

**COMMUNITY OCCUPATIONAL ROLE PERFORMANCE OF PEOPLE WITH
PARKINSON'S DISEASE AND THEIR ROLE PARTNERS**

INTERVIEW PROTOCOL

Based on the occupational performance role assessment manual

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Description

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

Part 1: Explanation of Purpose of interview and obtaining of 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 the provision of an information sheet. Following this, the consent form is signed.

Part 2: Recording demographic information

The date of interview, project identification number (e.g AH3, PM1 etc), and details of participant's age, ethnicity, living status, mobility, communication and personal care are recorded.

Part 3: Gathering information about role performance

Participants are invited to identify their community occupational performance roles. 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 community role and also 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.

Part 4: Participant confirmation of roles

The interviewer seeks confirmation that occupational performance roles have been identified and recorded accurately and to the satisfaction of the participant. The

participant is then asked to sort roles in order of priority, and further probing is done to discover the meaning specific roles have for the participant.

Part 5: Sorting roles under occupational performance area and socio-cultural headings

Identified roles are sorted by the participant using a board and post-it stickers with the named roles written on them. Roles are sorted under the headings of productivity, self maintenance, leisure and socio-cultural. Sometimes a role is performed for a number of reasons and may be categorised under more than one role area heading. However, participants are asked to nominate which of these is the most important to them. If the participant is unable to categorise the role in this way it is recorded under "other".

Part 6: Participant rating of roles

The participant is asked to rate on a 5 point scale for each identified role how frequently the role is performed, how much the role is valued and how satisfied he or she is with their performance in the role.

Equipment required:

- a) Aids to identification: Name badge and business card
- b) Aids to conducting interview effectively: OPRA manual
- c) Implements for recording information: Copy of OPRA, tape recorder, 3 blank tapes, microphone, batteries for tape-recorder.
- d) Administration:
 - Part 1: Clipboard, information and consent form and pen
 - Part 4: Post-it stickers, pen, Occupational Performance Role Board (plain A4 size board covered in white contact).
 - Part 5: Role Sorting Board (white-board ruled up in Rexumns with each role area and its brief description written at the top of each Rexumn.
 - Part 6: Scales (3 separate laminated sheets with scales for frequency, value and satisfaction).

ADMINISTRATION

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.

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

It is important that the participant is able to feel relaxed and can explain things in their own terms. Introduce yourself and ensure that she or he understands the purpose of the interview. In order to involve the participant in Rexlaborative 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 personal perceptions that are required, rather than what the participant believes to be the perceptions of those around him or her. Tell the participant that the interview will probably take just over an hour and that you will be taking notes and tape recording during the interview. Inform the person that a break can be taRex at any time and the interview will stop if she or he wishes it. An example of a verbal explanation is as follows:

Interviewer:

The contents of this interview are confidential. Your name is not recorded and you will be identified by a number only. The information that you give me will be compiled along with information from the other people we are interviewing. It may be published and used for educational purposes. At any stage with the interview, if you want to stop, just say so and we will stop.

For person with Parkinson's Disease:

What I am interested in is how the diagnosis of Parkinson's Disease is affecting you in terms of your everyday life. In particular, I am interested in your community roles and whether there have been any changes in your community participation. I am interested in your own personal views about that and also in the views of the most important people with whom you interact.

For Role Partner

What I am interested in is how X's diagnosis of Parkinson's Disease is affecting you in terms of the things you do with X, and whether it has any other effect upon your daily life. In particular, I am interested in your community roles and whether there have been any changes in your community participation. I am interested in your own personal views about that and also what you think X's views are about it.

Secondly, give the Participant Information Sheet. Allow time for it to be read. Provide the opportunity for questions to be asked. If the participant appears satisfied with the explanation, the consent form is signed.

Part 2: Recording demographic information

Note the following information:

- 1) date of interview.
- 2) identifying number (allocated by the researcher).
- 3) Age.
- 4) Living situation - alone, with partner, with son or daughter or other.
- 5) Ethnicity.
- 6) Self reported status for mobility, communication and personal self-care. Record status for each as mild, moderate or severe according to the attached definitions.

Record in Part 1 of the OPRA form.

Part 3: Gathering information about role performance and role repertoire

Ask single, simple questions.

Initial question or cue for the interview:

"Could you tell me about some of your community roles?"

If the participant has some difficulty with this approach an alternative opening prompt could be:

"Tell me about your life at the moment?"

Jot down routines, tasks and sub-tasks as they are given. As the participant identifies a role or areas of activity ask follow-up questions. For example:

Would you say that it is a role for you, or just something you do?

Tell me more about how you do this role.

What is it like being a ...?

What are some of the main things you do as a ...?

How much of your time does being a ... take?

How important is being a ... to you?

How much do you want to do ...?

How does being a ... make you feel?

Does ... link up to something else you do?

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 life areas and anything that may have a community element:

How much do you see of your family?

Tell me about your friends?

How much time do you spend outside your home?

How do you get around when you go out?

What particularly interests you?

Are you studying anything at present?

What about work?

Are you a member of any clubs or other organisations?

What about the shopping?

In the course of part (3) start identifying in your own mind possible occupational performance roles if and when it occurs to you that different activities being discussed could be seen as being done for similar reasons. As possible roles are identified, jot them down and check with the participant to see whether s(he) agrees. Try to determine to which role area roles might belong to by further questioning if necessary (see attached role area definitions). 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 as both being part of the larger role of family member. Use questions at this stage that relate mainly to doing. Ask about frequency, value and satisfaction in this section. These questions help 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 he may see these activities as part of another role. Finally, ask the participant to confirm which of these roles they consider to be community roles (see attached definition).

When both you and the participant are satisfied that all the major areas of activity have been identified, bring this part of the interview to a close.

Make a list of the identified roles and place them under the role area heading you think most appropriate, given what the participant has been saying (see attached definitions of role areas).

Record this in the interviewer's table in part 3 of the OPRA form.

Part 4: Participant confirmation of roles

Discuss roles again with participant and write them on post-it stickers. put these stickers on a the role board where the participant can see them. They are not sorted at this stage.

Say something like:

While we have been talking, I have been recording information. It seems to me that I can sort the things that you do into different categories or groups. I call these occupational performance roles. I would like to go through with you what I have done. Could you tell me whether I have got it right or wrong, and also if we have missed anything?

As roles are identified, discuss each one further as necessary and possible.

Once all the roles have been confirmed, ask the participant to sort his roles in order of priority, from most important down to least important.

Record this in part 4 of the OPRA form.

Select an identified community occupational performance role and ask a range of the following questions about it. Then move on to another community role. These questions

relate to doing, knowing and being, in order to expand on information given in section (3) "Gathering information about role performance".

Some participants with Parkinson's Disease may have difficulty with the latter half of the interview because of poor endurance or because of cognitive difficulties due to depression or possible dementia. Questions need to be judicious, and it is not possible to ask all the following questions systematically about each role or role area. The purpose is more to get a flavour than to acquire detailed information across the whole role repertoire for every participant. Try and ask specific questions about the roles identified by the participant as the most important and the least important and perhaps one or two others. The following are examples of questions that you may ask at this stage:

For both types of participants

QUESTIONS THAT ARE MAINLY ABOUT DOING

How much time do you spend doing this role now?
How do you feel about what you are doing in this role?
How much of your time do you think this role takes up?
How hard is that for you to do just now?
Why do you think you have stopped doing this?
What do you do to keep going in this role?
Tell me about any changes to the way you do this role

QUESTIONS THAT ARE MAINLY ABOUT BEING

What do you think others expect of you in this role?
How important is this role to you?
How well does being a ... fit with the sort of person you are?
If you only had yourself to think about, would you give up being a ...?
How do you feel about the way you do this role?
How does being a ... make you feel?
What are some of the things you like about being a ...?
What are some of the things you don't like about being a ...?
If you could do anything you wanted, what would you do?
Does anything worry you about ...?
How much would it matter to you if you stopped being a ...?
Could you tell me about something that made you feel good in the last week or two?
So what is it like when things go wrong?
Could you describe something that makes you glad you have this role?

QUESTIONS THAT ARE MAINLY ABOUT KNOWING

How do you know when things are going right with ...?
What would you say is your main aim in this role at the present time?

*Is there anything you would like to change about the way you do ...?
What would be your main worries about this role at the present time?*

How have you changed the way you do ...?

What do you think helps you to do ...?

What do you think is stopping you from doing ...?

What would you say was your main aim in life just now?

If you have a problem, or something you want to change in your life, how do you usually go about it?

What do you think makes a good ...?

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

Could you tell me how you would describe a role?

About the community role repertoire as a whole:

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

Are there any roles you would rather not have?

Does this role fit in well with your other roles?

Which is the role that is most important to you?

THE PERCEIVED EXPECTATIONS OF ROLE PARTNERS

If information about what they believe are the expectations of their role partners has not already been forthcoming, then you can ask such things as:

Is there one particular person you do this with?

Who would you say was your main role partner for this?

And what does X think about that?

Why do you do it that way?

What does X want you to do?

Do you think X is happy about that?

Is that what you want?

THE PERCEIVED CONTRIBUTION OF ROLE PARTNERS

Does X let you ...?

Could you do that without X?

How much does X help you?

What sort of contribution do you each make to ...?

What sort of team do you think you make?

GENERAL SATISFACTION WITH LIFE

- If you had more hours in the day what would you do with them?*
- Is there anything in life you would like to do just now, just for yourself?*
- What would you say is your main aim in life at the present time?*
- What would be your main worries at the present time?*
- What would you like to change about your present situation?*
- What kinds of things make you feel really happy?*
- When you feel really down or depressed what makes you feel like that?*
- What do you do when you feel depressed?*
- How would you describe your satisfaction with your life?*
- Is there anything else you would like to tell me?*

(Some of these questions used with the kind permission of Professor B. Wearing, Social Work Department, University of NSW)

Part 5: Sorting roles under occupational performance and socio-cultural meta-role headings.

Ask the participant to take each role sticker in turn from the interviewer and place it under the appropriate heading on the role sorting board. Try and get confirmation of the reason for the position chosen as necessary. If the participant is unable to decide which role area the role is part of it may be sorted under "other". Try to obtain information about why it was difficult to place under one of the other headings.

Record each role under the appropriate role area in part 5 of the recording form.

Part 6: Participant rating of roles

Taking each role area in turn, ask the participant to report on the frequency of role area performance, how much he values the role area and how satisfied he is with his performance in this role, using the three five point scales included in this package.

For each role area, show the participant the three scales in turn, and ask him to indicate by pointing where his answer falls. If the participant is unable to read the scale, read it out and ask the participant to respond verbally.

Scales:

I do things in this role:

1	2	3	4	5
Almost Never				All the Time

I consider this role:

1	2	3	4	5
Not at all Valuable				Highly Valuable

I feel satisfied with my own performance of this role:

1	2	3	4	5
Almost Never				All the Time

based on Salamon & Conte (1984)

<p>Record the participant's responses for each role area in part 6 of the form.</p>
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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 community role partners who we could invite to participate. Explain what it entails - that we will ring the person up and invite them to participate. If your participant prefers, they

can ask them themselves and contact us. However, make sure that you make firm arrangements so that we can legitimately follow up, such as we will ring you in a week's time etc.

Record the nominated partners and their contact details in part 7 of the form.

Finally

Please ensure that you 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.

LIST OF DEFINITIONS FOR THE OPRA

Level of Disability

The Symptoms of Parkinson's Disease

Parkinsonian symptoms are more obvious. These are as follows: the person may experience akinesia or bradykinesia, rigidity, tremor and impairment of the postural mechanism. They may have stooped posture and slow shortened steps. They may have difficulty starting, changing direction, turning and stopping. Falls are common (Hooks, 1996). The person may also experience the side effects of medication such as sustained muscle contraction, twisting or repetitive movements, or abnormal postures and sudden non-purposeful movements.

Mild: May be newly diagnosed or up to approximately 8 years following diagnosis. Person is medically well managed and symptoms may not be readily apparent, or they may be in the mild range for at least two of the following definitions for mobility, personal care and communication and moderate for the other one.

Moderate: The person may be in the moderate range for at least two of the following definitions for mobility, personal care and communication and either mild or severe for the other one. Symptoms are present and more pronounced than in the mild stage.

Severe: The person is in the severe range for at least two of the following definitions for mobility, personal care and communication, and moderate for the other one. Symptoms are strongly pronounced.

Definitions for Part 2

Mobility:

Mild - generally independent in community mobility. The person is able to move about her or his 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 their 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 housebound. They are unable to move about their local community without the full assistance of others.

Communication:

Mild - generally independent in communication

Moderate - able to communicate with some difficulty e.g tires after 20 minute conversation

Severe - Finds communication very difficult and 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 all activities of showering, dressing, feeding and toileting.

Definition of Terms for Part 6

Scale A - Frequency

1 ("almost never"):	has not done it in the past 12 months
2:	at least once or twice a year
3:	at least once a month
4:	at least once a week
5 ("very often"):	at least every two or three days

Scale B - Value

1 ("not at all valuable")	This has no worth for me.
2:	If I had to lose a role, this is one that could go.
3:	This is something I would rather not lose.
4:	This is something I need to do or I want to do.

5 ("highly valuable"): I would not give this up. It is something I really need or want to do.

Scale C - Satisfaction

1 "almost never": I am always unsatisfied with my performance.
2: I am not pleased with my performance.
3: I would prefer to do this better.
4: I feel comfortable with my performance.
5 ("all the time"): I am always satisfied with my performance

The interviewer takes the participant's own interpretation of meaning. These definitions are intended as a guide only.

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THE OCCUPATIONAL ROLE ASSESSMENT

Devised by Anne Hillman

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RECORDING SHEET

Date of Interview:

Name of Interviewer:

Part 1

Project ID No:

Age:

Living Situation:

Ethnicity:

Self reported status:

Mobility:

Communication:

Personal self-care:

Comments about the interview as a whole:

Part 2

Notes:

Part 3: Interviewer's naming and sorting of participant's roles

Productivity	Self Maintenance	Leisure	Socio-Cultural	Other

Part 4: Roles sorted in order of priority by the participant

Part 5

Participant's identification and sorting of roles:

Productivity	Self-maintenance	Leisure	Socio-cultural	Other

PART 6 - ROLE RATING

Role Area	Frequency of performance	Value of role	Satisfaction with role
Productivity			
Self maintenance			
Leisure			
Socio-cultural			

SCORING

Scores are recorded on this summary sheet. Points are allocated according to the position on the scale indicated by the respondent.

PART 7 - ROLE PARTNER(S)