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A discussion of the information needs of people with multiple sclerosis (MS) and the implications for information provision based on a national UK survey of people with MS

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A discussion of the information needs of people with multiple sclerosis (MS) and the implications for information provision based on a national UK survey of people with MS

Mark Hepworth, Janet Harrison and Nicole James
Department of Information Science, Loughborough University, LE11 3TU

Correspondence to: M.Hepworth@lboro.ac.uk

Abstract

This research took place between January and October 2002. It was conducted by the Department of Information Science at Loughborough University and was commissioned and funded by the Multiple Sclerosis Trust (MS Trust). In this article the identified information needs are discussed and possible solutions explored including the use of Extensible Mark-up Language (XML) and Extensible Stylesheet Language (XSL).

Qualitative and quantitative methods were used to study the information needs of people with multiple sclerosis (people with MS) in the United Kingdom. 103 people with MS were involved in focus groups that helped to identify significant situations that people with MS had experienced. 4100 people with MS were sent questionnaires (approximately 5% of the MS population). 2030 (49.5%) responded in the time specified.

Categories of information need were identified. Their importance and difficulty in obtaining them quantified. The research highlighted how, although people shared many information needs, there were significant differences in terms of:

- ◆ people's desire for the information (some people did not want apparently useful information);
- ◆ the topics they were interested in (due to their situation);
- ◆ how they wanted that information (due to the physical and psychological condition of the person).

Information provision to people with MS was found to have improved dramatically over the last seven years. Out of those respondents who had been diagnosed in the last five years 71% thought they had received information whereas 29% did not, whereas only 29% diagnosed in 1980 stated that they received information. Taking the total surveyed population 43% thought they had not received information. Information provision was found to be inconsistent in terms of subjects covered. However it should be borne in mind that at the time of diagnosis, and also afterwards, it may be difficult for people to take on board information for a variety of reasons. Furthermore, as indicated above, different individual needs means that information provision is a complex task. Many intervening factors can make it fail.

The research made it clear how access to relevant information, provided in an appropriate way, could significantly improve the quality of life of the person

with MS and that there is considerable scope for improving provision of information to people with MS.

Introduction

This research took place between January and October 2002. It was conducted by the Department of Information Science at Loughborough University and was commissioned and funded by the MS Trust.

Research into the information needs and information provision for people with MS (people with MS) was driven by a belief, supported by previous research, that information provision was inadequate (Robinson et. al. 1996, Baker 1997). Also that information and knowledge are beneficial to the well being in terms feelings of control, depression and reduced dependence on the health service, of the people with MS (Somerset et. al. 2003).

The aims of this study were to:

- ◆ systematically provide a comprehensive understanding of the information needs of people with MS;
- ◆ determine what information needs were most important to people with MS;
- ◆ determine what information was currently most difficult to find;
- ◆ specify what information should be made available to people with MS;
- ◆ recommend how information should be made available to people with MS.

The results of the research were expected to help determine the information policy of the MS Trust and also provide guidance, in terms of information provision, for service providers in the health and social services as well as other voluntary organisations and public information providers.

This paper focuses on the information needs that were identified, explaining the subject matter and why this information is important, the form in which it is required and the way it should be provided.

Overview of Multiple Sclerosis

There are approximately 85,000 people with MS in the UK. MS affects more women than men (approximately 2 women for every 1 man) and is generally diagnosed between the ages of 20 and 40. In parts of Scotland it is estimated that 1 in 500 will have MS; for the rest of the UK it is approximately 1 in every 1000.

In MS the myelin sheath around the nerve cells is attacked, the nerves become demyelinated and may not function as they should. MS can affect any part of the central nervous system and can potentially alter movement and muscle activity at several different sites, giving rise to a variety of physical and psychological symptoms. Although it was first identified in the 1860s the cause(s) of MS remain in dispute and a cure is elusive.

MS is a particularly challenging disease in that it is highly unpredictable, and can result in a wide range of psychological and physical challenges that can

vary from year to year and day to day – which can lead to a high degree of uncertainty and a need for information (Wilson et. al, 2002).

Previous research

Little specific research has previously been conducted on the information needs of people with MS. Earlier research tends to be general and does not attempt to identify comprehensively and categorise the information needs of people with MS. It has been recognised, however, that people with MS need to make long-term, information-based decisions about their condition (Wollin et al 2000).

In 1996, in the UK, Robinson et al. conducted a qualitative study of the needs of people with MS. Part of this study concerned information. They found that appropriate information was hard to find and use and that it was not available when and where they wished to access it. The information needs that were identified included:

- Information on the condition itself
- Symptoms and managing symptoms
- Current research
- Benefits and entitlements
- Insurance and mortgage advice
- Transport for the disabled
- Suitable holiday venues
- Respite care
- Medical and complementary therapies
- Social and support groups
- Voluntary organisations
- Employment and statutory rights advice
- Home adaptations and aids

The report highlighted that individuals might have different information needs at any particular time due to different circumstances. The report concluded that a centralised source of information would be useful.

In 1977 Matson and Brooks in the US studied people with MS to determine how they had adjusted to the condition since diagnosis. They concluded that most adjustment takes place in the first ten years after diagnosis. Based on their findings they proposed a four-stage model of adjustment to MS, in which information plays a role. Newly diagnosed patients entered stage 1 (denial) immediately. Here they sought information through different medical channels in an attempt to dispute the diagnosis. In stage 2 (resistance) it was shown that people acknowledged the possibility of having MS and anxiously sought information about the condition and a cure. Patients also turned to others with the same condition and participated in groups or classes to garner any information that might be helpful. Stage 3 involved telling other people about MS. Stage 4 began when a person had fully accepted the condition.

Matson and Brooks stated that information given by the consultant was seen as inadequate, perhaps because patients desired life-encompassing direction,

which might be beyond the knowledge of the individual consultant. Most people with MS wanted practical information that would help them live with their condition. To find this information they used a variety of sources, with varying degrees of success.

Stewart and Sullivan (1982), in the US, found that information seeking activity starts in the pre-diagnosis period and continues until a diagnosis of MS is confirmed. They also found that, because symptoms could be fleeting and might vary from one exacerbation (attack) to another, people engaged in 'physician shopping' until they found a doctor who could diagnose their condition. People also sought information from popular literature and medical texts, as well as from health professionals, family and friends. Matson and Brooks (1977) noted that in the post-diagnostic period, people with MS wanted practical information to help them live with their condition and sought information from other people with MS.

Baker (1997) in the US undertook a study of people who had recently undergone an acute exacerbation of MS. This study involved a questionnaire survey of 260 women. The results helped to identify categories of information need and contributed to the questionnaire design in the current study. Categories of information need included:

physiological (general information about MS, nutritional literature, fatigue, bowel and bladder disturbances etc.);
psychological (dealing with a hidden disability, emotional behaviour, spiritual material etc.);
social (education, support for family members, branches for women etc.);
economic (insurance, employer relations etc.).

Baker revealed gaps in people's knowledge about physical symptoms people with MS were experiencing, emotions they felt, and drugs that could be used. Various sources of and barriers to obtaining information were identified. The results also suggested that health professionals needed to be aware of the continuing need for relevant, current and specific information to help people with MS retain their independence and to enable them to make informed decisions.

Baker (1994) also found that people tended to fall into the category of either 'monitors' or 'blunters', that is, people 'either want information to handle an uncontrollable event or turn away from it because information is perceived to increase their level of anxiety'.

A New Zealand-based study by Gregory et al. (1996) discovered that people with MS found generic information regarding MS readily available, but that practical information at a local level was frequently difficult to obtain.

In a review of health care preferences of people with MS in the UK, Somerset (2001) found that three quarters of the people surveyed reported lacking advice about at least one MS related issue and 17% lacked advice in five areas. The most frequently consulted health professional was the GP followed by the hospital consultant. The professional that most people said they would

have liked to see, however, was a MS specialist nurse. The study concluded that people with MS displayed a wide variation in their unmet needs, and that information about MS management (both conventional and unconventional), relevant tailored advice and access to appropriately skilled professionals should be components of high quality care.

The literature does, therefore, provide some insight into the information needs of people with MS, their information seeking behaviour and information provision. The needs can be seen to be broad and people with MS might not be successful in satisfying them. There was, however, insufficient detailed empirical data to enable a comprehensive definition of the information needs of people with MS.

The research, discussed here, aimed to build on the previous research and to provide a more comprehensive view of the information needs of the MS population in the UK both at the time of diagnosis and thereafter.

Methodology

Qualitative and quantitative methods were used. Eleven focus groups involving 103 people with MS of differing severity took part. These were held in England, Wales and Scotland in MS therapy centres. People were recruited through the centres, via local MS Society support groups and newsletters of the MS Trust and the MS Society. The population was therefore self selected. However each focus group session recruited people from one of three groups: people who needed no walking aids (59%), wheelchair users (20%) and used a walking stick or walker (21%). This breakdown corresponds to national figures on mobility for the MS population (Compston 1998). At the start of the sessions respondents were asked to identify significant situations during their time with MS. Three to four of the most common situations were discussed by each group. Dervin's sense-making methodology was used to structure the discussion (Dervin 1999). The information needs associated with situations were identified as well as barriers to access. This qualitative approach helped to understand the experience of people with MS and ensured that the categories of information need were grounded in the reality of the people with MS.

This data, along with the published literature and input from stakeholders and the MS Trust, was used to inform the development of a questionnaire. The questionnaire was distributed to 4,100 people with MS through: the MS Trust, MS Society, therapy and respite centres, newspapers and the Internet. To aid completion by the MS community, the questionnaires used large print and tick boxes. 2030 questionnaires (49.5%) were returned. No follow up was instigated partly because a 49.5% response rate was felt to be good and also because of the time scale of the project. Again this was not a random sample; people chose to be respondents. 1509 were female 512 were male 9 did not disclose gender (a ratio of 3:1 which compares with the national norm of 2:1). Respondents were aged between 16 and 75. The earliest diagnosis was 1937 the most recent 2001. 553 people with MS were diagnosed within the last 5 years. Data gleaned from the returned questionnaires helped to

quantify the demand for and value of categories of information, the difficulty in finding information and what was required generally and specifically at diagnosis. The survey also determined how information provision has varied over time.

In addition audio-diarying was used to capture data on the day to day experience of a person with MS. Audio-diarying was undertaken by only five people, all who had severe symptoms of MS. Each person was given a small, easy to manipulate micro-cassette recorder and tapes and were instructed to record events, situations in their daily life where they needed to know something or wanted to find out something or had a problem that they needed to resolve. Any time a situation like this occurred they were asked to record what they were trying to resolve, why and whether or not it was resolved and if it was, how. This technique of data collection was done primarily to see what kind of data would be generated rather than as a primary survey tool. This method did prove effective in providing detailed data on the situations the respondents confronted and their thoughts at the time – and generated greater detail than that generated by the other two methods. The audio data made apparent, for example, the range of symptoms that a person with MS could experience over a short period of time and also the importance, in terms of general well being and quality of life, of taking an active role in life. However due to the small sample the audio data was given little weight in terms of the overall findings.

Findings

Qualitative data

Focus group sessions were all tape recorded and later transcribed and then coded. One hundred and thirty two, generally problematic, topics were identified by focus group respondents. Topics were categorised under the following headings:

- ◆ a lack of knowledge when dealing with new situations associated with having MS, particularly at the time of diagnosis but also subsequent situations such as finding out about state entitlements. This topic included discussion of how information is and should be provided. For professionals who are involved with MS it is hard to remember what it is like for a person who knows nothing about the condition or how to cope with a condition like MS.
- ◆ general symptom management including finding out about symptoms and possible actions they could take that could help;
- ◆ the difficulty of communicating with family, friends and colleagues and the need for appropriate information to help;
- ◆ the problems associated with disabled access and transport and the lack of supporting information;

- ◆ the need to make contact with and talk to other people with MS for both emotional and informative support.

Discussion of these topics helped to identify information needs and also provided an insight into how information should be made accessible.

Quantitative data

The questionnaire design was informed by the data gathered from the focus group sessions, the published literature and discussion with the stakeholders and the MS Trust. The questionnaire focused on:

Information provision and information needs at diagnosis

Determining the importance of categories of information and the difficulty in obtaining them and also

The best format (paper, face to face, Internet etc.) for access and delivery.

The aggregated data for all respondents was analysed. In addition the data from people who had been diagnosed in the last five years (553 respondents) was also analysed separately to see whether the picture had changed over the last five years. It was found that information needs remained consistent and that information provision was still inconsistent in terms of topics covered and at provision. However, the number of people who said they received information at diagnosis has increased dramatically over the last twenty years (in 1980 only 20% of respondents received information whereas in 2000/1 70% received information). In the last five years more information was provided on two areas, drugs and MS nurses. This reflects the introduction of disease modifying drug therapies and the increase in the number of MS nurses.

At diagnosis over 50% of the respondents wanted information on managing symptoms, drug treatments, disease course, physical symptoms, exercise, diet and information for the family. A distinction, however, was found between the information needs at diagnosis and long term information needs. This is discussed later. When respondents were asked whether or not they wanted to know about the different categories of information they generally welcomed this information. However not all people with MS wanted the same information or wanted to be informed at all. This may be because the severity of the condition can vary dramatically and people can experience very different symptoms. It may also be related to the information seeking behaviour of the individual and intervening variables such as self-efficacy or coping strategies (Wilson 1999) and Baker's (1994) conception of 'monitors' and 'blunters'. These individual differences may influence how people react to situations; whether people seek information; and what information they require; and how it should be provided.

Discussion of information needs and implications for information provision

The need for a holistic approach

The whole community

Information provision needs to be targeted at three communities. These are people with MS, the general public (including the family, friends and colleagues) and state and voluntary service providers. As far as I am aware, with regard to MS, little has been done to tailor the provision of information about MS specifically to the different 'communities' that are involved with MS. Each of these communities requires similar information but they require it in a different form and depth. Emphasis will also need to be placed on different types of information for different communities.

The public

The public need a basic understanding of MS. Even people who currently have no direct contact with a person with MS need to be informed about MS. Some of the problems experienced by people are due to ignorance of the general public. For example in the workplace, a person with MS who experiences severe fatigue, in several cases was considered lazy. A lack of knowledge about MS could also influence employment practice. In the domestic situation the lack of understanding of the family also led to difficulty. In extreme cases this led to partners leaving due to misconceptions about MS. Again through ignorance some family members were concerned with whether MS was contagious.

Information needs to be made available to the general public about MS through the national and local media. This would need to relate to the information needs of the employer, colleague, friend or acquaintance. In addition, and probably a more effective way in the long term, would be to incorporate in secondary schooling, probably under the heading of 'citizenship', information about MS. Ideally other conditions, particularly those that lead to care in the home, would be covered since there is similar ignorance about other conditions and the help available (Hepworth, Harrison and Odhiambo, 2000).

Information also needs to be designed that is appropriate for the family. Some headway has been made in this direction, for example, a book entitled '*My Dad's got MS*' (Hetherington and Young, 2001). This approach needs to be more comprehensive so that similar information (although with differing content) would be developed that was designed for other family members.

To enable access for this community information would need to be provided that was relatively simple, for example, not laden with medical terminology, clearly presented, and in a factual and positive manner (Ward, 1997). This would include an overview of what MS is, the possible effects, medical support, social services support and voluntary groups. Information that helped people deal with specific situations would have to be provided separately and when appropriate. Geographical personalisation, so that people are informed about local support groups and services, should be practiced.

If the person with MS is helped by someone who acts as an informal carer then the information needs of the carer are going to be significant, particularly if the condition of the person with MS is severe. The informal carers would require far more information than other members of the public. They would also have a need for different types of information over time, as the condition of the person with MS changed. Ideally the situation of the carer as well as the person with MS would be monitored and appropriate information and support provided as necessary. This may sound ambitious from the perspective of service providers. However, the cost of enabling a person with a critical medical condition to stay at home, through information and need related services, is far cheaper than maintaining that person in state care. According to Walker and Dewar (2001) informal carers save the UK government £57.4 million per year.

Service providers

Similarly service providers would need general information about MS, the help and information that is available. The latter would help them to direct people with MS to informational and practical support. For example, a recent study of the information needs of hospital social workers who work with adults leaving hospital, confirmed that they required overviews of medical conditions, medication and possible side effects as well as information about legislation, policy guidelines and other relevant agencies (Harrison, Hepworth and Chazal, 2002). This would help them to assess the kind of support the person would need and what can be provided.

Service providers, including health and social care professionals and support groups, would benefit from training in the information needs of people with MS and how these might be satisfied. This would help them to understand what questions people with MS may have and hence what information was needed, when this may be required and how it should be provided. Service providers need to be aware of the variability of the condition and how the nature of MS may change over time. This implies that needs should be monitored over time and that health and social records need to be maintained so that people do not need to instigate help from scratch, when it is needed in the future. A better knowledge of the condition could also place service providers in a position to recommend services that the person with MS may not have been aware of or found it difficult to ask for. For example it took people with MS who had bladder problems a long time to find out about catheters, partly because they were embarrassed to discuss such personal problems and because information about bladder disturbances and catheters had not been found or given to them. Once they did know about these areas, and were able to take advantage of this equipment, it was easier to travel from the home. This had a big impact on their lives.

In the focus group sessions diagnosis was the most common topic discussed. Where unsatisfactory experiences were described (49% of people attending the focus groups) these were associated with 'a lack of support', 'poor attitude' and 'providing no information'. However it should be noted that being

diagnosed is in itself a negative experience and is likely to colour a person's judgement of the situation. Furthermore the majority of people who did attend focus groups had been diagnosed more than ten years ago since when the situation has improved. Nevertheless from the questionnaire it was seen that 29% of those diagnosed in the last five years felt they received no information at diagnosis. This indicates that information provision by health care professionals is not always successful and could be improved. However understanding what information is likely to be needed and knowing how to provide that information is not easy, bearing in mind that there are individual differences in terms of what is relevant to a person and what they actually want and also how they want it. Health professionals involved in diagnosis would therefore probably benefit from training in the information needs of people with MS and also how to provide information at diagnosis in a supportive and sensitive fashion.

The person with MS

Someone with MS should be seen as a person, and not only as a person with MS, who is likely to want to take an active role in life. Information should be provided that helps achieve this goal. Enabling people to participate actively in life as a result of access to information, and becoming better informed and more knowledgeable, whether in the home, workplace or elsewhere has a positive impact on their self-esteem and general well being. This may seem self-evident. It is, however, easy for service and information providers to focus on the condition and information specific to that condition rather than seeing the person with MS in the broader light and understanding the impact access to information can have. As a result they may underestimate the importance of information provision and fail to provide information that helps the person with MS really engage and participate in life. The audio tapes, for example, provided a good illustration of where an individual had become informed and had found out about adapting his car and sources of finance to do so which meant he could take his daughter to graduation. This meant a great deal to the person with MS, including increasing their mobility and independence, and importantly in this case, being able to fulfil their parental role.

Failing to take into account that the person with MS is, like any other person, fulfilling numerous roles, such as parent, wife, wage earner etc. and is having to deal with situations associated with these leads to simplistic and inaccessible information provision. Firstly without an understanding of the significance of information it is hard to prioritise what information to offer. Secondly organisations that do not take this on board tend to provide information that only relates to the function of the organisation rather than the wider needs of the person.

Thirdly research has shown that information seeking tends to take place when people have to resolve specific situations and tend not to seek information on topics that do not immediately concern them (Osiboe, 1998). When browsing for information people recognise useful information partly because it obviously relates to their current situation (Bates 1989). The success of frequently asked questions is largely to do with this. The user does not have to wade

through an A-Z of functions that they may or may not understand, in other words, they recognise the task and then the solution. A booklet called 'Tips for living with MS' (Tips, 2002), about how to deal with common situations experienced by people with MS, was popular, for similar reasons, among people with MS. These tips were collected from people with MS by the Department of Information Science at Loughborough University and collated, synthesised and published by the MS Trust. Therefore one way of providing information for people with MS is to identify common situations that people have to deal with, such as driving a car or dealing with an employer, and provide the necessary information. Information that enables someone to drive a car, who has a physical disability, would include, for example, information about mobility schemes, car adaptations, possibly the usefulness of a catheter, disability access and so on. This 'package' of relevant information, related to solving a particular life problem, would be easily recognised by the person with MS, when needed, and the fact that the information was integrated would mean that the person would not have to locate and interrogate numerous sources.

However as well as providing information in a way that relates to specific situations, information also needs to be provided in a discrete way so that people can find out about a specific topic quickly.

The information that people with MS stated that they wanted at diagnosis is shown in the table 1. What is evident from Table 1 is that, although there was a significant demand for most of these categories of information, there was a significant proportion of people who did not want that information. This highlights the complexity of information provision and raises questions, such as, whether offering in a particular way would change the percentage of people who wanted it.

Table 1: What information would you have liked at diagnosis?

What information would you have liked?	Liked	% Liked	Not liked	% Not liked
Managing symptoms	1334	65.7	685	33.7
Possible drug treatments	1232	60.7	787	38.8
Indication of disease course	1121	55.2	897	44.2
Possible physical symptoms	1118	55.1	901	44.4
Information on exercise	1093	53.8	926	45.6
MS specialist nurse	1089	53.6	929	45.8
Information for family	1072	52.8	947	46.7
Information on diet	1017	50.1	1002	49.4
Benefits and Entitlements	995	49.0	1024	50.4
Physiotherapy	986	48.6	1031	50.8
Contact for group of newly diagnosed	948	46.7	1071	52.8
Alternative therapies	939	46.3	1080	53.2
Organisation addresses	913	45.0	1106	54.5
Possible psychological symptoms	885	43.6	1133	55.8
Counselling	804	39.6	1215	59.9
Work related information	714	35.2	1305	64.3
Driving	637	31.4	1380	68.0
Occupational Therapy	570	28.1	1449	71.4
Other	115	5.7	1906	93.9

After diagnosis, drawing on both the qualitative and quantitative findings, it was determined that the following categories of information would help to satisfy the information needs of people with MS. These categories fall under two headings:

(i) '*information about MS*' and (ii) '*information that helps the person with MS interact with the world around them*'. This distinction may seem misdirected in that it could reinforce the mistaken perception of seeing the person with MS primarily in terms of their condition rather than as a person. However, as mentioned earlier, it would be good design practice to provide information through life situations as well as through a 'directory' of topics.

(i) Information about MS

In general people with MS should be provided with information about:

MS, a general explanation. This would include an explanation of what MS is and how the body is affected. Diagrams can be very effective at communicating this kind of information.

MS research trials. This was one of the areas that respondents found either difficult or very difficult to find out about (45.8%). Due to there not being a cure for MS, at present, people with MS are keen to find out about new clinical trials. For example, the findings of the cannabis trials. People with MS were also interested in getting involved in trials but did not know how.

Drug treatments. For similar reasons people wanted to know about drug treatments and whether new drugs were becoming available to people with MS and the regulations and costs associated with them. 44% found this difficult or very difficult to find out.

Symptoms. MS can result in many symptoms, such as loss of balance and mobility in general, sight problems, pain, severe fatigue and stress. Symptoms that people highlighted as difficult to find out about were balance problems, emotional changes and memory problems. People with MS can experience new symptoms. Each time this occurs they need an explanation of what is happening, how serious it is and what can be done. Support groups proved particularly popular because people could ask others about a symptom and someone else who had experienced it would inform them. Respondents, however, did indicate that one could not always rely on the views of other people with MS. Another route for discussing symptoms (and other topics), that the MS Trust have offered, was via electronic chat sessions where people can exchange information. An expert was also present who could give a professional view and act as a moderator.

Treatment and management of symptoms was highlighted as a separate topic. There is a distinction between knowing what something is and how to treat or cope with it. This kind of information can be provided in a factual way. However where coping is more relevant than treatment, through the use of drugs, physiotherapy etc., information provision would need to be broader and require thoughtful design in that it should be motivating and include coping strategies.

Information on the full range of symptoms experienced by people with MS and their treatment or management is therefore required.

Prognosis. Providing information on this area requires sensitivity. Some health professionals, in conversation, say that people do not want to know how the condition could develop either at diagnosis or any other time. This was born out to some extent from our findings (47% did not want information). It is also an area of uncertainty due to the unpredictable nature of the disease. However, 53% of the respondents who had been diagnosed within the last five years wanted, at diagnosis, an indication of the disease course. It is likely that this response would depend, to some extent, on the condition of the person and also on how they are dealing with the situation emotionally. Prognosis can, however, help people to plan and take control assuming a suitable state of mind.

Physiotherapy. 80% of all respondents thought it important or very important to know about physiotherapy. However it was generally less difficult to find out about than other topics.

Complementary therapy. 68% of respondents thought it was important to know about complimentary medicine. This includes hyperbolic oxygen as well as other complimentary approaches such as massage, acupuncture and complementary medicines. One concern expressed by respondents and the MS Trust was that there is little quality control in this area and now, through the World Wide Web, people can become aware of and use 'alternative' approaches that are harmful.

Nutritional advice. There is evidence that diet can have an effect on MS symptoms and that certain foods exacerbate the negative symptoms of MS. As a result (and also because drug treatments may not be effective) there was a lot of interest in diet.

Health and fitness. Similarly maintaining health and fitness is thought to be beneficial. People with MS wanted information about what exercise could help and how to take part in appropriate exercise. Aquatics, for example, is felt to be particularly appropriate because the water provides support for the weakened body and also reduces body heat which has an adverse effect on people with MS (The national, 2003).

Emotional changes. This was a topic that people with MS found difficult to find out about. As well as suffering from depression and mood changes people with MS can also experience severe fatigue that can have a negative impact on people's state of mind. Being aware of the likely emotional changes that can take place and also ways that can help to ameliorate them is therefore important.

(ii) Information that helps the person with MS interact with the world around them

Information that helps the person with MS interact with the world around them is not directly concerned with the medical condition. This includes information about:

Service providers (health service, social service, benefits agency, non-government and voluntary organisations) and the services they provide. Previous research with informal carers (Hepworth et al 2000) and recent work with people with Alzheimer's disease (Pritchard 2003) highlight the difficulties people have with dealing with the various bodies that can provide help for the person with MS. The lack of knowledge people have about state and non-government organisations means that when people have a need they find it very difficult to understand exactly what organisations do, the responsibility of different roles, such as a community nurse, and how to instigate services (including how to fill forms appropriately). Organisational charts need to be made available to help people contact the right people. In addition advice on how to complete application forms needs to be provided. Increasingly we are seeing attempts to provide more 'joined-up' services. This will be helpful in

that organisational boundaries will be less likely to get in the way of information provision.

Support groups. These groups played a key role for many people with MS. However it should be noted that some people were not keen on joining groups. This was partly because they did not want to see people in a worse condition as this indicated what the future may bring or they did not want to be constantly reminded of their condition. Other people found support groups extremely useful for exchanging information, learning about their condition, identifying additional support and providing emotional support. Generally the atmosphere in therapy centres, for example, was extremely supportive and helped people maintain a positive state of mind.

Aids and appliances. This was a category of information that related to people who had more severe MS and had, for example, problems with mobility. Again finding out about aids and appliances and their relative merits as well as potential sources of funding was not easy. In fact once one knows where to look there is a wealth of information on this area and Disability Living Centres, that show a wide range of aids and appliances, are found in most large towns.

Facilities for the disabled. Similarly to the above this category is not specific to MS. However severe MS does tend to be associated with problems that require access to facilities for the disabled. Finding out sufficient detail about disabled access is not easy and in the UK disabled access is poor. This situation is primarily due to ignorance about disability among the general public and presumably weak legislation enforcing good design. A conversation with people with MS about a building that was supposed to be 'disabled friendly' indicated that it was not. They thought that disabled people should be involved in the planning and design. Poorly designed buildings provide a severe barrier for people with disabling MS who want to take an active part in life. Hence information needs to be made more readily available on disabled access and facilities in public buildings.

In addition people with MS with problems with mobility also needed to find out about making their own home 'accessible' and possible sources of finances to do this.

MS and work and the issues associated with giving up work. Being able to work and bring in an income is of course of fundamental importance to most people. It was therefore not surprising that people with MS wanted information about work, their rights, employer obligations, dealing with their employer and also what would happen and what they could do if they had to give up full time employment.

Communicating about MS with family, friends, colleagues and the public. As mentioned earlier information for the family, friends, colleagues and public is very important. It was difficult for people with MS to communicate to others about their condition. People with MS need information that they can give to

such people. Material specifically designed for this purpose would therefore be useful.

Leisure activities including, when necessary, provision for the disabled. Information about leisure was not the most important type of information that people wanted. However 31% of people with MS did state that they found it difficult or very difficult to find out about appropriate leisure activities and holidays. It was important for people with MS to know what was possible, rather than assuming that it would be impossible to take holidays and enjoy leisure activities, especially if disability was an issue.

These categories of information are similar to those generally recognised as required by people with an illness (Duman, 2003). However the categories listed here cover a wider range of topics and include information not directly related to the condition but are important for the person's well being and ability to participate in life.

How should information be made accessible?

From my experience of conducting studies of people's information needs and information seeking behaviour I feel that there is still considerable scope for understanding how information should be provided and what factors influence whether information is taken on board and has an impact on the consumer of the information. As we have seen from the data provided here within a community, such as people with MS, the demand for different types of information is varied, as is how people want information. Generally, with regard to people with MS in this study, a number of information characteristics were important for successful information provision.

Information should be provided:

in a positive manner. People with MS stated that the majority of information they received emphasised the probable negative outcomes rather than stating what can be done. Publications that talked about how people coped with their MS, and specific conditions, were very popular. Information can be provided about a particular condition. However, if the information is combined with positive instruction and 'tips' and reassurance about the things that can still be achieved then the information is more likely to be absorbed and a more positive frame of mind maintained. This can help a person take a proactive and positive approach to managing their condition.

in a way that helps and motivates people to take action. This is similar to the last point. However more thought is required into what kind of information is going to enable people to take action. On the one hand, as noted above, information can be phrased in a positive way and practical instruction given that will help people cope. It may also be the case that at different points in time and depending on the frame of mind of the individual information should be provided in different ways. In counselling, for example, the theory behind motivational interviewing techniques (Miller and Rollnick, 2002) states that people go through a cycle of stages, when they are trying to change their

behaviour. These stages are contemplation, determination, action, maintenance and relapse. During these stages they are open to certain types of information, factual, positive, supportive etc. They argue that helpful information will correspond to these stages or states of mind. It is possible that similar or identifiable states of mind are associated with dealing with a condition such as MS and a greater understanding of how changes in people's state of mind affect their need for information would be beneficial.

that corresponds to the physical, psychological and social situation of the person with MS. People tend to want information that relates to their specific situation. This needs to be taken into account when providing information. In other words people need to be able to identify information that relates to their situation and receive information that is relevant or takes into account their situation. Technological approaches to doing this will be discussed later.

in a way that is sensitive to the desire for information and its possible impact on the individual. As noted not all people demand all categories of information or any at all. This has to be taken into account by the information provider and catered to accordingly rather than assuming, for example, one message for all. As discussed earlier this requires the information provider to be sensitive to the needs of the individual, whether in face-to-face situations or when interaction is through a machine.

using the most effective means of communication. This will vary depending on the nature of the information and the cognitive and physical ability of the person with MS. For example, face to face communication was found to be more appropriate for sensitive or complex issues, such as balance problems, bowel and bladder disturbances, drug treatments, emotional problems etc.. Leaflets and booklets were thought to be more appropriate for topics such as access and transport, aids and appliances, benefits and entitlements, working and MS etc.. Newsletters were felt to be most appropriate for information about research in general and specific research trials. Discussion groups helped answer questions and enabled people to share experiences.

Different types of information resources have different characteristics that may or may not be attractive to different users. For this reason access should be enabled to different sources of information that satisfy different needs, for example: academic and professional articles, popular press, experts and other people with MS. Each of these sources have different characteristics in terms of the depth, detail and style of presentation that will be more or less appropriate depending on the information need of the person with MS and their preference for how information is presented. For example other people with MS are valued for their insight into specific situations and their ability to provide relevant information in a way that others can relate to. Academic articles are popular with independent learners who want detailed information about research, that has gone through a peer review process, and have the ability to understand the terminology used and feel unthreatened by the

academic style of presentation. People should therefore be given a choice as to what type of material they can access.

using different presentation techniques to cater to individual conditions that a person with MS may experience. Overall 60% of respondents stated that MS affected their information seeking and finding information. For example, severe fatigue was cited by 47% of respondents as affecting their information seeking. This was followed by mobility (45%). Problems with concentration also affected access to information. The design of information provision therefore needs to take this into account in both paper based and electronic domains. People with high fatigue and low concentration levels are going to require information in a succinct form with emphasis on a graphical rather than textual presentation of information. Mates (1995) has shown that good design, for example using large print and contrasting colours, makes information easier to interpret.

The quality of design of information for people with MS is very varied. Different organisations provide different as well as the same information that is aimed at different audiences, such as health professionals or people with MS. Some follow good design standards others do not. Greater cognisance of good practice by information providers is necessary. For example notice needs to be taken of the work of The Centre for Health Information Quality (The Centre, 2003). The latter have developed criteria for checking the quality of public information. The Plain English Campaign (Welcome, 2003) as well as the Kings Fund book (Duman, 2003) on producing health information, also provide guidance. In addition Web designers need to conform to good practice. In particular the World Wide Web Consortium's Web Accessibility Initiative should be taken into account (WAI, 2003). The NHS have also sponsored the Discern project (Discern 2003) which provides a tool to help to evaluate Web sites.

Currently, however, much information available via the World Wide Web is difficult to access by people with physical disabilities such as poor sight due to poor design of Web sites and their inability to be read by screen readers (Scherer and Galvin, 1996, Oppenheim and Selby 1999). In addition small font and a lack of contrasting colours inhibit access. Hence information provision needs to be designed so that people can access it despite their disability and can take advantage of adaptive/assistive technologies. Legislation, concerning electronic access to information, will come into force in 2004 (RNIB, 2002) that should help to improve the current situation.

Further research

Further work is required into the effect of individual differences (psychological and physiological) on the desire to learn and to be informed and the use of information. Research is also needed into how technology can help to provide personalised information.

A number of technological approaches have been taken to offer personalised Web pages. Bental et al (1999) summarised a number of projects in this area. At the University of Brighton the ICONOCLAST project (ICONOCLAST, 2003) investigated how appropriate style and layout of documents can be determined through interaction between the author and the system. Patient leaflets were analysed to understand effective layout. At Loughborough we are currently investigating how Extensible Mark-up Language (XML) can be used to provide personalised information delivery based on the users' situation.

XML is a sub-set of Standard Generalised Mark-up Language (SGML). XML is designed to describe data and what data is. It is not a replacement for Hypertext Mark-up Language (HTML). HTML is designed to display data and to focus on how data looks using pre-defined tags. In XML the publisher defines the tags. For example <prognosis> could be a tag that is then used to identify material about prognosis. A browser does not know how to display an XML document. Therefore there must be something in addition to the XML document that describes how the document should be displayed. This is the role of XSL. XSL consists of three parts: XSLT (a language for transforming XML documents); XPath (a language for defining parts of an XML document) and XSL Formatting Objects (a vocabulary for formatting XML documents) (Introduction to XML, 2003).

XSL is a language that can: transform XML into XHTML; filter and sort XML data; define parts of an XML document; format XML data based on the data value, like displaying negative numbers in red; can output XML data to different devices, like screen, paper or voice. (XSL tutorial, 2003),

A screen was designed that allowed the user to make choices and indicate their situation, condition and information needs. For example they could request large font and specify that they suffered from severe fatigue and that they had recently been diagnosed. This generated XSL scripts that then worked on the XML document.

For example: Having selected large font the following XSL code was generated:

```
<xsl:variable name="font">5</xsl:variable>
```

where the number five signifies large font. Other characteristics of documents such as subject matter, level of depth, text density, relevance to stage of MS, would have to be defined and a taxonomy would need to be developed that describes documents and their content so that appropriate content can be generated when required.

If a portion of text in the XML document was tagged <start stage="a" den="ab"> . This meant that when the XSLT code was generated that stated the person with MS was at stage "a" i.e. recently diagnosed and wanted information in brief "ab" then a positive motivational piece of brief text was displayed from the XML document. XML and XSLT therefore work in

conjunction where XSLT is the programming language that develops the logic using standard conditional statements that act on the XML document. Using this approach one highly structured document can be presented in very different ways to the reader.

Conclusion

This paper has described the information needs of people with MS. Possible solutions were also discussed. The need for people with MS to have access to information about MS as well as to information that helps them interact with the world round them was highlighted. To improve the situation of people with MS, information and training should also be made available, about MS and the information needs of people with MS, to the general public and service providers.

The information needs of people with MS was seen to be complex because:

- ◆ the needs change over time;
- ◆ the range of topics they may or may not need to know about;
- ◆ variations in the desire for information;
- ◆ differences in how they want the information due to the physical and psychological state of the person with MS.

To achieve the level of personalisation required to effectively provide information to these communities evolving technology can be exploited as well as standard methods of information provision and exchange. However our current understanding of exactly how the state of the individual affects their need for information and what this means for the design and delivery of personalised solutions is still relatively crude and requires further investigation. For example what is the most appropriate taxonomy to describe different types of information held in XML documents? What is the most appropriate way of communicating different types of information about MS to a person experiencing severe fatigue or lack of concentration? Can information be presented in such a way that a 'blunter' becomes a 'monitor'? How would it be best to package information for the public and family? How can information be packaged in a way that people with MS can easily recognise the situations that they are dealing with and then find all the appropriate information that will help? For many of these questions we can envisage possible answers. However, to achieve a better understanding, individual differences need to be studied in more detail; an appropriate methodology for storing information needs to be developed; and access to this information through a range of techniques needs to be enabled. Having done this these solutions need to be evaluated in terms of their impact on the MS community and the other target communities. The lessons learnt through this kind of exercise would enable the full-scale implementation of relevant and personalised information solutions to people with MS. This work would also be relevant to other information providers who want to provide similar information services on different topics.

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