping, backache, weight loss, etc).
- 4) Respite needs (sitting service to give relief from caring).
- 5) Health education (carers complain about a lack of advice on future maintenance of their own and the stroke survivor's health).
- 6) Hospital aftercare (a need for a follow-up to discuss new post-discharge problems with a consultant).

Most of these needs resulted from the carers feeling 'abandoned' once away from the hospital situation. This was also found by Pound et al.⁸ In this study carers were satisfied with the care the stroke patient received while in hospital, but 61 % of the carers were dissatisfied with some aspect of the services received since discharge. Areas of greatest dissatisfaction were the provision of information on allowances and services needed after discharge, the provision of aids and adaptations and carer domiciliary support.

Overall, the one thing that is mentioned most is the lack of information, particularly about the causes of stroke and recovery^{5,8,9,39}. Also important is help with physical care^{5,8} and discharge arrangements^{5,9,39}.

McKevitt and Wolfe³⁹ asked people about the need for a community service for stroke families. About half of the interviewed felt they would benefit from such a service. They envisaged it as a service providing information about what to expect in caring for their relative and advice on practical issues. They would like someone to take the time to sit down with them and discuss things they needed to know. It's not surprising that carers feel there is no time for them, because research suggests that less than two per cent of community health workers' time was spent advising carers⁴⁰ with district nursing visits initiated only when a specific task is identified⁴.

In some cases carers have unmet needs because they are unaware of the services available^{5,28}. Information about local services is therefore extremely important.

3.4. Support actions and their results.

Three different support actions will be discussed here:

- 1) Stroke clubs (group education and counselling).
- 2) Family care worker/specialist nurse.
- 3) Respite care.

These are not all the possible support actions, but they are the most frequently used ones.

3.4.1. Stroke clubs (group education and counselling).

Support groups do not only exist for carers of stroke patients, but for carers (and patients) of many other chronic illnesses. They thrive on members sharing their personal experiences⁴¹. They provide information and promote interaction with others facing the same situation⁴¹⁻⁴⁴.

A study of 15 carers for Alzheimer patients found improved understanding of the disease the most important outcome. A sense of support, acceptance and realisation that emotional reactions were

normal were secondary outcomes⁴². Another study found a decrease in family burden and a decrease in levels of depression in carers of demented adults as a result of attending a support group⁴⁴. Using a similar approach Printz-Feddersen⁴⁵ sought to investigate burden of caregivers of stroke survivors. In this study no difference was found between the experimental group and the control group. This might be the result of the fact that the experimental group was not randomised. Printz-Feddersen simply used an existing stroke club to find participants for the study. Because of this self-selection the results are dubious.

The design of the study by Mykyta et al.⁴⁶ is slightly better. They did institute a “relatives group” themselves for the purpose of the research. Carers then had a choice of attending as little or as often as they wanted. The object of the group was education and supportive counselling. All carers attending the group found it extremely beneficial, but again, since they selected themselves as part of the group this result cannot be generalised for all carers.

Support groups are probably not an answer for every carer. Some carers take great comfort in sharing their experiences with other carers, but some don't. On top of that, not every support group is the same. Education seems to be an important aspect of support groups. Helping carers understand the disease will help them cope with the consequences of it. But this information should also be available to carers that don't want to share their personal experiences with people in the same situation. Separating the two (education and sharing personal experiences) will help to find out the benefits of these two aspects on their own.

This is exactly what happened in a research by Evans et al⁴⁷. They sought to find out the effect of education and counselling on caregiver knowledge, family function, and patient adjustment. In their study there were three groups of carers. One group received no treatment additional to what they received through the usual channels. Another group had to attend two 1-hour classes, which included basic information about the consequences of stroke and explanations on the individual treatments of the patients. The third group also attended these 2 hours of education and on top of that received seven individual 1-hour counselling sessions with a social worker. Results showed that six months after stroke both treatment groups had a better stroke knowledge than the control group. On top of that, the counselling condition significantly improved patient adjustment relative to control. These initial effect were maintained a year after stroke, and there was a delayed effect on family functions problem

solving, communication, affective involvement and global family function. Evans et al.⁴⁷ conclude that caregiver education facilitates and maintains adaptive changes in family function. Further, counselling helps maintain the benefits of education in several areas of family function and results in better patient adjustment.

This shows that even when not initiated by carers themselves, education and counselling are beneficial to them.

3.4.2. Family care worker/specialist nurse.

An alternative to support groups in getting carers information and counselling is sending someone to their homes to help them with whatever problems they face. A family care worker or specialist nurse can fulfil this role.

Unfortunately studies into this form of support haven't provided evidence that it is beneficial either to the patient or the carer⁴⁸⁻⁵¹. Forster and Young⁴⁹ assessed a treatment group and a control group at time of recruitment (as close to the onset of stroke as possible), at 3, 6 and 12 months, but no difference was found. At best, the specialist nurses' visits had a small effect in improving social activities in the subgroup of more mildly disabled patients with stroke. Dennis et al.⁴⁸ were also unsuccessful in finding a definite beneficial effect of a stroke family care worker on the physical, social, or psychological outcome of patients or their carers. They did manage though, to improve both patients' and carers' satisfaction in respect of various aspects of communication.

It is puzzling that there seems to be no beneficial effect of stroke family care workers or specialist nurses on the carers of stroke patients, and yet there is a beneficial effect of support groups. It is possible that the same rule applies to this type of support: it might be beneficial, but definitely not to all carers. Research into support groups more often wasn't randomised. This will have influenced the results. Carers could also see the family care worker or specialist nurse as an intrusion upon their privacy. This might reduce any beneficial effect it could have.

3.4.3. Respite care.

It is commonly known that caring for someone with a chronic illness is a heavy task. One way of alleviating the burden of caring is through respite care. Respite care involves the individual with a disabling condition being supported in a hospital/nursing home environment or at home for a short period of time, with the aim being to exert a positive effect on the carer's well-being during and after the intervention, thus enabling them to continue in their role⁵².

The beneficial effects of respite care on carers have been measured in different ways, psychological well-being and carer burden being the most popular terms in the evaluation of respite care. Some studies found a beneficial effect of respite care on psychological well-being⁵³⁻⁵⁷, but other studies found no effect⁵⁸⁻⁶¹. Further, the effect on psychological well-being or burden that was found was sometimes maintained up to 1 week after the end of the respite, but beyond 1 or 2 weeks the psychological well-being or burden seemed to return to baseline levels^{53,57}. So even though respite sometimes leads to improvements, these don't seem to last.

McNally et al.⁵² sought an explanation for this and found it in a study by Berry et al.⁶². They analysed carers' activity during respite and found that although carers did use the respite time to get on with other work, they were not engaging in more social or family activity, and therefore not using the time to maintain relationships that may serve to support them in the future. McNally et al.⁵² suggest that interventions to facilitate social contacts and relationships during respite may produce more long lasting effects by influencing carers' social resources. This is exactly what Hinchcliffe et al.⁵⁵ found when they not only offered respite, but also an individual comprehensive programme, which addressed issues such as the development of independent social activities outside the home. Carers receiving this intervention showed a significant improvement in mental health, which was maintained at a 16-week follow-up.

So even though the results of respite care aren't overwhelmingly positive, it is hopeful that more recent studies (from 1992 onwards) seem to be more likely to show benefits from respite care than those in an earlier period (1985-1991)⁵². This could very well mean that the respite provision has improved. A more 'carer-centred' provision of respite service, taking into account the way the respite time is spent, could increase the positive effects of respite.

3.5. Comparison of stroke carers to carers for patients with other illnesses.

When trying to tackle the problems stroke carers face it is important to not just look at stroke research, because a lot of the issues stroke carers deal with are the same for other carers. Caring for a stroke patient has been compared to caring for a dementia patient. Draper et al.⁶³ compared the two in a study with 48 stroke carers and 51 dementia carers. They found that both groups experienced similar degrees of burden and similar and high degrees of psychological morbidity. Dementia caregivers have also been compared with caregivers of elderly depressives on measures of burden⁶⁴, and with cancer caregivers on measures of psychological distress⁶⁵ without significant differences being found. Nor was there a difference on measures of distress between caregivers of Alzheimer's and Parkinson's dementia patients⁶⁶. These findings suggest that in the care of chronic disability, the nature of the patient's diagnosis is not a significant factor in determining the impact upon the caregiver⁶³.

Wright et al.⁶⁷ compared caring for a stroke patient to caring for a patient with Alzheimer's disease over a period of a year, at the very early stages of the diseases. They expected a difference between the two, because "Alzheimer's disease is characterised by irreversible, progressive cognitive and functional decline, whereas a stroke results in sudden cognitive and functional disabilities, of which the victims can recover to some degree, mostly in the first six months after stroke".

They found some differences. As expected by Wright et al.⁶⁷, stroke carers' depression decreased over the period of a year, whereas Alzheimer's carers' levels of depression increased. This is inconsistent with the results of Carnwath and Johnson²⁴ who reported that the proportion of depressed spousal stroke carers increased over time.

They also found that Alzheimer's caregivers experienced higher levels and rates of depression than stroke caregivers. This is inconsistent, both with the report by Draper⁶³ and with one by Reese et al.⁶⁸, who also compared the impact of Alzheimer's and stroke on caregivers in their study.

It's difficult to draw conclusions on a comparison between stroke carers and carers for Alzheimer's disease patients. For this study, it's probably more useful to look at the similarities between the two. Both types of carers deal with depression and distress^{63,67,68}, both find their social life disrupted⁶³, and for both early intervention and counselling is advocated^{63,67}.

It seems that, no matter what the disease of the person receiving care, carers bear high emotional and economic burden^{63,67,69-72}, are generally dissatisfied with the professional support and information they receive^{70,71}, and find their social lives undesirably changed^{63,69,70}.

According to Schure⁷³ caring for a stroke patient can be compared to caring for a patient with a heart attack or a brain injury, because of the acute and life threatening character of those diseases. Because of the chronic nature of stroke it is also comparable to dementia patients or patients with neurological diseases like Parkinson.

3.6. Caring in Northern Ireland.

In Northern Ireland health and personal social services are administered together by four appointed Health and Social Services Boards. When these boards were introduced in 1973 particular emphasis was laid on the importance of integrated administration in developing effective community care policies for groups such as elderly people and people with mental health problems⁷⁴. In reality this usually means that the larger part of what is called “care in the community” is provided by women, whether they are spouses, daughters, or daughter-in-laws of the recipients of care⁷⁴.

From the study by Evason et al.⁷⁴, that took place in Belfast, it appeared that carers were reasonably satisfied with the quality of services provided. What carers actually wanted was an expansion of provision of these services. Four key statutory services mentioned were home help, day centre, district nurse and respite care. The majority of carers in this study were also fairly positive about their General Practitioner. Nevertheless, a third of the carers interviewed said that they were occasionally or often worried that they would not be able to cope much longer. Carers were particularly anxious that their own health or the health of the person cared for would deteriorate and they would no longer be able to cope.

The most important conclusions of the study are listed below:

- 1) The majority of carers were female, in late middle age or older and not engaged in employment outside the home.
- 2) The bulk of care required was provided by the main carer with limited support from other family members and a significant contribution from statutory services.
- 3) The majority of carers reported that the total caring task involved 50 hours a week or more.
- 4) In general services were rated highly in terms of the quality of care provided. There was however a substantial volume of unmet demand/need for most services.
- 5) Voluntary and private provision of services played a limited role being used by only a minority of carers.

- 6) The majority of carers said they were currently coping well, but many were worried about the future.

Carers had several suggestions for improvements when asked to comment on provided services⁷⁵. Carers wanted more help from the start from social workers. They wanted the district nurse service more often. They had a strong demand for a respite care – home sitter service, which would probably prove more acceptable than respite care in hospitals etc. Overall the comment that was made most was that carers wanted an expansion of the services. It should also be mentioned that a lot of carers were not aware of all services available. Information on these services might have diminished the demands for expansion.

In a report by the Eastern Health and Social Services Board⁷⁶ it is underlined that without the involvement of informal carers the statutory services would be overwhelmed. It is essential therefore that any strategy for elderly people must include significant recognition of the need to provide appropriate and local respite facilities. Increasingly partnership with voluntary agencies can assist in providing such support for carers⁷⁶.

3.7. Conclusion.

- Carers have an influence on the recovery of the stroke patient through their willingness and ability to support. They should therefore be included in the rehabilitation program of the patient.
- There's a great lack of information to carers, especially at discharge, in the areas of:

- clinical information.

Carers like to know more about stroke; what causes it; what can be done to prevent another one; the effects it can have, and about the recovery of the patient.

- practical information.

This involves information dealing with day-to-day care.

- information on services and benefits.

Carers want to know what they are entitled to and how they can get to these services and benefits.

- The figures with regard to the number of carers that suffer from depression are inconclusive. There have been reports of figures varying from 18 to 61 per cent of carers.
- Overall carers were satisfied with the support they receive in hospital, but less satisfied with services after discharge. Carers wanted more:
 - carer training
 - discharge arrangements
 - follow-up
 - communication
 - information
- Three types of interventions were reviewed:
 - Stroke clubs
 - Family care worker/specialist nurse
 - Respite care

Though outcomes vary, there seems to be at least modest benefits for carers from these interventions. A key point in this is that each intervention isn't suited for each carer. Carer's individual needs should be taken into account when providing these services.

- There are a lot of similarities between caring for a stroke patient and caring for a patient with a different chronic illness. It can be said that carers in general:
 - bear high emotional and financial burden, sometimes even depression.
 - have a disrupted social life.
 - need more information than they are getting.
 - need support and counselling in the early stages of the illness.
- In Northern Ireland carers are reasonably satisfied with the service provision, although in a lot of cases they are not aware of all the services available to them. Carers mainly want an expansion of the services to meet their needs.

4. Findings and Discussion.

4.1. Demographic details

Participating in the research were 7 females and 1 male. Mean age was 58.1 (s.e.m.= 4.62). All participants were the patient's spouses and they all lived with the patient. Of the participants, 3 lived in a rural area and 4 in cities. The patients had all had 1 stroke, 3 of them had had TIA's before this stroke. The mean number of years since the stroke was 3.09 (s.e.m.= 0.74). When asked to describe the severity of their spouse's stroke, 2 carers described it as "severe", 3 as "quite severe" and 3 as "moderate".

The demographic details of the participants are summarised in table 1.

Participant:	1	2	3	4	5	6	7	8
Gender:	M	F	F	F	F	F	F	F
Age:	75	68	62	36	71	54	41	58
Living in city or rural area:	R	C	R	C	C	C	R	C
TIA before the stroke:	No	No	Yes	No	Yes	No	No	Yes
Years since stroke:	1.5	4	3.5	0.25	5	7	2.5	1
Severity of stroke:	Mo	S	QS	S	QS	Mo	QS	Mo

Table 1. Demographic details. M = male. F = female. R = rural area. C = city. Mo = moderate. QS = quite severe. S = severe.

4.2. Multiple-choice questions

Table 2 shows the answers given by the participants to the 12 multiple-choice questions.

Participant:	1	2	3	4	5	6	7	8
1) Has your role in life changed since you became a carer?	Vm	Vm	Jal	Vm	Vm	Naa	Vm	R
2) Do you ever feel down in mood?	S	Vo	S	Vo	S	S	Vo	S
3) Do you ever feel depressed?	Naa	Naa	Naa	Naa	Naa	Naa	Vo	Naa
4) Does it give you trouble to ask for help?	No	Yes	Yes	No	No	Yes	No	Yes
5) Does it give you trouble to accept help?	No	Yes	No	No	No	No	No	Yes
6) Do you have any leisure time?	Yes	Yes	Yes	No	Yes	No	Yes	Yes
7) Do you have enough opportunity to share any concerns you may have with an appropriate person?	No	Yes	Yes	Yes	Yes	Yes	No	Yes
8) Do you ever feel as a carer that you are forgotten about?	No	No	Yes	Yes	No	Yes	Yes	Yes
9) Were you satisfied with the amount of information you received about stroke (recovery etc) when your partner had the stroke?	Yes	Yes	Yes	Yes	Yes	Yes	No	No
10) Were you satisfied with the amount of information you received about practical help and support when your partner had the stroke?	Yes	Yes	No	No	Yes	No	No	Yes
11) Were you satisfied with the amount of information you received about (state) benefits when your partner had the stroke?	No	No	Yes	No	Yes	No	No	Yes
12) Is the support you receive sufficient to meet your needs?	Yes	Yes	Yes	No	Yes	No	No	Yes

Table 1. Answers to multiple-choice questions. vm = very much. jal = just a little. naa = not at all. r = reasonably. s = sometimes. vo = very often.

The majority of carers (5) said their role in life had changed very much. The carers that said they felt their role in life had changed very much felt down in mood more often than the other three carers. One of these also felt depressed very often. When looking at the themes mentioned in answer to the question "Has your role in life changed since you became a carer?", this connection makes sense. The themes that come up are:

- having taken up new tasks
- being responsible for everything that needs done
- being bound to the house
- having to do everything
- patient can't do what he/she used to
- loss of (full-time) job

All of these have in some way to do with the physical disabilities of the patient. This becomes even clearer when looking at the way the carers described their partners stroke. Those that said their role in life had changed very much described their partner's stroke as being more severe than the others. It also turned out that the more severe carers described the stroke, the more often they said they were down in mood. This supports the idea that carers' depression (or in this case, being down in mood) is linked to the physical impairment of the patient.

The literature is inconclusive on this subject. Most studies did find a link between carers' distress and the patient's physical disability^{23,24,77,78}, but some studies disagree^{17,79}.

Carers whose role in life changed very much also had less trouble asking others for help. Half of all carers had trouble asking for help, which is roughly the same proportion as in Schure's study⁷³. Since the carers that had trouble asking for help described their partner's stroke as more severe, it might be that they feel they have no choice but to ask for help. Whereas the others might feel that they don't really have to ask for help. These carers may feel that they can actually manage on their own, and therefore they feel guilty asking for help. It could also be explained by Anderson's²² comment, that perhaps supporters of patients with severe or moderate disability find daily life more defined and predictable, and find it easier to accept difficulties following stroke. Carers for patients with milder forms of disability will have more problems with this, maybe not in the least because the help they need is less defined. This theory is confirmed when looking at the themes mentioned in relation to this question ("Does it give you trouble to ask for help"). The three carers that mention feeling guilty are the three carers that didn't feel their roles in life had changed very much.

Two carers said they didn't have any leisure time. These carers were also less satisfied with the information they received at the time of the stroke and they felt the support they received wasn't sufficient to meet their needs. This could be explained by the findings of Greveson and James^{28,33} and McLean et al.⁵ that patients and carers are unaware of available sources of help, or how to obtain advice. They don't know who to turn to, therefore do everything themselves and end up with no leisure time at all. The carers that said they didn't have any leisure time both mentioned not knowing what support services are available to them:

"I don't know what to expect. What sort of support we are entitled to." [Interview 4]

"I don't know how to get that sort of support [respite]." [Interview 6]

The majority of carers (5) felt forgotten about. These carers were less satisfied with the information they received at the time of stroke, especially the information about practical help and support. Most of these carers also felt the support they received was not sufficient to meet their needs.

When asked about the information received at the time of the stroke, only one carer was satisfied with all information. Another one was dissatisfied with all information. Of the other six, four were satisfied with two kinds of information, and two were satisfied with one kind. Most carers were satisfied with the amount of information about stroke (6 carers). The information about benefits was satisfactory for the least carers (3). This dissatisfaction with the provided information in the hospital has been reported repeatedly in the literature^{7-9,31,33,39}.

Two carers said they didn't have enough opportunity to share their concerns. This unmet need for someone to discuss problems with was also found by McKeivitt and Wolfe³⁹. Besides family and friends carers seem to also have a need for someone professional to take time to discuss problems with them and prepare them for things to come. The visits by a district nurse might not be very helpful in this perspective, because this contact is usually about a specific task and most of the time has something to do with the patient's illness or treatment²².

The themes that came up in the interviews were divided into 8 major categories:

1. Complexities of the carer role.
2. Unpredictable nature of support network.
3. Emotional demands of caring.
4. Need for carer education and support.
5. Personal and social impact carer.
6. Need for planned respite service.
7. Emotional impact of changed relationship on life carer.
8. Coping with caring.

4.3. Findings per category.

The findings will be discussed per category as they are defined above. For a table of frequencies per theme, see appendix 5.

4.3.1. Complexities of the carer role.

In this category "change of character patient" was mentioned most, but only by half the carers. One woman described this as:

"The person as he was is no longer there. There's been a wee bit sort of death of his personality." [Interview 8]

The loss of companionship and interference with social and leisure activities were described as the major reason for loss of enjoyment of life for spouses of stroke patients in a study by Coughlan and Humphrey⁸⁰.

Change of character was mentioned by two carers in combination with "being responsible for everything". They felt they couldn't rely on their partner to make decisions any longer. According to Anderson²² wives of stroke patients are particularly sensitive to changes in the patient as a person, which might result in them experiencing caring as a burden.

Six carers mentioned three other themes: "patient can't do what he/she used to", "being responsible for everything that needs done" and "having to do everything for the patient". Though with this last theme, two carers meant it as temporary and three others meant it in the sense of constantly checking up on the patient. One carer said:

"He has become nearly like an old relative that I'm looking after instead of a husband." [Interview 8]

Another important theme in this category was "having taken up new tasks", mentioned by five carers. This theme was highlighted by two carers in combination with "being responsible for everything" and "having to do everything for patient". This referred to the consequences of the patient's disabilities.

Three carers mentioned the loss of a (full-time) job, though for one carer this meant not taking up a part-time job, something she might have wanted to do. In Anderson's study²² more than a quarter of the carers who had been working before the stroke had given up or changed their job in some way since the stroke. The number of carers losing a job as a result of caring might have been higher if the mean age of this sample would have been below retirement age.

Though only mentioned by two carers, I'd also like to point out the theme "importance of not 'overcaring'". One carer stressed this three times during the interview. He said:

"It's so much easier to do so many things for them, and it's so easy to do them automatically. But it's hard work to be checking them all the time. But it's so important." [Interview 1]

There is some evidence that overprotection of the stroke patient can jeopardise their independence⁴. This 'overprotectiveness' may be the result of differences in opinion between the patient and the family about what the patient can do⁸¹. The right balance between promoting the patient's independence and caring for them is difficult to find. It is important that carers stimulate patients to do as much as possible themselves, but also recognise their limits.

4.3.2. Unpredictable nature of support network.

This category had the largest number of fragments overall, and per carer. Within this category "family support" was the theme mentioned most, and this was also the only theme mentioned by all carers, although this support wasn't the same for all carers. Five carers said their family was always there for them if they needed anything, but three mentioned that it was more moral support, since their family didn't live close to them. Family support was linked with "not satisfied with professional support (after discharge)" by two carers, indicating that they relied on their families for support, since they didn't get enough from professionals. One carer noticed the importance of family in the hospital:

"I noticed that the people who were single people, on their own, were having a lot more difficulty in the hospital. [...] For them their family was the radio.... Very lonely." [Interview 1]

Five carers highlighted family support in combination with good professional support and four with support from the community. Support from friends, the community and satisfaction with professional support were also mentioned together. All this referring to the participants' support network. According to Shanas⁸² 'old people tend to turn first to their families for help, then to neighbours, and finally, to the bureaucratic replacements of family – social workers, ministers, community agencies, and others – because they expect families to help in the case of need'. This also seemed to be the case for this sample. Family was by far the most important source of help, and apart from family, it was mostly neighbours helping out.

Family support and support from friends were both linked to "carer feels forgotten about". In these cases carers said they felt forgotten about, but not by family or friends, who offered them great support.

Half the carers mentioned support from the community, which often meant neighbours helping out. A minority of three carers mentioned support from friends. Two carers mentioned the theme "having no-one to turn to for support". The family of these two carers lived far away, which again shows that without family, a very important source of support and practical help falls off.

Two carers mentioned a carer support group. One would like to be in one, because she wanted to talk to someone who would understand, to get rid of some of her frustration. Another had been in one as part of an experiment, but didn't really like it, because she didn't feel the need to share her experiences with other people in the same position. She felt hands-on care was far more important.

This is consistent with literature on support groups, which has showed that support groups can be useful, but aren't suited for all carers⁴⁴⁻⁴⁶.

Since carers were asked directly for their opinion about the professional support they received, this topic was mentioned quite a bit. The opinions on professional support (after discharge) were pretty much fifty-fifty. Four carers mentioned being satisfied with this support more often than being dissatisfied. For three carers it was the other way around. And one carer mentioned both equally as much.

The opinions on the support received in the hospital were a bit less evenly divided. Dissatisfaction was mentioned nearly twice as much as satisfaction. Five carers mentioned being dissatisfied more often

than being satisfied and for three carers it was the other way around. Most carers seemed to feel they didn't get enough information:

*"Neither the GP nor the neurologist at the hospital gave us any information.
Just that he had a stroke. He may take another one, he may not. End of story." [Interview 7]*

“Not satisfied with information and support in hospital” was mentioned by two carers in combination with “satisfied with professional support (after discharge)”. This is in contradiction with what can be found in the literature. Several studies have found that carers are overall satisfied with the support from the hospital, but less with services after discharge^{8,9}. The addition of the word “information” might be crucial in this. Carers were asked specifically whether they were satisfied or not with information at the time of stroke. This would usually be in the hospital. Although they might have been satisfied with the support in the hospital, they didn’t feel they received enough information about what was going to happen after discharge. They didn’t know whom to turn to for support where to find out about benefits, etc. Carers felt this kind of information should have been handed to them at the time of stroke, this is, in the hospital, instead of finding out by themselves, as they did. There is a lot of support for this idea in the literature^{7-9,28,31,33,39}, and it is a crucial point for improvement of services to both patients and carers.

There was no difference in appreciation of the support network between the two carers that had already been in contact with NICHSA and the other six carers. The two carers that had been in contact with NICHSA were very satisfied with the support they received from NICHSA. But because this research was done on request from and in association with NICHSA, carers that weren’t satisfied with the services probably chose not to participate.

4.3.3. Emotional demands of caring.

The theme mentioned by most carers in this category was "being down in mood". Only one carer also said she felt depressed very often. Another said it was more being stressed than depressed.

The theme mentioned most was "needing a break from caring", though this was only mentioned by half the carers:

"I can't go away for the weekend and I would love that some time. I'd really like that. A wee break. Just for myself [...] To get my head cleared. Not to think about my duties" [Interview 8]

Of these four, three also mentioned getting a break from caring, showing that getting a break was a necessity to them. Two carers mentioned getting a break from caring in combination with “satisfied with professional support (after discharge)”. Professional support (patient going to day centre or professional carers coming in the house) enabled these carers to get a break from caring, which was much appreciated.

“Needing a break from caring” was linked with “patient can’t do what he/she used to” by one carer. It was the constant care that got to her:

“It’s that sort of thing I’m needing a wee break sometimes from.” [Interview 8]

Respite care, as well as a stroke club, has been found beneficial in some studies⁵³⁻⁵⁷, but not in others⁵⁸⁻⁶¹. To the carers in this study it seemed to be important to get away for a longer period of time. McNally et al.⁵² suggest that respite care might not be as beneficial as it could be because of the way carers spend the respite time. Having a longer period of time away from the patient might enable them to spend their time engaging in social activities, instead of catching up with other work, as one carer said when asked what she did when her husband was away at his stroke club:

Sometimes it's catching up with things. I'll go to the shops. [Interview 8]

On top of that it might be hard for carers to completely relax and forget about their situation while they are having a break from caring. Five carers in this study mentioned the theme "patient is always on carer's mind":

"I worry every day, all day, that the next phone call is going to be: There's a problem." [Interview 6]

"It's always on the back of your mind, you know. You can't get away from it, because although he's there [at a day centre] and he's not here, I'm still thinking, you know, anything could go wrong there." [Interview 2]

This shows that even though half of the carers say they need a break, they can't really relax while they're away from the patient.

Four carers mentioned frustration with the patient. This usually had to do with the patient being slower, the memory being affected, or other disabilities. In Anderson's²² study increased irritation with the patient was more pronounced among the carers of older patients. In this study the age of the patient wasn't asked, but the carers were all spouses of approximately the same age as the patient. The age of the carer was not related to the frustration of the carer with the patient.

Half the carers felt guilty asking others for help:

"I don't like doing it too often. It makes me feel a wee bit sort of guilty. [...] I feel very much that he is my responsibility." [Interview 3]

This theme was also mentioned along with family support. Although most carers gave to understand that their family didn't mind helping out, carers still felt guilty and solely responsible for the patient.

4.3.4. Need for carer education and support.

Four of the five themes in this category deal with the professional support the participants received. To illustrate that carers felt there was a lack of information in the hospital with regards to what was going to happen after discharge, here are some suggestions made by participants:

"Maybe the hospital should organise some sort of a mailing list" [Interview 6]

"If I could adapt anything; a wee bit more realism. To say to a person: here's the situation. Here's the best and here's the worst. [...] I know where I am then, and I can cope with it." [Interview 8]

"I felt really lost that first day [when her husband came home]. The girls [personal care assistants] were to come at night. I didn't know what they'd need, what I'd need. I feel if they had a little booklet or something, with all the information in it [...] To prepare you more." [Interview 3]

These last two carers highlighted two important shortcomings in the provision of information. One is the information about recovery of the patient, together with information about what a stroke is and how reoccurrence can be prevented^{7,9,22,32}. The other is information about what to expect after discharge. Carers feel that they are not well prepared for the problems resulting from the stroke²².

The fifth theme in this category is "carer feels forgotten about". Six carers mentioned this theme. In this category it's more important to know whether carers felt forgotten about by professionals, rather than family and friends. Of the six carers mentioning the theme, five felt forgotten about by professionals:

"Professional people don't know... or the medical people don't know what it's like for a carer to look after somebody." [Interview 2]

"I just feel that there isn't enough support or understanding for what it's like for the carer. All the sympathy and all the support goes to the patient. [...] In order to be a good carer, you need relief and you need support." [Interview 7]

It has been reported that carers feel abandoned once the patient is discharged from hospital⁵. It seems that the transition from the safe environment of the hospital to the home environment is too big. Carers realise once they are at home that there are still a lot of questions unanswered and they bump against problems they didn't think of before. A follow-up shortly after discharge could help them in those first weeks of getting used to being a carer.

4.3.5. Personal and social impact carer.

The most mentioned theme in this category was "being bound to the house". This theme came up in six of the eight interviews. Some carers didn't really seem to mind this, probably because they were quite used to being at home, even before the stroke:

"Fortunately I am content at home. I keep myself very busy." [Interview 3]

To others being bound to the house meant having to give up a lot of things outside the house:

*“From the type of busy life I had to just home-based chores...
Quite an adjustment really.” [Interview 8]*

This decline in social activities outside the house has also been found in other studies^{17,22,63,73}. The effect this has on the carer and the extent to which it's distressing very much depends on the social life the carer had before the stroke.

“Being bound to the house” was highlighted in combination with three other themes, all by two carers: “having to do everything for patient”, “getting a break from caring”, and “being down in mood”. The first shows one of the reasons why carers are bound to the house. The second was mentioned as something that's important to them, because they are bound to the house. And the third is a consequence of not being able to get out.

Three carers said there was no change in their social life, because they didn't go out much before the stroke. The other five mentioned social isolation:

"For me social life is non-existent." [Interview 6]

"You're not fit to go out." [Interview 4]

Social isolation (mentioned by 5 carers) was linked to “change of character patient” by two carers. They said that because of the changes in their husband's character they were reluctant to take them out or invite people over, which resulted in social isolation. Social isolation among stroke carers was also found by Anderson²⁰.

Three carers said they didn't have any leisure time at all.

4.3.6. Need for planned respite service.

Two important themes in this category are needing and getting a break from caring. Both were mentioned by four carers:

"I think that's my basic need at the minute. To get away, with friends, just socially, for a length of time, rather than just a couple of hours." [Interview 6]

Three carers mentioned both needing a break and getting a break. They said they occasionally got a break and needed that:

"You definitely do need a wee break, relieve the stress just and get out." [Interview 5]

Though results of research on respite services are inconclusive⁵³⁻⁶¹ to some carers this service might bring them a very welcome relief of the every day life of caring for the stroke patient.

The most mentioned theme was "carer feels forgotten about". Six carers mentioned this, though 1 of them also mentioned not feeling forgotten about. She felt forgotten about by professionals, but not by family and friends. Schure⁷³ also found that carers want more attention for their situation and more support and help with their caring role. They felt forgotten about by their GP and expressed a wish for regular check-ups.

Three carers specifically mentioned not getting enough professional support to enable them to get a break from caring. Respite services are still too scarce to give every carer that wants to use it the opportunity to do so.

4.3.7. Emotional impact of changed relationship on carer.

Two themes are important here: "change of character patient" and "frustration with patient", both mentioned by four carers (three carers mentioning both). Change of character of the patient has been found to cause distress and feelings of anxiety in the carer¹⁷. It can also affect the relationship between the carer and the patient:

"Because I feel his personality had changed since the stroke it actually affects my life and our relationship" [Interview 7]

Anderson²² found that carers' rating of their relationship with the patient declined over time. This was particularly the case for female carers. The carers had much less happy views of the relationship than

did the patients. Williams²⁵ looked into the impact of aphasia on marital satisfaction and found that even when the communication deficit is mild, spouses are not as satisfied within the marital relationship as they were prior to the stroke.

I think that when the relationship between carer and patient has deteriorated (because of a change of character of the patient, or because of communication problems), carers will more easily get irritated and frustrated with the patient, which results in the caring being more of a burden. This is what Zarit et al.^{83,84} found in their studies. Carers with a less close relationship and whose activity had been restricted were more likely to resent the carer role. Thompson et al.⁶ found something similar. Carers who had a poor relationship with the patient often perceived their role to be more of a burden and had a more negative interpretation of their situation. A poor relationship with the patient has indeed been found to have a negative effect on the carer's well-being^{17,22,24}.

When the relationship is strong even after the stroke, the caring will be less burdensome. Two carers in this study mentioned their love for the patient and how this influenced their perception of the caring role:

*"I personally feel that once I begin to feel this as a burden I'm lost.
But I don't feel it as a burden. I feel, he's my husband and I love him dearly,
and we have to be content without any of those things [socialising]" [Interview 3]*

Two carers expressed a fear of the death of the patient:

"Sometimes, when we're very stressed and very tired, I have a wee sort of: oh, wouldn't it be nice to have no responsibilities. But then you realise that that would mean that the person is not there. And you don't want to accept that. [...] The only end to the caring would be if he's not here." [Interview 3]

One carer said there was no more romance between her and the patient. I suspect that this might be the case with more carers, but culture or shame might have prevented them from saying so. A loss of partnership and impairment of marriage has been reported, especially when the patient is aphasic^{22,85}.

4.3.8. Coping with caring.

Most mentioned (by five carers) was taking it a day at a time. Carers said they didn't know what was going to happen to the patient, whether he was going to get worse or not, and whether their health would stay the same. This led three carers to mention being worried about getting less able to cope. The key point here again is information. Carers don't know what to expect, because they haven't been given information about the recovery of the patient, or about what the options are when things do get worse. A lot of the worries about the future could be taken away by educating the carers better.

The first shock after hearing their partner had had a stroke was also mentioned by three carers:

"I actually was absolutely wrecked. I wasn't coping." [Interview 3]

"Well, at the time, you know, it knocks you off your feet. You don't think straight." [Interview 2]

This is a confirmation of the fact that the time of admission is probably not the best time to provide carers with a lot of information³³. It is important for professionals to make sure that carers understand the information given to them and that they receive written as well as verbal information.

4.4. Conclusion.

Caring for a stroke patient does not just involve physical care. It's mostly the consequences of the patient's physical and cognitive disabilities that make the carer role complex. The results show that the physical impairment of the patient has an effect on three different aspects of caring. The more severe the stroke had been, the more often carers felt down in mood, felt their role in life had changed, and the less guilty they felt asking others for help.

Some carers feel frustrated with the patient from time to time as a result of the patient's physical and cognitive disabilities.

With physical care, carers should be careful not to do too much for the patient. They should try and stimulate the patient to do as much as possible for themselves.

The most important factor in the support network of carers is their family. Without this carers feel unsupported. Carers whose family lived far away felt they had no one to turn to for support.

But even though most carers feel they receive great support from their families, they feel guilty sometimes to ask them for help. They feel the patient is their own responsibility.

Apart from family support, to some carers support from the community and professional support were important resources as well.

The opinions on professional support are divided, though most carers are not very satisfied with the information and support received in hospital. Especially when it comes to preparing them for the time directly after discharge and on the longer term, carers feel that there's a lack of information. They also feel professionals do not consider carers enough. All attention seems to go to the patient, and carers therefore feel forgotten about. They don't know whom to turn to for practical help, support and benefits. More information about this is necessary.

Carers feel down in mood from time to time as a result of the caring role. Often this is a result of being bound to the house because of the patient's physical disabilities. They express a need for a break from caring, to relieve stress. Those carers that actually get a break from caring through professional support are very grateful for this. This doesn't mean that they can forget about it while getting a break, because most carers always have the patient on their mind, worrying about them.

Some of the carers that expressed a need for a break didn't know how to realise this. More information about services available to them should be provided.

The changed character of patients had an effect both on the relationship between carer and patient, and on the carer's social life. It led some carers to get frustrated with the patient.

The relationship between carer and patient seems to have an effect on how the caring is perceived by the carer. Some carers felt their love for the patient made the caring less of a burden. Some carers also expressed their fear of the death of the patient.

Carers feel uncertain about the future. Most carers mention taking it a day at a time. The uncertainty also includes carers feeling worried about becoming less able to cope with caring, either because of deterioration of the patient, or of their own health.

It has been shown in this research that a stroke sometimes hits the carer equally as bad as it hits the patient. One woman expressed it like this:

"I'm like a stroke victim myself, if you know what I mean. [...] I feel like I've had the stroke along with him." [Interview 2]

5. Discussion of methods.

The literature review wasn't designed as a complete survey on the literature about caring. Therefore it might be incomplete in some areas, and some important literature might have been overlooked. Yet it does give an overview on the most important topics for this research and is a valuable supplement to the findings of this study.

One obvious shortcoming of this research is the sample size. It seems odd that only two carers responded to the letters that were sent out to stroke clubs and the carers group. But since these clubs are organised by NICHSA and the research was also requested by NICHSA, carers that feel their needs are not being met might not want to talk about this when they're already involved with NICHSA. They might feel guilty about not being completely satisfied with the help they get and therefore would rather not say anything.

If the target of 15 participants would have been met, the results would have been more reliable than they are now. Nevertheless, I think the most important problems faced by carers were brought to light by the 8 participants in this study. The reason I believe this to be the case is that the themes that were talked about by the carers in this research are the same as those in previous research^{32,86}. The results of this research will help NICHSA to improve their services, because they reflect the most pressing problems of carers.

Another problem is the fact that the sample consisted mainly of wives of patients. This might have influenced the findings, because female carers tend to rate their health more negatively than men, feel more need for the help and support of family and friends, are more likely to feel that their social lives are restricted and are more likely to experience caring as a large burden²². On the other hand, men might be more difficult patients. Anderson²² found that more than female patients, they were enjoying life 'much less' since the stroke and more of them than seemed merited by their physical disability felt unable to look after themselves in some way. Moreover, the caring population consists of more women than men, and they provide the most demanding and time consuming care⁷⁴. As a result of that nearly all studies that involve partners of stroke patients have a majority of female participants⁷³. So even though this sample does not represent the sexes evenly, it does represent the reality of the caring population.

Two of the participant had been recruited through NICHSA. This might have influenced the type of carers that participated. Carers that had complaints about NICHSA wouldn't be likely to participate in a research that is requested by NICHSA.

6. Recommendations.

In this research I tried to answer the following questions:

- What are the issues carers deal with in caring for a stroke patient?
- What are carers' needs with regards to services and support?
- How can NICHSA meet these needs?

The first two questions were mostly answered in paragraph 4.4. Here I will expand on the carers' needs, give some general recommendations and explain how NICHSA can meet carers' needs.

6.1. General recommendations.

An important finding in this research is the perceived lack of information. Carers don't know enough about stroke, about the recovery of the patient, about services and benefits available or about the adjustment necessary when the patient returns home from the hospital.

- 1) Hospitals should make sure carers are informed about what a stroke is and how reoccurrence can be prevented. This information should be written as well as verbal, because carers are often too shocked to take verbal information in.
- 2) Hospitals should make sure carers know what to expect of the recovery of the patient (where possible to speculate about this).
- 3) Hospitals should make sure carers know about NICHSA, so that any additional information carers may need can be obtained from this organisation.
- 4) Possibilities of a follow-up by a professional should be explored. Carers feel left to their own devices once they're away from hospital. A follow-up could reassure them.

6.2. Recommendations for the Northern Ireland Chest Heart and Stroke Association.

Hospitals usually don't have the time to inform carers about the help and support they can get. NICHSA could take over this task. There should be a greater extend of collaboration between the hospitals in Northern Ireland and NICHSA, to make sure NICHSA is able to do so.

6.2.1. Information.

Lack of information doesn't just occur in the hospital. Especially at discharge and afterwards, carers are left with a lot of questions. Since hospitals don't have a lot of time for aftercare, NICHSA should take over the provision of information.

- 1) NICHSA should make sure all hospitals in Northern Ireland know the organisation and will refer patients and carers to them. An information package with general information about the organisation at the hospital, which can be handed out to every stroke patient brought to the hospital and his/her carer, will help to establish this. Reference from hospitals will make sure all carers know whom to turn to for information and help. Too many carers still don't know of NICHSA's existence, even though they do try to reach them at hospitals.
- 2) NICHSA already provides home visits at which a lot of information can be given. NICHSA should try to make sure that these home visits occur as soon as possible after discharge from hospital. Any lack of information from the hospital can then be assessed and supplemented with an individual information package, provided by NICHSA. The Department of Health, Social Services and Public Safety (DHSSPS) should make funding available to NICHSA to expand their programme and make sure all the information reaches both carer and patient. Carers should know that they don't have to just rely on themselves and their family.
- 3) The right moment for providing them with the information might not be directly after the stroke, or even directly after discharge, as both patient and carer are still too shocked to take the information in. It is therefore important to time this moment for each case individually. It is also important to return at a later stage to the information given to them, to make sure carers and patients aren't left with questions. To avoid too many questions it is advisable to provide both verbal and written information.
- 4) The information given should apply to the personal situation of the patient and carer.
- 5) Information packages should be put together, attuned to individual needs and to the local situation.

6.2.2. Respite care.

Respite care is another unfulfilled need amongst carers. Carers need to relieve stress every now and then and can only do so by getting away from their situation, without the patient. Carers that do get

these breaks appreciate this a lot and carers that don't are longing for them. Carers should know that they are not forgotten about by professionals. At the moment NICHSA provides Stroke Clubs for patients, which give carers a few hours for themselves. This is not enough, though. Carers should have some time in which they engage in social contacts, and should be encouraged to do so, instead of getting work done, which many carers do during these breaks.

- 6) Funding should be made available to provide respite care. NICHSA should either refer carers to the resources that can provide them with respite care, or set up a programme themselves to make sure carers get a break on a regular basis and for a reasonable amount of time.

6.2.3. Carer support groups.

Carer support groups can provide valuable support and respite, but are not suited for all carers. Some don't feel the need to share their experiences with other carers, but some do. Each carer should have this opportunity. It can make them feel less alone and can help them cope better with their situation.

- 7) The DHSSPS should provide NICHSA with resources to extend their Family Support Scheme. Family Support Groups should be started up throughout Northern Ireland, so that every carer has the opportunity to attend one.

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Appendix 1.

Short story by one of the participants.

THE DAY MY LIFE WENT TO THE DOGS.

Why me? Why am I standing in dressing gown and wellies at 4am on a cold, wet morning, watching three hulking greyhounds pee lavishly over what used to be my prized lawn? Why? Because five years ago I received a phone call that changed my life.

“Mrs Carter? – I work with Sam – I’m at the hospital – Sam’s been taken ill.....”

“What’s happened? How is he?...”

“He’s had a wee turn.....”

A wee turn? What was that? Phrases sprung into my head like corn being popped. A turn around the garden.....his turn on the swings....what?

“What sort of a turn ... a heart attack?”

“Eh, no –no- they think it’s a stroke...”

Two days later I had heard all the medical terminology. Asphasia, ischaemic attack, carotid doppler..... Three days later Sam was starting to come to terms with the fact that he was human after all. “Never a day sick in my life” he used to boast - not counting the self-inflicted illnesses courtesy of the Golf Club bar, that is. Meantime I did the rounds of nurses, doctors, consultants, compared notes with other patients and visitors and eventually came to realise that Sam’s life, and mine, had changed for good.

“What exactly does it mean?” I asked the consultant, when I finally cornered him.

“In simple terms, his body isn’t paying attention to the messages being sent by his brain.....”

Like when your brain tells you you’ve had enough and your mouth orders another gin ... what’s new? I watched the consultant’s spectacles slide further down his Roman nose. His opaque eyes, marbles in a plaster bust of Julius Caesar, glanced coldly across the top of my left ear. Had I spoken aloud?

“Does your husband drink?”

“He used to But he gave it up six months ago – it was having a bad effect on our bank manager..... and no, he doesn’t smoke any more...”

Not for a few days anyway. Not since the doctor who saw him after the stroke had tightened the sheet around his throat and, nose-to-nose, stared into Sam’s petrified blue eyes and hissed, “If I ever see you with a cigarette in your hand again I will personally strangle you!” Her bedside manner was as sensitive as Hitler’s but it worked. The first words Sam managed to slur with any clarity were, “I’ll never smoke again”.

I wondered at the time if I had used the same technique to get the dishwasher/Golf convertible/state-of-the-art coal bunker etc would it have been more successful than abject pleading. Fear works in marvellous ways. I was just beginning to learn.

It was probably the fear of being totally within my power that gave Sam’s brain the kick-start towards recovery. Within two weeks he was home from hospital. I was relieved of the 40 mile return journey to the hospital twice a day but now I had to entertain the visitors. A never-ending stream of doctors, health visitors, work-mates, golf club buddies flowed through the house. Sam would plead tiredness and disappear to bed while I had to relate the details of his illness, and, of course, listen to the horror stories about so-and-so’s aunt/granny/cousin-twice-removed who had had a stroke and never recovered. I began to avoid friends and acquaintances in the street and considered making a tape so that I could play it every time I was asked, “How’s Sam?” A selfish little devil screamed in my brain – what about me? Nobody asks “How are you?” Except once when the assistant pro

at the golf club informed me that, after his grandad suffered a stroke, his granny had a heart attack as a direct result. We ignored that.

Life changed for Sam. Goodbye pubs, clubs and golfing glories, fry-ups and real butter. Hello gentle walks, cholesterol checks and...hours of freedom and leisure with his new state-of-the-art flat-screen TV. My life changed too. Farewell to ladies' golfing weekends, girlie nights out, 'indoor recreation' and ... freedom. Hello to keeping the accounts (too stressful for Sam), cutting the grass (wrong exercise for Sam), providing treats and sticky buns (diets were too boring) – and watching for signs of the next stroke. Sam settled into his new-found idleness. I adjusted accordingly.

Then Sam needed a hobby. Something to interest him and fill the long days while I was at university – a very mature student struggling through a four year degree course. The stroke hadn't left paralysis as such but Sam's left side was weak. He wasn't fit for the old life, he tired easily and, now that he was medically retired at 57, he needed something to occupy his time other than TV. He wasn't able to play golf anymore. He could have played a gentle three or four holes but the Warfarin hadn't thinned the competition in his blood and he couldn't get competitive over a few holes.

"I've always wanted to buy a greyhound...."

"You used to be interested in fishing – I think the rods are still in the garage...."

"The doctor said I should exercise...."

"Bowling is good exercise....."

"But you don't get any fresh air....."

"Gardening! Good exercise, fresh air – and something to show for it....."

"But gardening costs money what with fertiliser and all a greyhound might make us some money....."

When you have returned to further education in your forties and suddenly your husband's income falls by two thirds of the original, the prospect of a money-making venture, no matter how tenuous, acquires a certain attraction like the hypnotic gaze of a snake preparing to strike.

So Sam bought his first greyhound and the garden shed became a five star kennel. Then two more greyhounds arrived and my beautiful garden turned into a Canine Country Club. Lawn? Forget it. Just fence to fence muck and dog.

'Twenty nine twenty' is now recognised, not as the price of a new shirt or a hair-do, but a good time around Dungannon race track. Once a 'good time' had been a booze-up in the Golf Club with a raging hangover next day now 'Gin and Tonic' sounds like the name of a dog I once lost £2 on at the tote.

Instead of relaxed wining and dining and generally socialising, weekends soon became motoring marathons to Lifford, Dundalk and Dublin with a couple of slaving dogs slobbering down the back of my neck as I drove Sam and his 'sure things' to the various tracks. The car window remained open, they needed air. Feeling the wind and rain in my hair became less of a romantic notion and more of an endurance test. And, if you've ever been to a dog track with a committed 'doggie man' you'll know that conversation, scintillating or otherwise, or even polite chit-chat is not on the agenda.

But, 'every dog has its day', they say and, eventually, after another six strokes, or TIAs (transient ischaemic attacks) as they are affectionately known, racing became more of a spectator sport. Sam wasn't able to exercise the dogs fully and the odd win didn't compensate for the expense involved. Besides, Sally, Diamond and Sparky were getting on in greyhound years.

"Whaddya mean get rid of?"

"Well, you're always complaining about no dogsitters we could go out more....."

“Out? And come back to an empty house?”

“You would get your garden back and we could use the kennel for storage....”

“They only use the kennel at night Haven’t I put mattresses and duvets in the dining room so they have freedom to come and go all day?”

“You would have a nice dining room again entertain.....no cot mattresses, or duvets, or chewed wallpaper, or biscuits in the corners.....”

“And no tails wagging when I come home from work.....and nobody to talk to when you’ve gone to bed, or petand no-one to tuck into bed at night.....”

“I wouldn’t have to walk them every day..... I’d save money on meat....”

“You’d spend it on electricity You’d never leave the tele.....”

“But you never wanted them in the first place....”

“That was four years ago..... now they’re my family..... my babies I can’t sell my babies. They’re staying – for the duration – that’s that!”

Three pairs of brown eyes watched this intercourse warily. Who says dogs can’t understand human speech? With reprieve assured, Diamond laid her head in my lap, Sally nuzzled under my arm and Sparky licked the fake tan off my foot. How’s that for gratitude? Sam’s face, meanwhile, had acquired a distinctly smug expression.

Which is why I am the one who cleans the kennel, bathes them, deals with their various ailments, and the vet’s bill and opens the kennel in the middle of the night when they need to pee.... Still, it beats being a golf-widow (with all appearances of becoming the real thing). My life may have gone to the dogs but, looking back, I’ve also had a ‘stroke’ of luck!

ENDS

Appendix 2.

Interview

The interview we're about to do will take about one hour. There are 30 questions in total. I've brought a tape recorder with me and would like to ask for your permission to use it. I will code the tapes so that no one can trace them back to your name, and they will be destroyed after the research is finished.

Are you clear on what we're going to do now? Do you have any questions?

Is it all right with you if I use the tape recorder? Then I would like to test if it's working all right.

Now, before we start I'd like to ask you to sign this form (informed consent) please. The purpose of this is to be sure that I have your permission to be here and interview you in writing.

If you're ready I'll start the tape recorder and ask you the first question.

Demographic details.

First, let me write down some details about yourself and the person who has had the stroke.

- 1) What is your sex?
male
female
- 2) What is your age?
- 3) Where do you live?
- 4) Please tell me the first name of the person who has had the stroke.
- 5) What is your relationship to?
You are his/her:
spouse
child
grandchild
parent
sibling
friend
other:
- 6) Do you live with?
yes
no
- 7) How many years ago did have his/her (first) stroke?

8) Before the present stroke, did have any small turns (TIA's)?
yes
no

9) How many strokes has had?

10) How severe would you describe 's stroke?
.....
.....
.....

Actual interview.

Now that we've got your details we can proceed with the rest of the interview. There are 20 more questions. Most of them need a longer answer than the questions I've asked so far. If you're not sure about the meaning of a question, don't hesitate to ask. If at any time during the interview you'd like to stop, we can always finish another time.

11) How has 's stroke changed your life?
.....
.....
.....

12) Has your role in life changed since you became a carer?
very much
reasonably
just a little
not at all

Please comment freely:
.....
.....
.....

13) How has your social life changed?
.....
.....
.....

20) Do you have enough opportunity to share any concerns you may have with an appropriate person?

yes

no

If so, specify:

.....
.....
.....
.....

21) Do you ever feel as a carer that you are forgotten about?

yes

no

Please comment freely:

.....
.....
.....
.....

22) When you think of the future how do you see yourself coping?

.....
.....
.....
.....

23) Were you satisfied with the amount of information you received about the stroke (recovery etc.) when had his/her stroke?

yes

no

Please specify:

.....
.....
.....

24) Were you satisfied with the amount of information you received about practical help and support when had his/her stroke?

yes

no

Please specify:

.....
.....
.....

25) Were you satisfied with the amount of information you received about benefits when
had his/her stroke?

yes
no

Please specify:

.....
.....
.....

26) What support do you receive?

.....
.....
.....

27) Is it sufficient to meet your needs?

yes
no

Please comment freely:

.....
.....
.....

28) What support services do you feel you require most?

.....
.....
.....

29) How has the support you receive changed over the past ... years, since first had his/her
stroke?

.....
.....
.....

30) Thinking back on what we've talked about today, is there anything else you'd like to tell me?

.....
.....
.....

Appendix 3.

Example of transcription.

Interview 08, subject HD. 17/05/2001, 11:00 a.m. until 12:05 p.m.

Subject purposely planned the interview at a time when her husband would be away (to Stroke Club) so she would feel freer to speak.

I: Right, so you are a female. [1]

I: And what is your age? [2]

P: 58.

I: And you live in Bangor. [3]

P: Yes.

I: Would you please tell me the first name of the person who has had the stroke. [4]

P: A.

I: And you are his spouse, right? [5]

P: Yes.

I: Do you live with A.? [6]

P: Yes.

I: How many years ago did A. have his first stroke? [7]

P: One year. He had it on March the 21st.

I: Before the present stroke did he have any small turns? [8]

P: It wasn't actually diagnosed, but I think he did. Because there was a change in his pattern of behaviour. Things were changing Up to two years before the actual stroke.

I: How many strokes has A. had? [9]

P: Just the one. But to me that was just an extension, rather than his first stroke.

I: How severe would you describe A.' stroke? [10]

P: I'd say certainly moderate. I can look at other people and think: perhaps they're worst, cause they have the paralysis. And it comforts me that he doesn't have that. But then he has other problems. Others are mentally quicker than he is.

[Introduction to the second part of the interview]

I: How has A.' stroke changed your life? [11]

P: It has changed my life because it has changed him as a person. He's still a very nice, pleasant, placid person, but the person as he was is no longer there. There's been a wee bit sort of death of his personality. So that's a big thing. I can no longer really call on him for support or talking things over. He's become nearly like an old relative that I'm looking after, instead of a husband. Like an old uncle or a dad. That has changed. Although it's been creeping. It hasn't happened sudden. It's been coming on the last couple of years. So it's other things. Having to watch him all the time, watch he doesn't fall, and to do everything, think about everything. And I think most of all it's the loneliness.

I: Has your role in life changed since you became a carer? [12]
P: Well, I had retired early, at 55. I was a health visitor, so I'm used to looking after people. But I think right now I couldn't take that.
I: Was it a full-time job?
P: Yes. I was a nurse.
I: But you already retired from that job before A. had his stroke?
P: Yes.
I: So did your role in life change after the stroke?
P: Yes, well, it obviously changed my life. From the type of busy life I had just to a home-based chores..... Quite an adjustment really. And that has been sort of gradual, from when I retired. But I think I could have... I would have taken part-time, or I would have been thinking about part-time. Had A. not taken the stroke. I was considering that. But that's out of the question now, because of his deterioration.
I: And have you had to take up tasks that A. used to do?
P: Well, again, he was gradually getting worse anyway. And he spent most of the day sleeping, in the chair, watching television, very inactive. So really, all the tasks had fallen on me anyway. You could put down that tasks all fall on me, everything to do with anything I can think about. Not that I resent it. I tell myself that.
I: But you're saying that that was already happening before the stroke?
P: Everything that is happening now is like an exaggeration of what I had before. Of course I knew something was happening and I tried to get medical intervention, at least a diagnosis that would be able to pinpoint it. But they wouldn't give me a scan, that's too costly. So.....

I: How has your social life changed? [13]
P: It's changed quite a bit. I can't really go away. I can go away a few hours. I can go away even half a day. Down to my mum's and take her out to visit relatives. But I can't really leave A. over a mealtime, cause he couldn't cook for himself. He has got a shake on his left side. And even making a cup of tea, he would spill it all over the place around him. So I don't have to sit with him or stay with him, but I can't go away any longer than..... I can't go away for the weekend and I would love that. Some time. I'd really like that. A wee break. Just for myself.
I: What about meeting friends and family, or inviting them here?
P: Yes, I have my brother, and my mother who's 83, who has always been a great support to us. But she just can't... I find that she can't cope with A. very well, the way he is. She'd say: he's stupid. And I'd say: no, that's the stroke, that's not the way he was. Now, my mum is not an unkind person, but you see, she's getting older herself and is less patient with his conversation.
I: And when you compare your social life now to the way it was before A.' stroke?
P: Oh yes, very different. I'd say I had an active social life before the stroke. I mean, I can take A. places with me, but it's just not the same. Not for me. If I'm saying: it's me-time. It's just not the same with A. That sounds awful doesn't it?
I: No, not at all.
P: Well, there's no point in saying that you love every minute of every day. Cause you don't.

I: Do you ever feel down in mood? [14]
P: I do sometimes, yeah. Something would just trigger it. Like writing a letter to Australia for Christmas, telling my family in Australia what was happening to each one. A.' situation, he's going to the Stroke Club, he's going to a day centre, he's going to college, to do a course, all these great things, he's got his driving license back, all this. And there's John [her son, going to nursing school next year] and my sister is a singer and that's all going well. And then I came to myself, and I had nothing to say about myself. And I thought: there must be something. And I sat for half an hour trying to think of what interesting thing I could say about myself. And there was absolutely nothing. Just nothing. My life had just been cleaning and the chores. And then you see, it would hit me, I'd take a wee dip. But it passes, it passes.

I: And do you ever feel depressed? [15]

P: Well, I would know that it wouldn't be depression, in a clinical sense, because I've worked with that all my life and I know that it would have to stay with me, you know, for two weeks, etcetera. But it doesn't. Usually it's just something nice happening, or a wee change or something and I'm perfectly all right again. I wouldn't say that I don't feel.... Cause I do feel (trapped sometimes. But at the end of the day: doesn't everybody?) I've got my constant companion.

I: Does it give you trouble to ask for help? [16]

P: I think so, yeah. Yes, a little. Not a lot, but a little. I would rather be the one to be coming in with the help. You see that's been my life. Nursing, going home to the people. You know, I'm the one to give things. But I'm in the opposite position now and I don't like it so much.

I: Why does it give you trouble to ask for help?

P: Because I see myself... my perspective of me is to attend to other people, it's not for me to be getting. I have difficulty with that.

I: What about accepting help, does that give you trouble? [17]

P: Just a little. I think I would be glad at it really, but... I wouldn't be so silly not to take it, but I would have to gear myself again to receive it. For example I got my attendants allowance. And I'm surprised, cause I didn't expect to get that. And almost felt like: it's not really bad enough, I must tell them it's not really bad enough for this. But I decided not to. I didn't send it back [laughs].

I: Do you have any leisure time? [18]

P: Not a lot. I can go out with a friend, I have a nurse friend, or my sister-in-law, or a few friends. They would say: let's go out for tea, and we'll go out. And my mother, whom I would give support. I mean, there's my brother, but I would be the one to take my mum out down the coastline for a wee picnic or... Especially on Thursdays when A. is at the Stroke Club. So yeah, I go out, but none of it can last too long. That's the only thing. A friend asked me to go for a couple of days to Cork. I said: I couldn't. I couldn't possibly. I'd love to, but I couldn't go for two days. Someone would need to be here.

I: And what about when A. is away to the Stroke Club, do you get some leisure time then?

P: Yes, I do. But sometimes it's catching up with things. I'll go to the shops. And I'll go down to the beach. I love to walk on the beach. It's wonderful. I love the sea. So that to me is very restorative. I think I've been all right in that way....short breaks. It's just nice not too have to worry about A.' breakfast, dinner and his afternoon tea. Not having to be on hand. That's good.

I: Do you have enough opportunity to share any concerns you may have with an appropriate person.?

[20]

P: I suppose I do. The one I think of of course is the social worker, Jenny. Now, she would be there for me. But you see, I don't like troubling her, for something I would consider maybe to be trivial. Cause I know what their job involves, I know what the GP's job involves. And really, my little, as I call it, trivial...I just can't... I know so well what it's like for them. I don't really want to.... I think a friend, my nurse friend, she would be there, as I would be for them. I am... I shouldn't say that of myself, but... reasonably supportive of my friends.

I: So would you say you have enough opportunity to share your concerns?

P: Yes, it really does....It's enough for me. What I would like sometimes is to speak to someone professional, who is outside the family. Cause you're always protecting in the situation, those who know you. So someone professionally, who had time, who didn't feel you were holding onto them. That would be a very good thing. In saying that, I know the social worker would welcome me. But I would be very reluctant to do that.

I: Do you ever feel as a carer that you are forgotten about? [21]

P: Yes. Yes. I think every carer feels that. It's always about the other person... Everything is geared around this person. How is he, and how is he doing . Yes, very much so.

I: Do you feel that that is both by professionals and family and friends?

P: Yes. I'll go to the doctor and the GP would say: How's A. And we'd fill up the whole 5 minutes about A. And obviously whatever affects him affects me, but you know, not very often would you hear: And how are you? It's like, whenever he went home from hospital, the report said "home to care of wife". That was it. "home to care of wife". There was nothing else, that was it. And I think I'm not alone, I think every carer.(...)

I: So do you also feel forgotten by friends and family?

P: Not by my sister-in-law, who is a very close friend and who is a nurse. And not by Elizabeth, who's a nurse. And a few nurse friends. Being in that job has giving me lifetime friends, who do understand, as I would a friend in a similar position. I would (phone) right in to the difficulties in their lives. And they do for me, so that's quite good.

I: When you think of the future how do you see yourself coping?

[22]

P: That's a tricky one. It's knowing: is A. going to get worse. We can cope now. If he has another stroke or an extension, could I look after him at home? My reason for retirement was a back injury. I couldn't lift him. And John is going to live his own life. He will be away. He won't be at home, so I can't depend on him. That would be very difficult. I try not to think about it.

And sometimes I wonder about even the finances of it all. Should I go and put the house to John's name. Should I go and get advice about this, because if anything happened will care-costs be... And then I go: Oh dear. So it's these questions that are there. And I think I've made up my mind to go and take some advice about this. In case I get caught up in the system. To leave him without a penny...that sounds awful, talking about money, but nevertheless... It could be if A. needed attention. And needed daily attention in a place. I hope that doesn't happen. I just hope he's on a plateau now, that he doesn't get worse. I know he's not going to get any better, but I hope he holds it for as many years as possible.

I: Were you satisfied with the amount of information you received about stroke when A. had his stroke?

[23]

P: There's a lot of information circulating. Things that I wouldn't know as a nurse in my day. There's leaflets on every part of the subject. But perhaps not many people to speak to and tell you what this really means. There was no one to say: Now, look Helen, our prognosis here for A. is... No one ever really gave me the out-look. And I would have been very appreciative of that. I mean I knew certainly a lot myself. And I would read every leaflet and every article that is possible to read. But no one ever said what the out-look... Maybe they say: well, we don't know with strokes. People can surprise us. But I think... Cause you see, when we were applying for the attendants allowance, I didn't think we were going to get it, and yet someone must have sanctioned that, somewhere along the line someone gave us the full attendants allowance. So someone was aware of the prognosis. So I think that maybe a wee bit more from the hospital... Usually they're good at that. At specking to people about the....I think what it is, they want to be so positive. I think that's what it is. They told A. he was wonderful. He was doing great, great. But then he was disappointed. He said: they told me I was a star patient, but here I am six months later. And he had no physiotherapy or anything. They knew it wasn't going to benefit him. But they didn't say that. That's no criticism, cause they were very good. It was kind. But if I could adapt anything, a wee bit more realism. To say to a person: here's the situation. Here's the best and here's the worst. For me anyway. It fits me, I know where I am then, and I can cope with it.

I: What about the information you received about practical help and support?

[24]

P: Yes, that was quite good. The social worker, that was the hospital social worker, put me on to the Stroke Club. And the helper from the CAB came and would have filled up the form for the attendants allowance. So that was good. That was really good. And the Stroke Club organizer came to the house. Gave a very nice visit. Really, it's been quite good.

The only thing I wasn't happy with was the occupational therapy. That wasn't so good. It was good in the hospital, but in the community obviously they were very cashed out. And if they would just say that in the beginning instead of trying to persuade you. And everyone knows about that. I'm afraid it's the Cinderella of the Health Service a wee bit. They don't get the funding. And again, to me, if someone says: look, we have very little to offer you. We haven't got the money. I can say: right, I'm with you, I understand. Just tell me. But don't

(fault) me off. I always like to know. So we ended up having to get our own wheels, all by ourselves. So they never came back after that.

I: What about information about benefits?

[25]

P: Yes that was very good. The social worker at the hospital, very good. And the visit by the Welfare Rights, the officer from the CAB. She was excellent. Really excellent. She was here to get as much help for us as possible and it was much appreciated. I would never have asked about it. So that was good.

I: What support do you receive?

[26]

P: It wouldn't be a lot apart from family and friends. I'm able to keep things going. I just take care of it myself. I'm thinking certainly of getting some help in the house once a week, cleaning. That would really help me out. I feel as though I'm struggling sometimes to get on top of things. What ten years ago would have meant nothing to me is a wee bit of an effort now. And I think with me people don't see it. They look at me and think: yeah, you're fine. And I am in a lot of ways, but in some ways I'm full of arthritis, and I have back trouble, which makes housework quite difficult. So, just once a week would make a big difference. So that's what the extra help is for. And then there's someone to cut the grass and the hedges. And a bit of painting, but we pay someone to do that. And the attendants allowance.

I: Anything else?

P: Not really. There's really just family and friends. And then there's the Salvation Army. They're very good. They don't come about very much. I remember quite frequently, a man who's been a friend of A. for years said: How are you. And I said: I'm needing a day off. "Oh oh, we're busy, we're busy. I said: Oh, I didn't mean you. But he just took it up so courtly. "We're busy". And I thought: Oh dear, I won't say that again. Oh the reaction. I laugh right now, but.. It wasn't what he wanted to hear. "How are you?" I should say "fine". The standard reply to that" how are you?". Must be fine.

I: Would you say that that support is sufficient to meet your needs?

[27]

P: I would say just about. I would say that a wee bit more would be appreciated. This one gentleman, he's retired, he lives in England, but he has a summerhouse over here in Bangor. Now he would phone and he would say: A., I'm coming tomorrow morning to take you to the garden centre, for a wee cup. And the two of them go away off and to me that is so lovely. That is so nice and so appreciated. And I think just a wee bit more of that...

I: You mean you would like more breaks?

P: Yes. I mean I'm not bad, he has college on Monday afternoon, Stroke Club on Tuesday morning and on Thursday. The social worker offered another day for A., but he didn't want that. He wouldn't like two days in a row at the same place. So really short breaks. Someone just coming and saying: we're going out. Rather than somebody coming to see him. It's nice, someone visiting, but that ceases to be priority. Someone coming in I would have to make them tea. I never would have thought about that. But now, someone coming to visit and spending a long time. And I'm running in and out the kitchen, making sandwiches and all. If someone were perhaps to come and take A. out. Give him a wee bit of company. That would be much appreciated.

I: What support services do you feel you require most?

[28]

P: I think the medical. We have a very good GP. And the social worker, Jenny, who is GP-attached. She's very good. But again, I haven't seen her in a wee while, cause I don't want to trouble her. The Stroke Club is very good. Cause not only do they have a Stroke Club, but through that they have a college for A. and that gives him a wee bit of stimulation. And last week they had a dance and I was able to go. Not that A. would be able to dance, but the company was good. And it was a very happy time. So that's a good thing.

I: What about for yourself?

P: I think just being able to get a wee break. I think that would be it, I keep coming back to that. Say my daughter and I, of course again that's not a break is it, my daughter is having her second baby in August and I'm thinking: how can I get up to spend the best part of a week there as I'd like to do for her after she's had the baby. And I can't see a way around that. I was going to a nurses weekend in Scotland. They really pressed me to go and I really wanted to go, from Friday to Sunday. But I've had to pull out and I would have loved to go. Cause I

know it would be good, it would be old friends. And I've been in the habit for the past years of going and I would have loved to have gone, but I couldn't. So these are the things..

We had a holiday in a cottage, with mum and A. and I. But I'm still looking after him, still doing chores and doing all the driving. It's not so different. But a couple of days, a wee break, without A. Isn't that awful to say. Just with a friend maybe, would be lovely. But I don't know how. We had another bog family thing there in Jersey and they phoned me to say could I come. They knew A. couldn't come, it would be too much for him. But their way around it is: could A. not go somewhere. Go somewhere? He would not consider that. He would say: go on. But it couldn't be. He couldn't look after himself.

I: How has the support you receive changed over the past year?

[29]

P: It was more intense at the beginning. There was more high visibility from everyone. We were well up there on the list. And then things settled down a wee bit and it becomes more background. It's there if you need it. But something would have to happen, there needs to be a crisis situation, before I trouble them. It definitely lessens. I suppose it has to, cause there's new ones coming all the time.

I: The last question: looking back on what we've talked about, is there anything you'd like to add?

[30]

P: Ehm, I'm reasonably happy with what's there. As I said, a wee bit more respite, a respite situation.... I know the respite exists, but it would be a situation where the person who is the carer.....Last year we had an outing, it was lovely, we both enjoyed it, but I mean with respite just that wee short 24 hours or 48 hours of freedom. To get my head cleared. Not to think about my duties.

It's always the patient plus the carer. And sometimes the carer needs a bit of her own time, to get away from the situation.

The other day A. got up at 5:30, all dressed saying he slept in all day. He says: it's half 5. I said: yes, at night. He says: I'm going away out for a walk. I said: A. it's half 5 in the morning. He was all washed and shaved and dressed. He would've gone away in the car. You can laugh about it now, but I felt so sorry for him. I realised that he needs, not constant care, he can wash himself, he can feed himself, thankfully he can do all those things, but he needs someone to keep him right. So it's that sort of thing I'm needing a wee break sometimes from. And he certainly couldn't manage on his own.

I think some carers would feel guilty maybe about going away., think they shouldn't ask that. I don't think I would actually. If it was short. If it was longer I would. But I'd award myself, say two days, definitely.

Afterwards HD tells me a bit more:

She tells me she might want to join a carer's group, cause she thinks that would help her.

She also tells me she's been in bad health all year. She's had all possible viruses since A. took his stroke, and they hang on for weeks and weeks. She realises it's been a very stressful year and that that might have something to do with it. The doctor tells her it's stress. She says she knows from her job that a lot of carers have bad health.

She says she's constantly assessing A. Some days he's very good and some days he forgets what day it is.

Appendix 4.

Major categories and themes.

Complexities of the carer role.

- 01) change of character patient
- 02) having to do everything for patient
- 03) being responsible for everything that needs done
- 04) having taken up new tasks
- 05) loss of (full-time) job
- 06) no progress in recovery patient
- 07) importance of not 'overcaring'
- 08) patient can't do what he/she used to

Unpredictable nature of support network.

- 09) family support
- 10) support from friends
- 11) support from community (including neighbours)
- 12) satisfied with information and support in hospital
- 13) not satisfied with information and support in hospital
- 14) satisfied with professional support (after discharge)
- 15) not satisfied with professional support (after discharge)
- 16) overall satisfied with support
- 17) carer support group
- 18) not needing any help
- 40) having no one to turn to for support

Emotional demands of caring.

- 19) frustration with patient
- 20) being down in mood/depressed/stressed
- 21) patient is always on carer's mind
- 22) needing a break from caring
- 23) getting a break from caring
- 24) feeling guilty asking others for help

Need for carer education and support.

- 25) carer feels forgotten about
- 12) satisfied with information and support in hospital
- 13) not satisfied with information and support in hospital
- 14) satisfied with professional support (after discharge)
- 15) not satisfied with professional support (after discharge)

Personal and social impact on carer.

- 26) social isolation
- 27) being bound to the house
- 28) hobbies
- 29) social life is unchanged
- 30) not having any leisure time

Need for planned respite service.

- 22) needing a break from caring
- 23) getting a break from caring
- 25) carer feels forgotten about
- 31) carer doesn't feel forgotten about
- 15) not satisfied with professional support (after discharge)

Emotional impact of changed relationship on life carer.

- 32) fear of death patient
- 33) love for patient
- 34) no more romance
- 01) change of character patient
- 19) frustration with patient

Coping with caring.

- 35) first shock
- 36) taking it a day at a time
- 37) remembering well the moment of stroke
- 38) stroke hits two
- 39) fear of getting less able to cope
- 41) feeling things will get better

Appendix 5.

Table of frequencies of themes.

Theme	Times mentioned per carer.								Times mentioned in total	Mentioned by how many carers?
	01	02	03	04	05	06	07	08		
01	0	0	2	0	0	3	5	2	12	4
02	0	1	1	0	2	2	1	1	8	6
03	0	1	1	1	0	1	3	2	9	6
04	1	0	2	1	1	2	0	0	7	5
05	0	0	0	1	0	0	1	1	3	3
06	0	6	0	0	0	0	0	1	7	2
07	3	0	0	0	0	0	1	0	4	2
08	2	1	1	0	1	1	0	4	10	6
09	5	12	6	5	5	2	1	3	39	8
10	0	0	2	0	0	2	0	4	8	3
11	0	0	5	1	0	3	0	1	10	4
12	2	1	2	1	2	1	0	3	12	7
13	0	3	3	2	0	5	8	1	22	6
14	0	2	5	2	6	2	4	2	23	7
15	3	5	1	5	0	0	4	1	19	6
16	1	1	1	0	1	1	0	1	6	6
17	0	0	0	0	1	0	0	1	2	2
18	2	0	1	0	0	0	0	1	4	3
19	0	2	1	0	0	1	2	0	6	4
20	0	1	1	1	1	1	2	3	10	7
21	0	3	1	0	1	1	1	00	7	5
22	0	0	0	1	2	3	0	7	13	4
23	0	3	0	1	3	0	0	2	9	4
24	0	1	1	0	0	1	0	5	8	4
25	0	2	3	4	0	1	2	3	15	6
26	0	0	3	1	0	3	2	2	11	5
27	1	1	3	0	3	1	0	3	12	6
28	1	1	2	0	1	0	1	1	7	6
29	1	1	0	0	1	0	0	0	3	3
30	0	0	0	1	0	1	1	0	3	3
31	1	1	0	0	1	0	0	0	3	3
32	0	0	1	0	0	1	0	0	2	2
33	2	0	2	0	0	0	0	0	4	2
34	0	0	0	0	0	1	0	0	1	1
35	0	1	1	0	0	1	0	0	3	3
36	1	1	0	1	1	2	0	0	6	5
37	1	0	1	0	0	0	0	0	2	2
38	0	2	0	0	0	0	0	0	2	1
39	0	0	0	0	2	1	0	2	5	6
40	0	0	0	1	0	0	4	0	5	2
41	0	0	0	0	0	0	2	0	2	1