

APPENDIX 5.2

STAGE TWO

INTERVIEW ONE – DOING

Occupational Performance Role Assessment (OPRA)

People with Parkinson's Disease and their Role Partners

Interview 1 - Doing

Goals of interview

- 1) Gather demographic data
- 2) Establish level/stage of PD
- 3) Identify roles in role repertoire
- 4) Define roles in terms of routines and tasks
- 5) Establish role repertoire hierarchies related to *doing*: Level of complexity, and degree of definition of specific roles.
- 6) Role map: Links between roles (supporting and competing)
- 7) Doing with partner and doing alone
- 8) Frequency of performance in specific roles: Time allocation and time use
- 9) Barriers and facilitators of role performance
- 10) Role Development: Past, present and future roles, role transitions, role continuity
- 11) Styles of doing
- 12) Nomination of partner to be interviewed

Description

The Occupational Performance Role Assessment (OPRA) utilises the OPM (Australia) (Chapparo & Ranka, 1997) and the Model of Occupational Role Performance (Hillman, 1999). Interview one (doing) has ten parts:

Part 1: Explanation of purpose of interview and obtaining consent.

The interview commences with a request to start tape recording. An explanation of the purpose of the study follows. This is done by a verbal explanation and provision of the information sheet. Following this, the participant is asked to sign the consent form.

Rationale:

Required for ethical reasons

Part 2: Recording demographic information

The date of interview, identification number (e.g AH3, PM1 etc), and details of participant's date of birth, ethnicity (including, if born elsewhere, how long the person has lived in Australia), living status (if living with others, what is relationship to them?). Year of diagnosis with PD. Socio-economic status.

Rationale:

- Date and ID number required for data management purposes
- Date of birth permits socio-cultural cohort comparisons
- Ethnicity and length of time in Australia allows cultural comparisons
- Living status may have major impact on type of role interactions person has
- Year of diagnosis indicates duration of *being* chronically ill, rather than functional status.
- Socio-economic status has a major impact on the choices available to participant.

Part 3: Recording participant's perceptions of basic occupational performance

Self reported levels of mobility, communication and personal care are recorded.

Rationale:

Self-rated mobility, communication and personal care provides information about person's own perceptions of their level of basic occupational performance. When used in conjunction with interview data it allows an estimate of where each participant is in the development of the disease. It is part of the data used to crudely place participant in early, middle or late stage of Parkinson's Disease. This in turn allows comparisons between participants at different stages of the disease process.

Part 4: Gathering information about role performance

This occupies the major part of the interview time.

- a) Participants are invited to identify their current occupational performance roles at the time of the interview. The interviewer provides minimal prompts and examples to facilitate discussion. As a role is identified, further questioning helps the interviewer to determine whether it is a role rather than an activity and who the participant's role partner(s) are for that role. The information in this section relating to activities is included to clarify for both the participant and the interviewer that roles are active. It produces better role definition.

Rationale:

Participants are the experts about how they organise their daily life. The interview is designed to facilitate them being able to give their own account of how they see what they do.

- b) Confirmation of roles. Participants are asked to confirm each of the roles that are identified.

Rationale:

It is important to be clear about what the participant sees as a role so that in further discussion both parties are talking about the same thing.

- c) Participants are asked about the duration of each role.

Rationale:

- place the person's current role repertoire in a developmental context
- information about role continuity
- information about likely levels of knowledge and skill related to specific role performance

- d) Participants are asked to identify any important roles that they have lost and why.

Rationale:

- information about role transitions
- information about possible role performance problems
- information about expected role continuity

- e) Participants are asked to identify any important roles they anticipate they will hold in the future and why.

Rationale:

- information about expected role continuities
- information about expected role transitions.
- information about participant's view of the future.

Part 5 is part of *knowing* as well as *doing*, it is necessary to obtain this information in the first interview as it will form the basis for all further questioning. From the *doing* perspective, it allows access to the structure of the person's perceptions of their role repertoire.

Part 5: Role Sorts

Using the finally agreed roles, participants are asked to sort in the following ways:

- a) Roles that they do with their partner versus roles that they do by themselves or with others (not partner).

Rationale:

Provides a picture of what proportion of role repertoire is done with partner and what is done independent of partner.

- b) Frequency sequence

Rationale:

Provides a picture of how much time is spent in which roles.

- c) Difficulty sequence

Rationale:

Provides a picture of what areas of role repertoire represent a challenge for participant.

- d) Duration sequence

Rationale:

Provides a picture of how much of the repertoire is relatively new and therefore unfamiliar and how much is old and familiar.

Part 6: Interview Summary

- a) The participant is asked about their own perception of their person *style of doing*.

Rationale:

Provides an overall picture of how the participant thinks of him or herself as a doer.

The participant is asked to identify the most important aspect of what has been discussed.

The participant is asked if there is anything else he or she would like to say.

Rationale:

Provides an opportunity for participant to summarise, further explain or emphasise what has already been discussed or to offer something new.

Part 7: Nomination of role partner(s) to be interviewed (for person with Parkinson's Disease only)

The interviewer asks participant to formally nominate a role partner who is particularly important to his or her own ORP. The partner should be someone and that the participant is willing to have interviewed about their shared roles.

Rationale:

The participant's nomination is needed. The assumption should not be made that a spouse or family member would be the participant's choice of most meaningful partner. Consent to contact the participant's partner is needed for ethical reasons. The participant's partner should be interviewed within a similar time frame to ensure some temporal consistency in relation to accounts of shared experiences.

Part 8: Conclusion

The participant is thanked and asked if he or she is prepared to continue to the second interview. If this is the case, then arrangements for the second interview to be held approximately a fortnight later are made.

Rationale:

To avoid the assumption that the participant is willing to continue, and to ensure the person knows what is to happen next.

Part 9: Field Notes

The interviewer writes field notes as soon as possible after leaving the participant.

Rationale:

Field notes can provide an important environmental context to the participant and their ORP.

Equipment required:

- a) Aids to identification: Name badge and business card
- b) Aids to conducting interview effectively: OPRA Interview 1 (doing) Schedule
- c) Implements for recording information: form, pen, tape recorder, 3 blank tapes, microphone, batteries for tape-recorder.
- d) Administration:
 - Part 1: Clipboard, information and consent form and pen
 - Part 5: Digital camera, plain board and post-it stickers.

ADMINISTRATION

Privacy:

When arranging the interview, ask that no third party be present. This is to ensure that the person's own perceptions are elicited and for reasons of confidentiality.

Repetition:

Any information volunteered in this interview relating to a later section of the interview is noted by the interviewer. Participants should not be asked to repeat themselves needlessly. Ideally, the interviewer will speak as little as possible. The suggested questions in each section are only asked if the information has not already been volunteered by the participant.

Discontinuing:

If the participant appears tired or otherwise unwilling to continue the interviewer should immediately offer to stop and be prepared to do so. Similarly, if the participant appears to be flagging but says he or she wishes to continue, the interviewer will abbreviate the rest of the interview and terminate it as soon as possible.

Recording:

Try to start the tape recorder as soon as possible. Ask early whether the participant minds being recorded. Valuable information can be lost if not recorded.

Part 1: Explanation of purpose of interview and obtaining of consent

If there is someone else available, ask them to sit in on this bit of the interview as a witness. It is important that the participant is able to feel relaxed and can understand the explanation. Introduce yourself and ensure that the participant understands the purpose of the interview. In order to involve the participant in Rexploratory research, it is necessary to ensure that he or she is fully informed (Minichiello, Aroni, Timewell, & Alexander, 1990). Give a brief explanation on the telephone when contacting the participant to make the interview appointment. Do not assume that the participant therefore fully understands the purpose the interview. A full explanation must be given at the interview. This is done in two ways. Firstly, give a verbal explanation. In particular it is important that the participant understands that it is his or her own perceptions that are required, rather than what he/she believes to be the perceptions of those around him or her or the wider community. Tell the person that the interview may take around an hour, but that it is up to him or her how long it takes. Say that

you will be taking notes and tape recording during the interview. Tell the participant that he or she can take a break at any time or end the interview if she or he has had enough. An example of a verbal explanation is as follows:

Interviewer:

This is a tape-recorder. Do you mind if I start taping? I am interested in how Parkinson's Disease is affecting you in terms of your everyday life. I am also hoping I can interview an important role partner of yours to talk about everyday life from his or her perspective so that I can look at things from two perspectives. The interview process will be exactly the same as it is for you.

I am particularly interested in the areas of your life that are important and meaningful to you. For this reason, I want to ask you about the roles that you feel you have, what they mean to you and how you deal with any problems that arise with doing them.

This is the first of three interviews. It may be necessary to meet more than three times to make sure we have covered everything, but it is expected that three interviews will be enough. I want very much to hear about your own ideas and perceptions of your life, because you are the expert.

In this first interview, I want to talk to you about what you do. I will be asking you about your roles and what you do in them.

In the second interview, I will be asking you what it is like to do what you do. I will be asking you about what your roles mean to you.

In the third interview, I will be asking you how you think about what you do. I want to know about how you plan and problem solve and organise your roles.

Each interview is expected to take about an hour, but it is up to you how long each one takes. You can say as much or as little as you wish. You are not obliged to continue to the end of the interview process. So, if you want to stop or take a break at any time, just let me know, and we will stop.

The contents of this interview are confidential. It will be taped and a transcript is made for analysis. I will also be taking note of some things as we go through. You are identified at all times by a number only. You may be given a pseudonym later, but your real name does not appear anywhere. Nothing is linked to you. The information that you give me will be compiled along with the information from the other people I am interviewing. I will be using it to write papers for publication, for my PhD thesis, for talks and conference presentations and for teaching.

Hand the person the Participant Information Sheet. Allow time to read this written material. Give the opportunity to ask questions. If the participant appears satisfied with the explanation, ask for a signature on the consent form.

Part 2: Recording demographic information

Note the following information:

- 1) date of interview.
- 2) identifying number (allocated by the researcher).
- 3) Date of birth.
- 4) Living situation - alone, with partner, with son or daughter or other.
- 5) Ethnicity. If born elsewhere, how many years since arriving in Australia.
- 6) Year of diagnosis of Parkinson's Disease
- 7) Socio-economic status. This will be recorded by the interviewer in relation to the area the participant lives in, type of house, and other factors such as information given by the participant relating to financial comfort or discomfort. If socio-economic status is still uncertain the interviewer could ask: *In what way do financial matters affect what you do?*

Record on form.

Part 3: Participant's perceptions of basic occupational performance

I need to know a bit more about your general level of performance. I realise that people fluctuate, so I'd like you to answer the following questions in terms of how you are for the majority of the time.

Participants are asked about:

Mobility:

Do you drive?

How long can you sit in a car?

How about walking – do you have any problems when you are out?

What about moving around at home?

Communication:

Do you experience any problems communicating with other people?

In person?

How about the telephone?

What about writing cheques and so on?

How about reading?

Personal care:

Do you have any problems getting dressed?

How about eating?

Do you have any difficulties with bathing?

Are there any problems with going to the toilet?

Interviewer rates self perception of occupational performance as 1, 2 or 3. See attached definitions for how to rate.

Rate and Record in part 3 of the OPRA form.

Part 4: Gathering information about role performance and role repertoire

a) Identifying roles

Initial question or cue for the interview:

"Could you tell me about some of the roles you have right now?"

Jot down routines, tasks and sub-tasks as they are given.

Use prompts to ensure that as many roles as possible are covered in the discussion. At this stage, attempt to establish the person's whole role repertoire.

Examples of questions to ensure coverage of different performance areas:

Remember that the participant will have a very personal idea of the meaning of specific roles and may not sort them in the way that you might expect:

Possibly Socio-cultural

What about your family roles?

Could you tell me a little about your friendships?

Can you tell me about any clubs or other things you belong to?

Do you have any pets? Tell me about them.

Possibly Leisure

What about things you do for enjoyment or fun?

Tell me about something you do just for yourself.

If you want to give yourself a treat, what do you do?

Possibly Rest

How do you relax?

What do you do to unwind?

How do you reward yourself?

Possibly Productivity

Do you do any study? Could you tell me a little about it?

Tell me about any work you do.

Can you tell me some of the ways you do things for others?

Possibly Self-maintenance

How does the housework get done?

What happens about shopping?

Community environment

What takes you out into the community?

Home environment

What sort of events happen in your home?

As the participant identifies a role or area of activity, if necessary, ask follow-up questions.

For example:

How does this connect up to other things that you do?

May help to identify whether it is seen as a isolated activity or done for a role-specific reason. May give indications about how roles inter-relate, and their relative importance.

Thus may provide role structure information about role repertoire and role mapping.

Provides information mainly about *doing* and *knowing*.

What sort of planning do you do for this?

Gives indication of how much performance organization is required. Provides information mainly about *doing* and *knowing*.

How much time do you spend doing that?

Gives indication of where participant allocates his/her time. Provides information mainly about *doing* and *knowing*.

What is involved for you in doing this?

Provides possible information about planning, barriers, strategies, time allocation, environmental interactions etc. Provides information mainly about *doing* and *knowing*.

Is that a distinct area of your life, or part of something bigger?

Provides information about the level of *doing* that is under discussion. Provides information about *doing*, *knowing* and *being*.

Informs about role mapping and role level.

What is the connection between X and Y?

Again, provides information about how things fit together.

In the course of part (4) start identifying in your own mind possible occupational performance roles. Jot them down. Try to determine which role area a role might belong to by further questioning if necessary. As the interview progresses, try to ascertain the order or level of each role, that is, whether it can be made bigger or not. For example, does the participant see the roles of father and grandfather as separate, or are they both part of the larger role of family member? Jot this down too. Try to sort out what is and what isn't seen at the role level by the participant. Sometimes you will see a role where the participant just sees a series of activities, or the participant may see these activities as part of another role.

b) Confirmation of Roles

Write the name of each role clearly on a sticker. Say something like:

While we have been talking, I have been recording information, and I have a list of possible roles. I would like to go through them with you. Could you tell me whether I have got it right or wrong, and also if we have missed anything?

Pass stickers one by one to the participant and ask him/her if role is correctly named and really is a role. Ask them to place them on the board. As roles are identified, discuss each one further if necessary. When all the roles are on the board, ask them to look them over again and confirm that they are correct.

c) Duration roles have been held

Which of these roles would you say are new for you?

Which roles have you had a long time?

d) Lost roles

Have you lost any roles recently?

Have you lost any roles in the last five to ten years?

e) Future roles

Do you expect to lose any of the roles you have now in the future?

Are there any roles that you expect to hold in the future that you don't have now

If there appear to be any difficulties about role definition, ask:

So what would you say a role is?

Could you tell me how you would describe a role?

Whilst surveying the role repertoire on the board some of the following questions could be asked:

Of all these roles, which one would you least like to lose?

*Which of these do you enjoy actually **doing** the most?*

Can you point out any roles here you would rather not have? Why not?

How well do all these roles fit together?

These questions are about the structure of doing as it relates to *being*. Because they are about structure, they are more appropriate here rather than in the next interview.

Record the roles in part 4 of the OPRA form.

Part 5: Role Sorts

If necessary, write out further clear stickers with one finally agreed role on each. Explain that you are going to ask the person to sort their roles in different ways. Note each sorting before proceeding to the next one.

a) Partner sort

Could you please sort these roles into ones that you share with your partner, and ones that you mainly do without your partner?

Can ask subsidiary questions such as:

How has that changed in the past year?

Could you tell me about anything you are not doing that you would like to do on your own?

Could you tell me about anything you are not doing that you would like to do with your partner?

b) Frequency sort

Could you please sort your roles in order in terms of the amount of time you spend each week doing each one.

Can ask subsidiary questions once the sort is complete such as.

Which of these roles are you spending more time doing than before?

Which of these roles would you rather be doing more of than you are?

Which roles would you rather be doing less of than you are?

c) Hard to do roles

Which of these roles do you find most difficult, and which is the easiest? Please sort them in order.

Possible subsidiary questions:

What is it that makes that role easy?

How hard is that for you to do?

Why is this role difficult for you?

What stops you from doing this role ?

How have you managed to keep doing this role?

Which roles do you do differently now?

What has changed about the way you do that?

d) Developmental nature of role repertoire

Could you please sort these stickers in order in relation to how long you have held each role?

Photograph each sort

Part 6: Summarising Interview

a) Role Repertoire Style

Ask the participant about *styles of doing*.

If you look overall, do you think you have any particular approach to how you do things?

What do you think your personal style of doing things is?

b) Summary Questions

If you take everything we have talked about today, what do you think is the most important thing to you about what you have told me?

Is there anything else you would like to say?

Part 7: Nomination of role partner(s) to be interviewed (for person with Parkinson's Disease only).

Discuss with the participant with Parkinson's Disease who they wish to nominate as their role partner. Explain what it entails - that we will post the information sheet to the person and then ring him or her up with an invitation to participate.

Record the nominated partner and his or her contact details on the form.

Part 8: Conclusion

Thank the participant for his or her time. Ask if he or she is prepared to continue to the second interview and confirm or arrange a time in approximately two weeks.

Part 9: Field Notes

Write field notes of the interview as soon as possible after you have completed it. Include anything that you think is of interest. You might want to say something about the other people in the house, or about the house and surroundings themselves, or about something that happened, or how you found the person you interviewed - could be anything that you think is relevant.

Disability Definitions

Level of Disability

Level one:

Participant does not report any limitations that rate as moderate or severe using the following definitions for mobility, personal care and communication.

Level two:

Participant reports limitations that are rated as mild or moderate and has no severe ratings.

Level three:

Participant reports at least one limitation that is rated as severe.

Definitions by occupational performance modality

Mobility:

Mild - generally independent in community mobility. The person is able to move about the local community without assistance. This may include walking, driving a car and/or using public transport (including taxis).

Moderate - able to move about the community with assistance. The person is able to move about the local community but requires the assistance of others. This assistance may be in the form of lifts in someone else's car, assistance in negotiating architectural barriers in the community and/or assistance in managing mobility equipment.

Severe - the person is only able to go into the community on a very limited basis. He or she requires the full assistance of others for any kind of community activity.

Communication:

Mild - generally independent in communication

Moderate - able to communicate with some difficulty e.g. tires after two minute's conversation

Severe - Finds communication very difficult and/or is hard to understand.

Personal Care:

Mild - generally independent in all aspects of showering, dressing, feeding and toileting.

Moderate - independent in showering, dressing, feeding and toileting with minimal assistance from others. This may take the form of minimal assistance with transfers, verbal prompting or preparation and/or placement of equipment.

Severe - dependent upon others for one or more activities of showering, dressing, feeding and toileting.