Caregivers of people with multiple sclerosis: experiences of support

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The aim of this phenomenological study was to gain an understanding of the experiences of a group of caregivers of people with multiple sclerosis (MS). Sixteen caregivers from Northern Ireland and the Republic of Ireland participated in focus group interviews. The theme of support, either sought or received, emerged as a major aspect of the experiences described. Caregivers’ feelings about, and experiences of, support appeared to change over time. Four common phases that caregivers experienced in relation to support were identified as: ‘rejecting’, ‘resisting’, ‘seeking’ and ‘accepting’ support. This paper will present and discuss these four phases. The study findings highlight the complexity of issues surrounding a caregiver’s decision to seek and accept support. It is hoped that the phases identified within this study are useful in depicting how caregivers of people with MS may progress through stages in their desire for, and acceptance of, support. Findings from this study are useful to healthcare professionals who work with people with MS and their caregivers by increasing awareness that a caregiver’s attitude toward and acceptance of support changes over time.


Key words: caregivers; community networks; delivery of healthcare; health personnel; multiple sclerosis; social support

Introduction

Multiple sclerosis (MS) is a chronic and progressive demyelinating disease of the central nervous system. It is widely acknowledged to be the most common cause of chronic neurological disability amongst adults in the western world1,2 and is estimated to affect in excess of two million people worldwide.3 MS is a complex disease that is polyclinically related in nature. The progress, severity and specific symptoms can vary greatly from time to time and from person to person.4,5 MS may involve motor, sensory, cognitive and behavioural functions.6 Symptoms may include muscle spasticity, tremor, ataxia, paraesthesia, visual deficits, pain, fatigue, bladder, bowel and sexual dysfunctions. Cognitive dysfunctions may occur in attention, memory, executive functions, mental speed and verbal fluency. Behavioural changes may include depression, anxiety and emotional lability.6 Initially these symptoms can be intermittent, but often there is subsequent progress with an accumulation of disability that is resultant in a changing pattern of limitations and subsequently of care needs over time.7

As a result, MS has significant social, psychological and physical impacts upon the individual with MS, their family and friends.1 Research has demonstrated that persons with MS can experience major limitations on their ability to do everyday tasks.8,9 It has been estimated that 50% of people with MS are unable to walk without assistance 15 years after onset10 and more than 50% of people with MS are unemployed within 10 years of diagnosis.11

As a person’s disease progresses, disabilities often become more permanent and their need for personal assistance increases.12 Many individuals with MS rely upon some level of assistance from a caregiver to remain in their own home. The chronic, progressive and unpredictable nature of MS may result in long term demands being placed upon caregivers. In spite of this, a recent systematic review has shown that few studies have been conducted with caregivers of people with MS.13 Indeed, only 24 studies regarding the experiences of caregivers of people with MS were published between 1990 and 2002. The majority of these studies highlighted the detrimental impact of providing care for a person with MS, including the effect on a caregivers quality of life,14,15 physical health,16–20 psychological well-being,14,16–17,19–24 social life,17,25,26 financial situation,14,19,21,22,27 and career.22 Studies have also demonstrated that these caregivers experience lower levels of perceived social support28,29 and have a low uptake of formal community support services.30

The purpose of the study reported here was to examine and gain a greater understanding of the experiences of a group of caregivers of people with MS. Focus group interviews were conducted with caregivers who were members of an MS charity in Northern Ireland and the Republic of Ireland. Caregivers were asked to share their experiences of providing care for someone with MS.
**Methods**

A phenomenological approach was used in this study. Phenomenology is a qualitative research methodology, which is concerned with investigation of people’s experiences of everyday life events and the meaning that these events have to them. According to van Manen, phenomenology offers a descriptive, reflective, interpretive and engaging mode of inquiry from which to derive the essence of an experience. The goal of phenomenological research is to ‘explicate how experience is meaningfully constituted and communicated in the world of everyday life’ (p. 140). In this study a phenomenological approach was used to gain an understanding of the lived experience of providing care to a relative or friend with MS.

Focus group interviews were employed in order to facilitate interactions between participants about their experiences, and thus enable researchers to gain a rich understanding of the issues being discussed. Morgan describes focus groups as guided discussions that generate a rich understanding of participants’ beliefs and experiences. Focus groups were chosen because they elicit the exchange of beliefs and attitudes between people in similar situations. Indeed, focus groups are believed to offer a more natural environment [than a one to one interview] because participants are influenced and influence others, just as they are in life, (p. 5). In addition the interaction elicited between participants of focus groups can also sensitize researchers to issues which they may not have previously considered.

The authors of this study are all healthcare professionals, therefore their assumptions were based upon a health and social care framework and on the basis of current research in this area. For example the authors had the assumption that providing care to an individual with MS may impact upon the health of the caregiver. However, this was a phenomenological study the goal of which was to gain an understanding of the caregiving experience from the caregivers’ perspective; therefore the researchers tried to become aware of their assumptions and, as recommended by Becker (p. 36), attempted ‘not to impose their categories of understanding onto the data’.

Ethical approval for this study was obtained from the authors’ University’s Research Ethical Committee.

**Sample**

Participants for the focus group interviews were identified using purposive sampling techniques. Caregivers who were known by staff at an MS charity in Northern Ireland and a county branch of an MS charity in the Republic of Ireland to meet the inclusion criteria were invited to participate. Inclusion criteria were that the:

- caregiver was aged over 18 years;
- caregiver had been providing care to a person who had been diagnosed with MS for at least one year;
- care recipient currently or had previously required at least one hour of assistance with personal care each week.

These criteria were formulated on the basis of informal discussions with a group of caregivers of people with MS who were members of a carer support group. The criteria were intended to ensure that each caregiver had experience of providing ‘hands on’ care to the person with MS and had lived with the knowledge of the diagnosis of MS for at least one year. Caregivers meeting these criteria would likely have reached a stage at which they were ready to openly talk to a group of people about their experiences.

A total of 16 caregivers attended one of four focus group interviews. Each focus group interview consisted of between three and five participants. Table 1 outlines the demographic details of caregivers attending each focus group. In order to protect the participants’ confidentiality and to enhance their anonymity, each caregiver and care recipient was assigned a pseudonym and potentially identifying but unimportant details have been changed.

**Data collection**

Four single stand-alone focus group interviews were conducted during the period of March–July 2002. To accommodate the working patterns of all caregivers, two focus group interviews were convened in the early evening and two focus group interviews were convened mid-afternoon. Three focus group interviews were convened in a private meeting room at a resource centre of an MS charity, in a large city. One focus group interview was conducted in a small conference room in a local hotel in a smaller town. During all focus group interviews participants were seated around a table. Each session was convened by an experienced focus group moderator (second author) and the principal investigator (first author) was present as a recorder.

A list of themes for the focus group interviews were generated from a literature review conducted by the authors, informal discussions with a group of caregivers who were members of a carer support group at an MS charity in Northern Ireland, and from previous research with caregivers. Each focus group interview began with a general opening question and each participant was asked to ‘talk about who you care for and how long you have cared for him or her’. This opening question gave all participants the opportunity to introduce themselves and their situations to the group. The focus group questions were not predetermined; rather, the moderator carefully followed cues of the participants and the discussions proceeded from those cues. Ray refers to this method of not using predetermined questions as a ‘clue-and-clue-taking process’ (p. 129). In this way participants were given the opportunity to discuss experiences of importance to them. In addition the group moderator used the list of the themes as generated earlier and introduced these when appropriate to trigger discussions. For example, themes included the effect of providing care on the caregivers’ mental and physical health, effect on caregivers’ social life, time away from caregiving, social support, and support from formal agencies.

Each focus group lasted approximately two hours. With the participants’ permission, each session was audio...
<table>
<thead>
<tr>
<th></th>
<th>Group One (n = 3)</th>
<th>Group Two (n = 4)</th>
<th>Group Three (n = 5)</th>
<th>Group Four (n = 5)</th>
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<tbody>
<tr>
<td>Caregivers’ gender</td>
<td>2 females, 1 male</td>
<td>3 females, 1 male</td>
<td>3 females, 2 males</td>
<td>3 females, 2 males</td>
</tr>
<tr>
<td>Care recipients’ gender</td>
<td>1 female, 2 males</td>
<td>1 female, 3 males</td>
<td>4 females, 1 male</td>
<td>2 females, 3 males</td>
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<tr>
<td>Relationship of caregiver</td>
<td>1 wife, 1 husband,</td>
<td>2 wives, 1 husband,</td>
<td>1 wife, 1 partner,</td>
<td>3 wives, 2 husbands</td>
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<tr>
<td>to care recipient</td>
<td>1 mother</td>
<td>1 sister</td>
<td>2 sons, 1 daughter.</td>
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<tr>
<td>Caregivers’ age range</td>
<td>60–65 years</td>
<td>42–66 years</td>
<td>18–36 years</td>
<td>40–65 years</td>
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<tr>
<td>Caregivers’ employment status</td>
<td>3 retired</td>
<td>2 retired, 2 employed full time</td>
<td>3 employed full time,</td>
<td>4 retired, 1 employed full time</td>
</tr>
<tr>
<td>Consultant’s employment status</td>
<td>3 retired</td>
<td>4 retired</td>
<td>2 students</td>
<td>5 retired</td>
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<tr>
<td>Caregiver and care</td>
<td>All live in same house</td>
<td>All live in the same house</td>
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<td>recipients’ residency status</td>
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<tr>
<td>Care recipients’ range of dependency levels</td>
<td>Minimal assistance with personal activities of daily living to completely dependent on assistance with personal activities of daily living</td>
<td>Minimal assistance with personal activities of daily living to completely dependent on assistance with personal activities of daily living</td>
<td>Completely independent in all personal activities of daily living to completely dependent on assistance with all personal activities of daily living</td>
<td>Minimal assistance with personal activities of daily living to completely dependent on assistance with personal activities of daily living</td>
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Data were further coded as to whether support was desired, actively sought, rejected or accepted. During this phase of the analysis it became clear that the caregivers experienced a complex mix of concerns, feelings and emotions which impacted upon whether they could seek or accept support. It then became evident that the caregivers’ descriptions of their experiences of support suggested that their feelings about support were not static but fluid and ever changing in accordance with circumstances. The researcher was able to discern from the data patterns and similarities in the way that support was perceived, which ultimately impacted upon whether help was accepted by the caregiver. In depth reflection, discussions, writing and rewriting resulted in the development of the notion of phases in caregivers’ acceptance of support whereby the caregivers feelings about, and experiences of, support, appeared to change over time from ‘rejecting’ to ‘resisting’ to ‘seeking’ to ‘accepting’. Data were then further coded according to which of the above phases they related to (Table 2 summarizes the way in which the data were coded). The phases in the perception of caregivers’ experiences of support with caregiving. The highlighted text, describing experiences of, or related to, support, were used as units of analysis. The units of analysis were firstly coded in terms of the nature of support, i.e., if the support the caregiver sought or received was from informal or formal sources. Informal support related to any practical or emotional support with caregiving that caregivers sought or received from family, friends or neighbours. Formal support related to caregiving support caregivers sought or received from voluntary or statutory government agencies (for example, home help services provided by Health and Social Services). The units of analysis were subsequently coded according to the exact source of support.

### Table 2 How data were coded

<table>
<thead>
<tr>
<th>1st level coding</th>
<th>INFORMAL SUPPORT</th>
<th>FORMAL SUPPORT</th>
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<tbody>
<tr>
<td>2nd level coding</td>
<td>Source of informal support</td>
<td>Source of formal support:</td>
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<tr>
<td></td>
<td>Family</td>
<td>STATUTORY SERVICES:</td>
</tr>
<tr>
<td></td>
<td>Friends</td>
<td>* Respite</td>
</tr>
<tr>
<td></td>
<td>Neighbours</td>
<td>* Domiciliary Home Care</td>
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<td></td>
<td>Care recipient</td>
<td>* Occupational therapy service</td>
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<td></td>
<td></td>
<td>COMMUNITY/ VOLUNTARY ORGANIZATIONS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>* MS specific charitable organizations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>* Carer organizations</td>
</tr>
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<td></td>
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<td>* Churches</td>
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</tbody>
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| 3rd level coding | Phases in acceptance of support; |
|                 | Desired |
|                 | Actively sought |
|                 | Rejected |
|                 | Accepted |

| 4th level coding | Phases in acceptance of support; |
|                 | Rejecting; |
|                 | Resisting asking for support; |
|                 | Seeking; |
|                 | Accepting |
tions of the caregivers of caregiving support are presented below.

Results
C aregivers experiences of or related to suppor t with caregiving
The change over time or phases that caregivers appeared to experience of ‘rejecting’, ‘resisting’, ‘seeking’ and ‘accepting’ support with caregiving will be presented within this paper. Figure 1 depicts these stages; the statements in parenthesis indicate the events or instances which the data suggest may prompt a caregiver to progress from one stage of the process to another. The implications of the concept that caregivers may go through phases in their perceptions and or acceptance of support are also presented.

‘Rejecting’ support with caregiving
In the early stages, possibly at the time of diagnosis, some caregivers explained how their family and friends offered their support. However at this stage it seems that neither the caregiver nor the care recipient wanted support and consequently they tended to reject any support offered. This ‘rejection’ of support appears to be closely related to the caregiver’s desire to protect themselves, the care recipient and their family from the reality of MS. They also appeared to have a desire to exercise control over their situations and maintain normality, for as long as possible. For example, some caregivers stated in the focus groups that they did not want to know about the disease or how it affected people:

‘I didn’t really want to know anything about it, that’s the way I have always been. I just don’t ask any questions or don’t want to know anything.’ (Anna)

‘Well, I am sort of half ostrich in the fact I don’t really want to know.’ (Helen)

Marina, a spousal caregiver, described to the group how she stopped attending the MS carer support groups because of this:

‘Like yourself, there are some times you don’t want to know, you don’t want to know what the next best drug is. You don’t want to know it at the time... If you are not having to deal with it... and that sounds pretty okay to me when somebody doesn’t want to know something. I think if you’re not having to deal with it, I think most people are the same, you find out what you want to know.’ (Marina)

It seemed that by rejecting support and not involving anyone outside the caregiving dyad the caregiver was also trying to protect and shield the care recipient. Some of the caregivers talked about difficulties the care recipients experienced in coming to terms with their diagnosis and accepting that they now had functional limitations. These individuals wanted to maintain their independence and had difficulty accepting any type of assistance even from the caregiver. Thus, the caregivers appeared to take on tasks alone, so that family, friends and the wider community were unaware of the care recipient’s functional limitations. Eleanor stated; ‘My husband would be like that. I think that he hasn’t accepted, and people will say to him how are you? and he will say I’m fine, I’m great, I’m wonderful, everything is brilliant. But in actual fact it’s not... I think he won’t admit that he doesn’t accept it really.’ (Eleanor)

Denise described how her son had difficulty accepting his limitations, and how he struggled to maintain his independence and rejected her assistance:

![Figure 1](https://example.com/figure1.png)

*Figure 1  Stages a caregiver may progress through in their acceptance of support with caregiving.*
'With my son... if you go to try to help him he wants to try to do everything on his own, and its just impossible for him to do everything because of his tremors, along with his poor balance, he can't stand and make a dinner or anything... He couldn't use a knife at all, because his hands are shaking when he's eating food and there is no way if you go to say to him son will I give you a spoon to eat? No, no leave me alone I am alright., He's angry with the illness, and he's angry with the world, and everything has collapsed around him and he's just, he's just angry with everyone. If I go to help him, if he's struggling to get his coat, if he's trying to get one arm in and he's hanging onto this wee thing (referring to the zimmer frame) and I go to help him, he'll say I can do it myself.' (Denise)

Another spousal caregiver described to the group how she felt that her husband was embarrassed by his functional limitations to such an extent that he preferred that his family did not visit:

'And he doesn't like people visiting, because of the situation, he doesn't like, he's embarrassed... Before he was in the wheelchair we would have had friends visiting, but it all stopped when he went into the wheelchair.' (Lynne)

Lynne, went on to explain to the group that she felt her husband would not wish to have anyone other than her assist with his personal care:

'To tell you the truth, but he would hate anyone coming in [referring to care assistants]. I know he would dear, dear, he's just so proud... I suppose maybe if he was an older man he would change, but at the minute I know he wouldn't like anybody coming in... he'd hate anyone coming in, he would.' (Lynne)

Some caregivers also appeared to reject support in an attempt to maintain normality and thereby protect their family. This seemed to be particularly true of spousal caregivers who had children who still lived at home.

'I've two girls you see, two daughters and you try to hide it from them and it's hard sometimes, you know? They're a wee bit older now, but when they were younger it was harder to hide your feelings. You have to try and make their life as normal as possible.' (Lynne)

'You try to keep the family normal for the sake of the children.' (Eleanor)

'Resisting' asking for support
As time progressed the care recipient often became more dependent; caregivers appeared to become aware they needed support with caregiving, however, many seemed to be unwilling or unable, at this stage, to ask for help. This could be due, in part, to the gradual nature of the progression of the disease whereby the care recipient was gradually becoming more dependent and subsequently the caregiver took on more responsibilities without really noticing. It seemed that the caregivers' caring responsibilities gradually became the norm for daily life and consequently the caregivers did not experience a sense of gratification. As this spousal caregiver explained:

'You grow up to a certain extent, and you mature with it, your taking on extra things as the condition deteriorates and the illness progresses. You're taking extra things on over a period of time that you don't really realize sometimes, and in some instances maybe you take on more than you need to at the time, ... I think over a long period, you do, you take on things... I don't think you feel any better for what you are doing, because it is a gradual progress and you have taken more and more on.' (Maureen)

The caregivers who participated in the focus group interviews also gave the impression that they felt that providing care was their responsibility and as such they couldn't ask anyone to help them; this seemed particularly true for spousal caregivers. It also appeared evident that the caregivers derived great pride in their role as caregiver and that this also prevented them from seeking or accepting assistance. One spousal caregiver described to the group how she evacuates her husband's bowels. It seemed that she felt as a wife that it was her responsibility to do such intimate caring tasks and she could not expect or ask anyone else to do such tasks:

'Well a nurse won't do that, you need to have love and care.' (Fiona)

This great sense of responsibility that caregivers felt for the care recipient was often in evidence throughout the focus group interviews. In particular, the maternal and spousal caregivers interviewed expressed that they felt that they had sole responsibility for the well being of the care recipient. Many of the caregivers explained that this was a responsibility that they always felt, 24 hours a day, seven days a week. It appeared that even when these caregivers were physically away from the care recipients' they still experienced worry and concern for the care recipients' well-being. In the following excerpt, a spousal caregiver described this overwhelming feeling of responsibility:

'Having someone's well-being as your responsibility, you know there is an isolation factor to it. People don't understand that isolation factor in having someone's whole well-being as your responsibility... people can't take that away from you, even if you get respite, or you get someone to come in, you still have that responsibility... that's a big responsibility, knowing that not only somebody's physical well-being but their mental stability and everything else is your responsibility.' (Maureen)

Another example of the caregivers' perception of having sole responsibility for the well being of the care recipient was expressed when caregivers discussed their fear of becoming ill. The overwhelming concern of these care-
givers was of who would care for the care recipient if they were to become ill. The interaction between two spousal caregivers illustrated this fear:

‘I would say in the last four or five years he’s been house bound because he wouldn’t be steady enough on his feet to go out, and he doesn’t drive. So in the last four or five years he’s relied on me to get him out and get him ready to go out. He sometimes has to wear a bag now because he would be incontinent, so I lie at bed thinking if anything happens to me where would he be?’ (Eleanor)

‘Tell me about it. That’s an awful worry, that’s awful.’ (Lynne)

‘And then I think sometimes I worry so much about it you could really do yourself harm, it would be better not thinking about it.’ (Eleanor)

‘Every time you have a wee pain you think something is wrong.’ (Lynne)

‘And you know I don’t worry what’s going to happen to me, I worry what will happen to him without me.’ (Eleanor)

‘Yes, same here. I had a health scare and I was quaking, but they said no I am OK, but all I could think over the past couple of weeks was what’s going to happen if this is bad? You know, who’s going to care? There will be a lot of years and who is going to look after them?’ (Lynne)

Another factor which may prevent caregivers from asking for help was the perception that some of the caregivers appeared to have that no one knew the care recipient as well as they did and consequently no one could do the job of caregiving as well as they could. This is evidenced by Fiona’s explanation of why she could not place her husband in an institutional setting for respite care:

‘I would say in Archie’s case there is X [referring to a respite care home], it’s private, they have beds and of course Archie could go there in the morning, but no one knows Archie the way I know him. If Archie would need help, Archie can’t use a bell, so he’d be lying there using whatever wee voice he’s got trying to get some help. He would be worn out by the time someone gets to him.’

Some caregivers felt that it was unfair to ask family or friends for support. Many caregivers appeared to have the perception that their families have their own lives to which one may be adding an unfair burden. Fiona described how she and her husband felt that it would be unfair to ask their children to assist with caregiving:

‘I go back to my children, this was Archies attitude to the whole thing, he said Fiona its not the children’s fault I have MS. No matter how we manage I want them to have their life or they will grow up and say “Daddy I hate you, you were always ill and we never got anywhere”, he looked at it that way.’ (Fiona)

Similarly Henry said:

‘My son is in England, I should be able to talk to him but I don’t think it’s fair because he has a young family, that’s his life. He has enough on his plate without me burdening him about his mother.’ (Henry)

Other caregivers described how they are unable to share their problems with their family or ask them for assistance:

‘I mean who in your family, I am very close to my sisters, but there’s only so much you can burden them with, I mean I don’t tell them everything... Every family has their own problems, their own worries; you don’t want to burden somebody else with your problems.’ (Eleanor)

‘I am the same, I have two sisters and I wouldn’t tell them... You want everything to appear perfect, everything’s wonderful, you don’t want your family to [know].’ (Lynne)

Associated with the great sense of responsibility and pride in their role, many caregivers expressed how they wished family, friends and the wider community to perceive that they were coping and were not in need of any support or assistance with caregiving:

‘You put on a façade to a certain extent and don’t be as open as you could certainly. And I suppose too, it’s also that you don’t want to admit you are not coping.’ (Henry)

‘You don’t want to be seen as not coping.’ (Robert)

It seems that at this stage caregivers did such a good job of looking as if they were coping that family members were unaware that their support was needed. Lynne explained that she cared for her husband so well that if anyone else were to see him they would not realise there was anything wrong with him or indeed that she may need help to care for him:

‘If you came into my house and you’d think there was nothing wrong with him now... My family come up and they wouldn’t think of saying “do you want something done? Can I do a wee bit of painting, or out and do your garden”, they don’t, they come and visit and away they go. They don’t do anything for you. They think you’re coping fine on your own, but they don’t know behind the scenes what you have to do.’ (Lynne)

Some caregivers also felt that many people, including their family and friends, were ignorant about MS and were unaware of how much assistance the care recipient required. In addition some caregivers discussed that family and friends who had offered support in the past, stopped offering this support as time went on. A few
Caregivers tried to explain this, some felt that this was related to the chronic nature of MS, and that people were frightened that they may have to offer long term, sustained support. Lynne felt that people stopped asking if they could help because their support had been rejected so many times in the past: ‘No one would actually think of saying I’ll come and take Mark out for the day. I think because at the start he was so proud that he wouldn’t let anyone know, now nobody bothers asking him anymore. He refused them so much I think that’s why.’

It is interesting that although the caregivers were unable or unwilling to ask for support with caregiving, some did appear to be disappointed and annoyed that their close family members, for example their children, did not freely offer their assistance. Two spousal caregivers discussed how they felt about their children not supporting them and assisting with caring. One gentleman actually felt that his son had moved away to get away from his mother:

‘I have it in my mind he went to England to get away from the problems.’ (Henry)

Another spousal caregiver appeared angry that her son and daughter did not get more involved in their father’s care:

‘My daughter has the talent of coming to our house and sitting with her dad and talking to him, . . . she’s under the misapprehension she is helping me, she doesn’t do a continental thing! Nothing! The cats not even fed! The poor cats waiting on me coming back… He’s [her son] deeply involved in his church… He’s a lovely boy, but he’s out seven nights a week to church and there’s his daddy sometimes might, could, do with his companionship… He hasn’t got time, I can’t hack that. I found myself… I suppose after this time, I get angry in things I don’t understand in people.’ (Ella)

‘Seeking’ support with caregiving
Most of the caregivers interviewed expressed a strong desire to care for their loved one alone without assistance from informal or formal services. However, some caregivers appeared to reach what could be termed as a crisis point, a stage when the caregiver realised that he or she could no longer cope alone and was forced to seek out support with caregiving. As family and friends did not offer or had withdrawn their support (as described in the ‘resisting’ phase), caregivers tended to seek support from formal sources such as charitable organizations, Health and Social Services (Northern Ireland) and Health Boards (Republic of Ireland). Some caregivers described this point being reached when the care recipient’s functional limitations and/or the caregiver’s physical health meant that they could no longer transfer (move) the care recipient on their own. In one focus group, a participant asked Robert what led to him seeking assistance from domiciliary home care workers. Robert then shared the following account of a traumatic episode when he was unable to transfer his wife from the car to her wheelchair:

‘I had to transfer… it use to be well that hairdressers appointment has always been there and you know, well Eva always drove herself in the car if you know what I mean. She was able until, I suppose since 1989, I always took her to that, but then she started sliding out of my grip because she lost weight-bearing strength in her legs. Even in the wheelchair she had that until about five years ago when she lost it, and then because of my condition I couldn’t hold her up and sitting in the car park she used to slide, and of course you have an audience, I mean people just don’t think.’ (Robert)

However, all caregivers who had sought formal support described how they had to struggle to obtain this support. Barriers included a lack of information about sources of support, protracted waiting times for services, red tape and bureaucracy, all of which rendered services inflexible and unresponsive to the needs of the caregiver and care recipient.

In the following excerpt Robert discussed how he was never informed of the support services available to him:

‘I think if you are not worrying the professionals they’ll not come near you and I think they should be offering us more. But the professions the doctors, the physiotherapists they wont offer you… We have a social worker who comes every six months… but she has never in the five years she has been coming said “are you getting help with this? Are you getting help with that?” ’ (Robert)

Caregivers appeared to find out about available supports mostly via informal channels, for example, via communication with carers they encountered at carer support meetings or at hospital appointments or through reading articles in magazines or newspapers: ‘We didn’t know… It would have been a couple of years from my husbands bladder was bad, and we didn’t know about those things [referring to incontinence products], it was only I found out by accident… We seen them in a magazine.’ (Marina)

Some caregivers turned to voluntary MS specific charities for assistance. In some instances, the charitable organizations were perceived as unresponsive to the carers requests.

‘I rang [referring to MS charities help line] in complete despair… the response I got was “do you have MS? No, I am sorry we can’t help you” — the girl put the phone down.’ (Helen)

Some caregivers discussed that they often had to wait for long periods to obtain necessary services.

‘It took about a year and two months for her to get one [wheelchair].’ (Helen)

‘Accepting’ support services
It seemed that when caregivers were forced to seek out formal support (as described in the ‘seeking’ phase) and if
they were successful in finding a source of support, which they perceived to be suitable, they then reached a stage where they could accept the support service.

The caregivers reported varying experiences of formal support services. A few caregivers and their care recipients appeared to be satisfied and therefore accepted and benefited from the services. Alternatively, many caregivers described being dissatisfied with the quality of services offered, and it seemed in these cases that both the caregiver and care recipient had difficulties accepting and benefiting from the service offered.

In the following excerpt Marina, a spousal caregiver, described her satisfactory experience of an occupational therapy service from Health and Social Services. From this quotation it was evident that both caregiver and receiver were pleased with, and felt they had benefited from, the interventions:

‘We have a brilliant OT… she really impressed me about how in touch she is with people who are ill… She put in for an extension, she reckoned that my husband needed to come down the stairs to sleep because he kept falling down the stairs. The stair lift thing didn’t work and all the rest of it you know… so she came out, and they wanted to use our dining room and I said och it doesn’t matter because I would rather move first, you know it’s a family home as well, I didn’t want to turn it into a hospital… she came up with all these fantastic arguments and she came back and said “you’re getting your extension”… She had it all sussed out she’s fantastic. Anything you need you ring her, and she will come out. The thing I like about her most is she seems to know what you are talking about when you are talking to her… I think we are lucky because she had a relative with MS, and we were very lucky that she understood the progression of it and the way that it came and went and how it affected people in many different ways.’ (Marina)

In contrast, many caregivers expressed that they were very unhappy with the formal support services they had in place. Frequently, caregivers reported that services did not meet their needs or those of the care recipient. The services delivered were reported to be inconsistent, inflexible and of such poor quality that they caused both caregiver and care recipient much distress and angst. In some instances caregivers rejected this support completely and decided that they should cope alone. During one focus group interview Henry shared with the group his negative experience of domiciliary home care:

‘My wife has had MS for 28 years and she has been in a wheelchair for perhaps six or seven since she cannot stand at all. All toileting has to be done with assistance from either carers [referring to domiciliary care assistance who are employed by Health and Social Services] or myself… I gave up work simply because I was incapable of doing two jobs. It is really a demanding job and it is made worse by the fact of the inconsistency of the agencies who arrive and the fact that in the morning somebody just doesn’t appear… one agency that I actually threw out and told not to come back because they were coming at night, 10 o’clock, next night 11 o’clock, next night nobody came, the next time they would phone you at 10.45 pm to say that there wouldn’t be anyone there until 11.30pm and that inconsistency at night, I said look forget about it, its much easier if I do this because at least I can say to my wife set a deadline and I can decide whatever time I wish my wife and I to go to bed. But it’s the inconsistency and the inconsistency of people coming into your house, the way they treat you, the way they treat your belongings, your property. They came in some of them and said to me ‘I can’t move your wife’ I say ‘why not have you had no training to use a hoist?’ and I show them how to use a hoist… you don’t know what’s happening next…’ (Henry)

Unfortunately some caregivers and care recipients who were unhappy with the quality of the services provided actually rejected the services and chose to cope alone without any support.

Discussion

Caregivers from this study appeared to experience what could be described as an inner conflict between desiring independence in their role as caregiver, but also wanting others to offer them assistance. It seemed that over time and as the caregiving situation changed, the balance between these two opposing feelings shifted. It was apparent that many of the caregivers preferred to manage care by themselves for as long as possible without assistance. However as demands upon the caregiver increased, often the caregiver reached a stage whereby they realised they could no longer cope alone. At this stage some caregivers were ready to receive support from family and friends. However, often family and friends were unwilling or unable to offer sustained support and caregivers then seemed to feel they had no alternative except to seek out support from formal sources. Many caregivers then went on to experience barriers to gaining formal support and experienced difficulties when formal support services were in place.

The findings of this study highlight the complexity of issues surrounding a caregiver’s decision to seek and accept support and the importance of understanding how this process may evolve over time. The authors do not wish to oversimplify the experiences of the caregivers interviewed, however, it is hoped that the phases identified within this paper are useful in depicting how caregivers of people with MS may progress through stages in their desire for, and acceptance of, support.

It should be stressed that these phases should not be perceived as ‘steps’ through which all caregivers of people with MS will naturally progress. Rather, findings suggest that the way in which a caregiver views and or accepts support services were in place. Frequently, caregivers reported that services did not meet their needs or those of the care recipient. The services delivered were reported to be inconsistent, inflexible and of such poor quality that they caused both caregiver and care recipient much distress and angst. In some instances caregivers rejected this support completely and decided that they should cope alone. During one focus group interview Henry shared with the group his negative experience of domiciliary home care:
care services and consequently rejected this support but who, at the same time, desired that his children would offer him more support.

Cantor’s hierarchical compensatory model\(^2\) proposed that there is an ordered preference for the selection of a caregiver, which begins with the spouse, followed by other relatives, then friends and finally formal organizations. It appears that the caregivers interviewed similarly considered sources of support based upon the closeness of the care recipient’s relationship with the potential sources of support.

Research conducted with caregivers of people with MS has identified that these caregivers have a low uptake of formal support services\(^3\) and experience low levels of social support when compared to other groups of caregivers.\(^4\) It is hoped that the study reported in this paper takes this discussion a step further by highlighting the complexity of a caregiver’s decision to seek or accept support, and thus offers a unique perspective on possible explanations for low levels of support commonly reported amongst caregivers of people with MS.

The progression and changes in the caregivers’ perceptions and acceptance of support may be related to the very nature of the MS disease process. MS is a disease of many uncertainties, it affects each person differently,\(^4,5\) and has an unpredictable clinical course.\(^6\) People with MS and their caregivers are often unable to predict the progression of the disease, the onset of a relapse or even the functional ability of the person with MS over the course of a day.\(^7\) The uncertainty and unpredictability of the disease may account for the overwhelming feelings of responsibility and fear of leaving the care recipient alone described by the caregivers who participated in the interviews. Indeed, other researchers have reported that the uncertainty of the disease has been shown to add to the stresses of caregiving.\(^8\)

This change in the caregivers’ perceptions and acceptance of support may also be related to the long term nature and course of MS. MS usually affects people in young adulthood, typically between the ages of 20 and 40 years.\(^9\) Advances in the management of secondary complications now mean that people with MS have a near normal life expectancy.\(^10\) Therefore, caregivers may be expected to provide care for many decades, often into their own old age. Over this long period of time family and friends may withdraw from the situation or may be unable to offer sustained support.

**Implications for clinical practice**

Findings from this study provide useful understandings for healthcare professionals who work with people with MS and their caregivers. These professionals should be cognisant that a caregiver’s attitude and acceptance of support with caregiving may change over time and indeed that in many instances caregivers may experience a cognitive struggle in actually accepting that they require such support.

The data from this study suggest the process of a caregiver moving from being independent and autonomous in his or her role as caregiver, to actually seeking and accepting support is highly complex and probably differs for every caregiver. Therefore, it seems that the understanding gleaned from this piece of research should encourage healthcare professionals working with this client group to endeavour to ensure that their interventions are timely and appropriate. Healthcare professionals need to listen carefully to caregivers so they are aware of the stage in their acceptance of support. This would enable them to tailor interventions to the caregiver’s individual needs. Healthcare professionals have a responsibility to help caregivers identify their need for support and actually give themselves permission to accept support with caregiving.

The findings of this study regarding the inconsistent quality of formal services concurs with the suggestions of other researchers, as Nodder et al. stated, ‘services for people with MS and their carers still leave much to be desired’.\(^11\) Healthcare professionals have an ongoing responsibility to monitor the acceptability of services for caregivers.

The concept of a change over time, of ‘rejecting’, ‘resisting’, ‘seeking’ and ‘accepting’ support could also relate to caregivers of people with other progressive neurological diseases, for example, motor neurone disease and Huntington’s disease. Similar processes regarding acceptance of support over time have been described in studies that examine caregivers of people with Alzheimer’s disease and dementia.\(^12\) Coe and Neufeld found that male caregivers experienced similar phases in their acceptance of formal support services.\(^13\) These researchers describe the phases of ‘resisting’, ‘giving in’, ‘opening the door’ and ‘making the match’. Similarly in a study exploring the respite experiences of caregivers of people with dementia, Strang and Haughey\(^14\) described a three phase cognitive journey that the caregivers experienced in accepting respite, namely: recognizing the need for a break, giving themselves permission to get away from caregiving responsibilities, and realising the adequacy and availability of social supports which would enable them to get away. Indeed, the framework of change over time may relate more widely to other caregiving situations whereby a caregiver takes on more and more, for example parents of children who are born with profound learning disabilities may progress through similar stages in their acceptance and desire for support.

In this focus group study each group of caregivers met only once. One group interview consisted solely of younger caregivers aged between 18 and 36 years. Generally these younger caregivers were more inhibited and spoke in less depth about their experiences. It may have been beneficial to hold more than one interview with this group of caregivers to enable them to get to know one another. It would also be interesting to further explore in depth the experiences of caregivers of people with MS relating to support through a series of individual interviews.

All of the caregivers interviewed had experience of providing care for at least one year. Therefore, it may be beneficial to conduct interviews with caregivers at different stages of the caregiving experience to further explore
the concept of phases that caregivers at different stages of the caregiving process may have differing attitudes towards support.

These focus group study findings contribute to our understanding of the complexity of MS caregivers’ experiences of support. The findings of this study suggest that it is important that those who work with caregivers of people with MS are sensitive to the complex perceptions and feelings a caregiver experiences regarding support with caregiving.

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