LEAP-MS Topic guide

Interviews for people with multiple sclerosis

Version 1.0

This topic guide is for researcher use only. It will not be shown to participants.

Each section has several key open questions – asked with a view to eliciting a narrative response and to let participants tell their story in their own way so that what is most important to the person is foregrounded by them. A series of more specific questions detailed below can be used for probing further as required.

For those participants who suffer with fatigue, the interviewer will prioritise the questions highlighted in yellow after they have given the person being interviewed the opportunity to tell them a bit about themselves.

This interview schedule has also been written with the possibility of participants using communication aids and the need for the interviewer to ask more closed questions in these instances. This is reflected in the prompting sections indicated in blue. Such prompts will not however be used in the main.

Introduction

1) Tell me a bit about yourself? (prompt if appropriate ‘what are your interests’?, ‘can you tell me a bit about your family’, what do you do/did you do for work? or do you like [list activities as appropriate for response – take cues from home environment])

2) Could you please tell me a bit about when you were diagnosed with MS and about your journey so far, living with MS?

Opening questions – Physical Activity

[This opening section aims to find out about the general level of activity that the interviewee currently engages with, what they think constitutes physical activity and what it means to them]

3) What do you think of as ‘physical activity’? and what does it mean to you? [offer a selection of choices if person is unable to give open response - e.g. a) vigorous exercise or playing sport, b) anything that raises your heart rate, c) anything that involves physical effort for an individual]
4) What physical activity are you able to do at the moment?
   [list options if required focusing on activities of daily living in the first instance]

5) Do you think of these things as ‘exercise’? – and if not, what is the difference for you between physical activity and exercise?

6) In terms of being physically active - what have you done this morning? [Have you got from bed to chair using your sliding board/transfer aid?, washed your face and hands, stood in the shower, reached across to grab a box of cereal for breakfast etc. – take cues from the environment and info thus far about how to pitch this list]

7) What have you been doing recently?

8) Are there physical activities you’ve been doing up until recently but you are unable to do at the moment?

9) Is there anything you miss about [activity]?

10) How do you find getting out and about?

11) What do you do?

**Barriers and facilitators to physical activity**

[Picking up on what has been said in response to the above questions, the aim of this section of questioning is to draw out specifically what helps and hinders, what is a barrier to and what/who facilitates physical activity]

12) What helps you to do [activity]?
   [Give range of potential facilitators in the given context – probe on the basis of any positive response – apply this strategy to the two questions below as required]

13) What support do you have to be physically active at the moment?

14) Is there some form of activity that you think you would be able to do if you had some/more assistance? What is that – and what help would you need to be able to do it?

15) What gets in the way of you being more physically active?

**Exercise/physical activity with others**
[Due to the likely need of this patient group for day to day support – this section explores the interviewee's relationship with activity and others].

16) You have mentioned [family/friends] – what do you do together?

17) How do these people help you in your life and how do you help them?

18) Are there things you would like to do with those people that you can’t do?

19) What prevents you from doing those things?

What is available to you locally?
[Aim of this section is to find out what the interviewee is able to access locally and what they can’t, what they know about local facilities that may support physical activity]

20) Can you tell me about things, places, activities, groups that are available for you locally? [Research area in which interviewee lives ahead of interview and take list of nearby accessible facilities to list if required]

21) Do you access/use any of these things yourself? If so, why and if not, why not?

22) Do you know about [tell them anything I know about local to them that they haven’t mentioned] – would you be interested in trying out any of those?

23) If no, why not?

Relationship with exercise
[Aim of these questions is to draw out the persons life long relationship with physical activity and whether how they think about activity has changed with their MS one way or the other]

24) Did you enjoy being active when you were younger? [rephrase if the person is very young]

25) What did you do? Did you play any sport, go to exercise classes or dance for example? [provide a range of examples and narrow down as positive responses received to gain detail]

26) Has having MS changed how you think or feel about exercise? And being physically active?
Exercise and MS

[Aim of this section is to draw out the beliefs that patient holds about being physically active and the benefits or not of being active for their condition].

27) What do you tend to get told or advised in relation to exercise?
28) Is any of this information helpful?

MS, Physical activity and self-management

[The aim of this section is to draw out MS participants perceptions of physiotherapy provision and models of support in relation to exercise. This is key as we need to be clear whether or not the people we interview have the same wishes and goals as those consulted with who called for more self- management support for people with MS – on which this project is built]

29) How supported do you feel by health care professionals to be physically active?
30) Who do you think is best placed to support you with being physically active?
31) What is your experience of physiotherapy? [is your experience of physiotherapy positive, negative etc]
32) Have you ever heard of ‘self-management’? – Self management is….
33) Do you think self-managing with the occasional guidance of a physiotherapists would be helpful for you? – do you prefer other ways?

Change

[The aim of this section is to provide information about MS and physical activity and ask if this information changes the perspective of the individual about what physical activity is and what it could be in the context of their lives. This section is divided into two sections - for someone with low engagement and someone with high engagement]

34) [For someone with limited engagement with activity] If I said that being physically active includes [i.e. standing, transferring into your chair, sitting forward, reaching, using your hands to play games, picking things off the supermarket shelf and putting them in the trolley, breathing exercises, going out and meeting people -turning your head and shaking hands] would that change how you think about physical activity?
35) [For someone with high engagement with PA] What would you say to other people with MS who aren’t as active as you – what would you advise them to help them to start being more active?
36) What do you think would help you increase your own level of physical activity?

Helping others and new physical activity resource/models

[The aim of this section is to explore what the person might want from services and what type of resource(s) they might engage with]

Based on what the person has said about their experiences – use that as a base to discuss models of therapy delivery and the potential for self-management resources with physiotherapy support. Ask directly if they have any ideas for resources before asking the below.

37) Do you currently use a smart phone, tablet or computer? [probe with questions about their level of confidence and the type of things they use these technologies for]

38) Have you used a paper-based workbook for anything in your life recently? If so, how did you get on?

39) Could you see yourself using an online resource alongside support from a physiotherapist to help you be more active?

40) Would this be something you feel you could and would be willing to use together?

41) What would you like to see on such as resource?

42) How would you want to track your progress?

43) How would you know if something was helping you?

44) Any thoughts about how the resource should be put together?
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Interviews for physiotherapists
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This interview schedule is divided into 6 core areas. Key questions are highlighted in yellow which will be prioritised if the health care professional being interviewed is short of time.

The majority of the questions posed here are written in order to generate a narrative response. Most experiential based questions have been tested in other interviews with health care professionals working with people with a range of neurological conditions. Questions which refer to self-management have largely been piloted in studies with health care professionals working specifically with people with secondary progressive MS conducted by members of our team.

Introduction

1) Can you tell me a bit about yourself, your career to date as a physiotherapist/physiotherapy assistant [prompt around their pathway into neurological physiotherapy and to specialising in MS if relevant]

2) Can you tell me a bit about your current place of work and the services your place of work offer/provide for people with progressive MS?

3) What does it mean to you to work in this field/with this patient group?

4) What do you find most rewarding and most challenging in your work with this group?

MS patients and exercise

5) What does 'physical activity' mean to you in the context of people with progressive MS?

6) What barriers do these patients face in being physically active?

7) In your experience, what helps people with progressive MS remain as active as possible or re-start some form of activity?
8) How do you feel physiotherapists support people with progressive MS to be physically active?

9) Could the profession do more or work differently with this patient group in your opinion?

10) What would you do or change about your work with these patients if there were no restrictions on your time or money etc?

If the professional has not spontaneously given patient examples then....

11) Can you tell me some stories about how people with progressive MS that you have worked with or heard about has successfully been able to be physically active?

12) Can you give me some examples where it's been very difficult to support a person with progressive MS to remain active or engage them in being as physically active as they could be?

Self-management

10) What does the term ‘self-management’ mean to you?

11) What do you think of the ideas behind self-management?

MS and self-management

12) What do you think about using self-management techniques with people with progressive MS?

13) Have you used any self-management techniques with patients recently? Can you give me an example of a situation where you felt it worked well and a situation where it didn’t work so well?

If they have not used self-management with patients then:

14) Can you think about a patient you are working with at the moment/have worked with who has progressive MS that you think self-management is appropriate for?

15) Can you think about a patient where self-management wouldn’t be appropriate?

16) Have you ever tried to use self-management with patients with cognitive impairment? Can you tell me about your experience of doing that?
Self-management training and education

17) Have you had any training about/on self-management? - What did you learn from it/think of it?

18) [If training received] From the training you received – what worked well for you? What did you find worked well to support your learning? Do you feel you have further learning needs? How could those be best met?

[If training not received] Would you be interested in training about self-management? How do you learn best? [e.g. do you like lecture style teaching, workshops, a weekly course face-to-face or online?]

Physical activity and the community

19) Are you aware of accessible places or tailored activities carried out locally that may support this patient group to be more physically active? Can you tell me about them?

The intervention and approach

As you know, part of the LEAP-MS study is looking at developing an online intervention to support PwPMS to be more physically active. We anticipate that the intervention might be a type of online workbook with a range of physical activities as suggestions to be carried out with others e.g. games parents can play with their children/grandchildren and individually, tips about getting out and accessible places and schemes, exercise regimes (or links to those already established), sections to set aims/goals etc.

We are suggesting the exploration of a model where such a resource is used in conjunction with support from a physiotherapist where the patient would receive an initial consultation from a physiotherapist where activity needs were discussed and the resource introduced to them. Initial goals could be set and an initial period of time be given for the patient to explore the resource and begin trying different things. They would then be reviewed by therapist either at a set date or on a self-referral basis.

We would trial this idea with a small amount of people to check if any intervention developed was acceptable to patients and physiotherapists – and evaluate its impact/usability. If positive, the intervention and model would be put forward for a full trial.

20) What do you think should be included within such a resource?

21) Can you envisage the model working?
22) What could improve the chances of it being successful? What barriers should we be aware of?

23) Is there anything else you’d like to add? Or anything else you’d like to say, that I haven’t yet asked you about?