APPENDIX 5.15

EXAMPLE OF ANALYSIS

DOCUMENT AS A WORK IN PROGRESS
COMMUNITY OCCUPATIONAL ROLE PERFORMANCE OF PEOPLE WITH PARKINSON'S DISEASE AND THEIR ROLE PARTNERS

INTERVIEW PROTOCOL

Description ........................................................................................................................................... 341
Equipment required ............................................................................................................................... 342
ADMINISTRATION ................................................................................................................................. 342
Part 1: Explanation of purpose of interview and obtaining of consent .............................................. 343
Part 2: Recording demographic information ....................................................................................... 344
Part 3: Gathering information about role performance and role repertoire .................................... 344
   For both types of participants ............................................................................................................. 347
Part 5: Sorting roles under occupational performance and socio-cultural meta-role headings ........... 349
Part 6: Participant rating of roles ....................................................................................................... 349
Part 7: Nomination of role partner(s) to be interviewed (for person with Parkinson's Disease only) ............................................................................................................. 350

APPENDIX 5.2 .................................................................................................................................... 358
STAGE TWO ........................................................................................................................................ 358
INTERVIEW ONE – DOING .................................................................................................................. 358
Occupational Performance Role Assessment (OPRA) ........................................................................ 359

People with Parkinson's Disease and their Role Partners ............................................................... 359
Interview 1 - Doing ............................................................................................................................... 359
   Goals of interview ............................................................................................................................. 359
   Description ........................................................................................................................................ 359
   Part 1: Explanation of purpose of interview and obtaining of consent .............................................. 364
   Part 2: Recording demographic information ....................................................................................... 366
   Part 3: Participant’s perceptions of basic occupational performance ............................................... 366
   Part 4: Gathering information about role performance and role repertoire .................................... 367
   Part 5: Role Sorts ............................................................................................................................... 370
      a) Partner sort ................................................................................................................................. 370
      b) Frequency sort ........................................................................................................................... 370
      c) Hard to do roles .......................................................................................................................... 371
      d) Developmental nature of role repertoire ..................................................................................... 371
   Part 6: Summarising Interview ......................................................................................................... 371
      a) Role Repertoire Style .................................................................................................................. 371
      b) Summary Questions .................................................................................................................... 371
   Part 7: Nomination of role partner(s) to be interviewed (for person with Parkinson's Disease only) ............................................................................................................. 372
   Part 8: Conclusion ............................................................................................................................. 372
   Part 9: Field Notes ............................................................................................................................ 372
Disability Definitions .......................................................................................................................... 373
Level of Disability ............................................................................................................................... 373
   Level one: ....................................................................................................................................... 373
   Level two: ....................................................................................................................................... 373
   Level three: ..................................................................................................................................... 373
Definitions by occupational performance modality ............................................................................ 373
Mobility: ............................................................................................................................................... 373
Communication: ................................................................. 373
Personal Care: ................................................................. 374
APPENDIX 5.3 .................................................................. 375
Occupational Performance Role Assessment (OPRA) ..................... 376
People with Parkinson's Disease and their Role Partners ............... 376
Interview 2 - Being ............................................................ 376
  Goals of interview ........................................................... 376
  Description .................................................................. 376
  Equipment required ....................................................... 378
ADMINISTRATION ............................................................... 379
Part 1: Explanation of purpose of interview .................................. 380
Part 2: Confirmation and clarification of information from last interview... 380
Part 3: Priority sorting ......................................................... 381
Part 4: Gathering information about role meaning .......................... 381
Experience questions ................................................................ 381
Motivation/meaning questions .................................................. 382
Value questions .................................................................. 382
Sense of choice questions ....................................................... 382
Expectation of self questions .................................................. 382
Self identity and self-expression questions .................................. 382
Perceived expectation of others questions ................................... 382
Social fit questions ................................................................ 383
Ideal role performance questions ............................................. 383
Role continuity and role transition questions ............................... 383
Satisfaction questions .......................................................... 383
Sense of loss questions .......................................................... 383
Role Repertoire Questions ...................................................... 383
Part 5: Sorting roles under occupational performance and socio-cultural meta-role headings ............................................. 384
Part 6: Satisfaction with role performance .................................... 385
Part 7: Summarising Interview .................................................. 385
  Summary Questions .......................................................... 385
Part 8: Conclusion ................................................................ 385
Part 9: Field notes ................................................................ 385
APPENDIX 5.4 .................................................................. 386
Occupational Performance Role Assessment (OPRA) ..................... 387
People with Parkinson's Disease and their Role Partners ............... 387
Interview 3 - Knowing ........................................................... 387
  Goals of interview ........................................................... 387
  Description .................................................................. 387
  Equipment required ....................................................... 389
Part 2: Clarification of information from last interview .................... 390
Part 3: Gathering information about role knowing ......................... 391
  a) The impact of disability upon role performance ................... 391
  b) The impact of the environment upon role performance ........... 391
  c) Personal strengths and abilities that help participant to achieve ...... 391
  d) Problem solving tactics ............................................... 391
  e) Evaluation of outcomes ................................................. 392
  f) Controlling the future ................................................... 392
Definitions used to Determine Phase of Pd Parkinson’s Disease and their Role Partners

Part 4:
  Interview summary ................................................................. 393
Part 5:
  Conclusion ............................................................................... 393
Part 6:
  Field work notes ...................................................................... 394

THE OCCUPATIONAL ROLE PERFORMANCE OF PEOPLE WITH PARKINSON’S DISEASE AND THEIR ROLE PARTNERS ........................................... 396

Definitions used to Determine Phase of Pd ........................................... 398

Functional Performance .................................................................... 398

Early phase: .................................................................................... 398
Middle Phase: ................................................................................. 398
Late phase: ...................................................................................... 398

Definitions by occupational performance modality ............................. 398

Mobility: ......................................................................................... 398
Communication: .............................................................................. 398

Personal Care: ................................................................................. 399

APPENDIX 5.9 ................................................................................. 400

INFORMATION HANDOUT GIVEN TO ............................................. 400

PARKINSON’S SUPPORT GROUPS AS ............................................. 400

PART OF TALK ................................................................................. 400

The Community Role Performance of Women with Parkinson’s Disease and their Partners ................................................................. 401

Study Aim ......................................................................................... 401

Background ...................................................................................... 401

Method .......................................................................................... 401

Findings for Women with Parkinson’s Disease .................................... 401

Stage of Disease ............................................................................... 401

Primary Disease Process ................................................................... 402

  a) Impact of primary disease process on doing .............................. 402
  b) Factors that minimise the impact of the primary disease process upon the person's ability to physically do ........................................... 402
  c) Partner’s response to these issues .............................................. 402

Secondary Personal Limitations .......................................................... 403

  a) Personal limitations ................................................................... 403
  b) Factors that minimise secondary personal limitations ............... 403
  c) Partner’s Response ..................................................................... 403

Secondary social limitations .................................................................. 403

  a) Social limitations ...................................................................... 403
  b) Factors that minimise secondary social limitations .................. 404
  a) Partner's response ..................................................................... 404

Consequential barriers or losses in relation to community role performance .......................................................... 404

  a) Barriers and losses to community role performance .................... 404
  b) Factors that minimise the barriers to community participation .... 405
  c) Partner’s response ..................................................................... 405

Impact of Parkinson's Disease on Partner's Community Role Performance ............................................................................................................. 405

Frank Lewis - Summary of Doing .......................................................... 408
Doing - Primary Analysis - PD2

**Date of Interview:** 30/01/03
**Date of Birth:** 09/02/24
**Year of diagnosis with Parkinson's disease:** 1998
**Living Situation:** Lives with wife at home
**Ethnicity/length of time in Australia:** Australian (always lived here)

**Mobility:** 1

> Oh [pause] I suppose there are limits. As you know, we’re all getting older and when you get to 80 you’ve got to have a, a test every now and again and at 85 you’ve got to get a test every year. But I’m still able to drive alright. But as far as seeing goes, well I can see and read alright with glasses, but I find darkness or night time it’s harder to see things. I prefer not to drive at night.

> Oh well I walk down the street to the shops and back several times a day just to get my exercise.

> Well I don’t walk as briskly as I used to walk but I’m still walking alright.

> How’s your balance?

> Oh I’m usually quite steady. But not as steady as I was years ago. It’s all deteriorating with age.

**Communication:** 1 (2)

I had no problem talking to him on the phone. He said he did not find the telephone difficult. No problem hearing or understanding him in the interview.

> Writing – yes my writing’s a bit shocking. I need to print things rather than just scroll them.

> So it’s getting small and difficult?

> Well more shaky. My hand shakes with the Parkinson’s.

**Personal self-care:** 1 (2)

> Well I find my fingers aren’t as nimble as they used to be. Doing up buttons or shoelaces can be a bit of a problem.
Oh well I used to be able to touch my toes, bending down without bending my knees, but I can’t do that now. But anyway as far as doing things, doing up laces, well I prefer to have shoes with a strap on them so they’re easier to do up. (he pointed to velcro fasteners on his shoes)

Any problems cutting up food?
No, the only trouble I have is if I eat too big a lump of anything it’s likely to choke in my throat. I have to cut everything up small.

General health
(from Being interview)

Yeah. So you just gradually cut back as Parkinson’s made things more difficult, is that what you’re saying?

Well eventually it did, yes. But as you get older you slow down in every way. I do. I’m just talking you in general.

Yeah. So it’s not just the Parkinson’s that’s meant that you’ve slowed down?

Well you can have 2 or 3 complaints at once can’t you? No trouble having a sore toe and heart trouble at the same time. You can have various things wrong – in fact you do – I do, everybody does.

Response to role question:

So, could you tell me a bit about the roles that you have now?
Well, you mean what do I do to fill in my life?
Well uh, it’s hard to say outside of reading, listening to television, radio, um walking round shops, cause [theatre] [check tape] prices are going up. And I play bowls usually one day a week, outdoor bowls. Occasionally I play indoor bowls. My wife plays indoor bowls.

Roles

Husband

So first of all husband.
Well that’s a role yeah.
So ... could you sort out the roles that you do with your wife and the ones that you do on your own? Are there any that you do on your own?
Oh well I, for instance I play outdoor bowls on my own.
Sometimes with my wife I play with other people.
And shopping. Or alternately, J goes to get her hair done, she goes shopping after that and buys things or I just keep filling in time to exercise, go down the supermarket and wander round the shelves and see what I think we need, bread or jam or whatever and do it.
She does some of those things and I do some of those things.
Independently of each other.

Family member

Oh yes, we’ve got uh a daughter, 2 children – well they’re not children cause they 30 years of age now, grandchildren.
... one daughter and 2 grandchildren.
Do you see them very much?
Oh it depends on what’s on, time of the year and various other things. No they, they live over the north side or in the City.
Oh yeah, it depends on what’s on. Any special reason, any show on or the Club or something, they’ll come over.
So you’d see them sort of on a monthly basis - or every few months or ...?
Oh, probably every couple of weeks. And then the phone rings more often than that. Communicate by telephone.

When confirming roles:
Father?
Yeah that’s a role.
And grandfather – would that be separate or is that part of being a father?
Oh the same, part of being a father.
So what would you like to call that? Um father and grandfather or family member or?
Oh family member, yeah.
Patriarch? [Laughs]
No, nothing like that.
Do you have any brothers and sisters? I didn’t ask you that.
Yes, 2 brothers and one sister.
Right. And do you see them very much?
No, not very much. A couple of times a year is about all.

Friend

Well basically the only friends I have now are the ones at the RSL I suppose.
People we meet at the RSL and go to functions with.
The people I used to work with, well I’ve been retired 15 years or more. I
don’t see them any more.
Right. So you’ve kept up with the ones that you still see regularly?
Yes.
When confirming roles:
Friend?
Is that one or not?
I don’t know if you’d call that a role. What else could we call it? Cause
friends are important people but you don’t see them unless you arrange to go
out with them. You don’t see them that often. Like if you play bowls every
week, you see the same people every day, every week and you become friends
with them. Other people you’ve known for years, you go out for a meal with
them or to a show, the club or something. But they’re all part of the same
group I would think. Okay, what’s next?
When asked to sort in order of how long he had had a role he said:
I’ve always had friends but a lot of them have died along the way.
So, ones I used to go out with when I was single for instance, have all gone
and married off with their family, moved away to the country, whatever.
So you’ve lost quite a few friends?
Oh yeah, over the years.
Activities

Shopper

And shopping. Or alternately, J goes to get her hair done, she goes shopping after that and buys things or I just keep filling in time to exercise, go down the supermarket and wander round the shelves and see what I think we need, bread or jam or whatever and do it.

When asked to sort in terms of longest held he said:
As far as shopping, well I’ve always been a shopper, for some reason or other. Just for clothing or shoes or food or anything. Cause we all shop. So why do you do these things? (asked about role repertoire as a whole)
Shopping – curiosity in lots of cases, what the prices are doing, what type of goods they’ve got on the market these days. For instance when we were young we didn’t have televisions or mobile telephones or anything. Now we’ve got all those things. As a shopper you like to know what’s going on. There’s always new inventions and then you see the ads over television where they try to sell you anything. They tell lies basically, or don’t tell the truth, to try and sell you something.
But um as far as their importance go, well they’re all necessary but not necessarily important.

Club member

Oh I belong to a couple of RSL Clubs, yeah. Air Force Association. Go to meetings and various other things at the club – activities.
Well monthly, my club branch meeting I go to every month, at two clubs.
So that’s two meetings a month for the clubs?
Yeah, usually. And then the Air Force Clubs only a few meetings a year.
... //Okay, what’s next?
Well I had club member. So maybe would that be better than friend?
Oh
Or are they separate?
Well they’re separate things.
Separate things, okay. And then I had bowler.

Yeah, well that’s more like club member, bowling club member.

Okay. So that, if I put, take that one off and just, and put club member that would cover bowler?

Yeah I would think so.

Relaxation

Right, okay. The other area which I had was something, you were talking about reading, watching TV and watching the radio, and that you did that to rest or relax.

Yes.

Um, could I put that all under the heading of relaxation or?

I think so

Would you say that was part of this group? The relaxation? Which, where would that fit?

Oh I think it would be more on those.

Yeah, so on the doing side?

Yes.

Okay.

Even though it’s undoing, it’s really part of the relaxing or doing something.

They’re both related.

Yes. Undoing the doing, I like that. Yes.

Well you do something and then you stop doing something and they’re related.

Other

General level of activity (volunteered):

Um [pause] I’m not as active as I used to be and I don’t like going out that many nights and I like to get to bed by 11 o’clock if I can. But that’s not unusual for anybody my age.

(From Being interview)
Sounds like you have something on more days than not, would that be right? How many days would you have an engagement of some kind, something that you have to do or you want to do?

Oh we could say 3 days a week.

Three days a week. Ah ha. Does it feel busy to you?

Oh no. It’s not busy. It just keeps us going.

Parkinson's support group (specifically asked about):

Oh yes, I go to some Parkinson’s meetings. The Campsie one as you saw me. I sometimes go to the Burwood one. I go sometimes on the Monday to exercise classes at Concord Hospital.

With the Parkinson’s Group. And there’s another Parkinson’s Group, St George group, um the Bowling Club over – what’s the name of the suburb – anyway St George Group Parkinson’s.

That’s a huge group isn’t it?

Well that’s right. There’s about 50 people go there.

Going to the support groups, how many a month would you?

Oh well I’d say 2 a month generally.

Exercise group

The idea is to get you moving and practice it so you can do it at home I think. If you do it every day you become relaxed.

Leisure (specifically asked about)

Well um I used to enjoy mowing the lawns and things like that but it’s become too hard for me now. We pay a man to do the lawns. Or painting, well if we want any painting done we get a man to do it rather than do it myself.

Rest (specifically asked about)

All I can think of is just resting, is all we do to unwind or relax.

So what does resting look like? What do you do when you’re resting?

Sit down and watch the television or listen to the radio.

Work (specifically asked about)
Is there anything that you do that uh is like work – any voluntary work or anything that you do for other people?

No I don’t, I don’t feel inclined to do that.

Time

How, would you spend the majority ... of your time - at home or outside?

Oh the majority of time at home I would say.

Home maintenance

Cleaning:

Oh we have a lady comes in once a fortnight to do the cleaning the carpets and the upstairs/downstairs.

Washing-up:

Well we have got a dishwashing machine but usually we wash up. I usually do it or even J might say she usually does it, but I do it sometimes then.

Cooking:

Well most of the cooking’s done by J. She cuts the meat up and does whatever’s got to be done – casserole or browned up meat or whatever, or steak just fried or grilled, with vegetables. Notice the price of vegetables has gone up 50% in the last month, since Christmas.

Yeah. We can expect them to go up.

So do you do the shopping?

Yeah, most of the time, although J does shopping when she’s out there.

So you might, you might go by yourself or you might go together?

Yes.

Laundry

Oh we’ve got a washing machine. Joyce does most of the laundry.

Sort 1 - Spontaneous sort

He spontaneously sorted the stickers as follows:

Husband, Family member, Friend. He said these were his roles.

Then there was Shopper, Club member and relaxation. He said these were not roles they were things that he did.
Sort 2 - Frequency sort

See Sort 1. He was asked to sort in order of the frequency with which he did them - most often at top to least often at bottom.

*Oh they’re about the right order as it is.*

Sort 3

I asked him which were the most important roles to him.

Roles: Husband, Family member, Friend. Activities: Relaxation, Shopper, Club member

What do you think is the most important thing to you at the moment?

*Well I don’t know. What have we got to compare with?*

Well okay, which of these is the most important to you?

*Well being a husband is the most important. ... Then I suppose friends are next and family members are mixed with friends. ... Oh well put them in that.*

Okay. Any difference these?

*These are different, these are a different category really from those. As importance.*

Are they important to you though?

*Well don’t seem to have any significant importance. They’re all necessary but not important."

I then asked:

So why do you do these things


Relax because I feel like relaxing. If I feel tired, whatever the occasion may be. Shopping – curiosity in lots of cases, what the prices are doing, what type of goods they’ve got on the market these days. For instance when we were young we didn’t have televisions or mobile telephones or anything. Now we’ve got all those things. As a shopper you like to know what’s going on. There’s always new inventions and then you see the ads over television where they try to sell you anything. They tell lies basically, or don’t tell the truth, to try and sell you something. ... But um as far as their importance go, well they’re all necessary but not necessarily important.
Parkinson's disease

Would you say that you were someone um who had to take into the fact they’ve got Parkinson’s Disease in what they do? Or does it not interfere?
No, it doesn’t. ... (see being notes for more here)
Mm. But in terms of your daily life and what you do um do you, is it a factor that you have to?
Oh only to a certain extent when I get the shakes.
Cause I, usually in daily life I take the pills to cover the Parkinson’s then I forget all about it.
So there’s lots of other sicknesses of, my wife’s got bone, you know, osteoporosis and all those sort of things, things that you’ve got to take medicine for and worry about. But you do all your pill taking in the morning in most cases and then forget about it through the day.
while I was preparing to take a photo he said.
My mouth gets very dry.
He got himself a drink while I photographed the sort.

Doing Style

Do you think you have any particular way or style, particular way of approaching life?
I don’t think so. I don’t know. All you can say is that I just let it be. Find out what happens and just put up with it.
Yeah. So a fairly stoic sort of approach would you say?
It could be. I don’t intend it to be, but no use doing anything that’s unnecessary.

Potential Themes of Being

He has an interest in price watching
He mentioned price rises as part of his response to role question.
In relation to cooking he said:
Notice the price of vegetables has gone up 50% in the last month, since Christmas.
Past Doing

He has been retired 15 years.

So is there anything else you do for um fun or enjoyment reasons – leisure sort of things?

Well um I used to enjoy mowing the lawns and things like that but it’s become too hard for me now. We pay a man to do the lawns. Or painting, well if we want any painting done we get a man to do it rather than do it myself. Things we did when we were young don’t feel like doing them any more. Too tiring or too dangerous – whatever the case may be.

At the end of part 4 (role/doing discussion) I asked

Is there anything else that you can think of that you do?

He responded with great feeling.

No. Well I can think of things I don’t do. Like I don’t swim any more, very seldom, well I don’t even get to go sunbaking. It’s more on what I used to do and what I don’t do now.

Oh well I suppose when we were young we went out dancing. We don’t go out dancing now. Well of course the type of dancing is different to what we did anyway.

Yeah. Still there are still places where you can go.

Oh there are. There are clubs and that that are old time dancers and so on but no, we don’t do that. I’d just say things we used to do we don’t do any more. Used to do a lot of travelling. Don’t do a lot of travelling any more.

No. Well of course we used to play tennis when we were young and when I was younger than that I used to play football and so on. But, and swimming as I mentioned. But I tend to cut these things out just for the fact they make you tired if you do them.

Yeah. So you used to be very interested in sport and pretty active?

Oh yes.

Regular activities

Going for a walk (daily)

Plays outdoor bowls (one day per week)
Plays indoor bowls (occasionally)
RSL club meetings (2 per month)
Parkinson's support groups (2 per month)
See the family (twice per month - roughly)

Things done alone

Outdoor bowls:
Oh well I, for instance I play outdoor bowls on my own.

Shopping:
She does some of those things and I do some of those things.
Independently of each other.

Hard to do

Nothing