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**Well-being in dementia:
case study examination of the importance of interactions with the carer**

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Volume two

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Appendix one

Dementia Care Mapping

Behaviour category codes

| Code | General description of category |
|------|--|
| A | interacting verbally or otherwise (with no other obvious activity) |
| B | being socially involved, but passively |
| C | being socially uninvolved, withdrawn |
| D | unattended distress |
| E | engaging in an expressive or creative activity |
| F | eating, drinking |
| G | participating in a game |
| H | participating in a craft activity |
| I | activity prioritising the use of intellectual abilities |
| J | participating in exercise or physical sports |
| K | independent walking, standing or wheelchair-moving |
| L | performing work or work-like activity |
| M | engaging with media |
| N | sleeping, dozing |
| O | independently engaging in self-care |
| P | receiving practical, physical or personal care |
| R | participating in a religious activity |
| S | activity related to explicit sexual expression |
| T | direct engagement of the senses |
| U | communicating without receiving a response |
| W | repetitive self-stimulation |
| X | episodes related to excretion |
| Y | talking to oneself, or an imagined person; hallucination |
| Z | behaviours that fit no existing category |

The scale of well-being and ill-being (WIB)

Well-being and ill-being is considered as covering a range which is divided into six broad bands as shown below:

- +5 exceptional well-being – it is hard to envisage anything better; very high levels of engagement, self-expression, social interaction
- +3 considerable signs of well-being; for example in engagement, interaction or initiation of social contact
- +1 coping adequately with present situation; some contact with others; no signs of ill-being observable
- 1 slight ill-being visible; for example boredom, restlessness or frustration
- 3 considerable ill-being; for example sadness, fear or sustained anger; moving deeper into apathy and withdrawal; continued neglect for over half an hour
- 5 extremes of apathy, withdrawal, rage, grief or despair; continued neglect for over one hour

Appendix two

The Behaviour Rating Scale for Psychological and Social Problems (BPS)

Frequency

| | |
|------------|--|
| NEVER | the behaviour in question does not occur in a three week period |
| SELDOM | the behaviour in question occurs only once or twice in a three week period |
| SOMETIMES | the behaviour in question occurs more than twice a week |
| OFTEN | the behaviour in question occurs almost daily |
| VERY OFTEN | the behaviour in question occurs more than once a day |

The Behaviour Rating Scale for Psychological and Social Problems (BPS)

Name:

Age:

Date:

| | never | seldom | sometimes | often | very often |
|--|-------|--------|-----------|-------|------------|
| 1 Is irritated and grumpy <i>Quickly irritated, moody, abrupt, grumpy. Personal irritation is evident</i> | [] | [] | [] | [] | [] |
| 2 Is preoccupied with him/herself <i>Is preoccupied with him/herself, is not open to others. (Has little or nothing to say about him/herself).</i> | [] | [] | [] | [] | [] |
| 3 Is dissatisfied about the care <i>Makes negative comments about the care.</i> | [] | [] | [] | [] | [] |
| 4 Resists when he/she is told to do something <i>A downright resistance with words or physical opposition. Refuses and will not change his/her mind. Raises objections. <u>Active</u> resistance is evident.</i> | [] | [] | [] | [] | [] |
| 5 Talks incoherently <i>Changes subject rapidly. No line in story.</i> | [] | [] | [] | [] | [] |
| 6 Does not like to co-operate <i>Is unwilling, apathetic, not motivated. <u>Passive</u> resistance is evident.</i> | [] | [] | [] | [] | [] |
| 7 Ignores what is happening around him/her <i>Does not bother to take an interest in what is happening in and outside the home.</i> | [] | [] | [] | [] | [] |
| 8 Cannot find his/her way in the home <i>Does not know where he/she is at a certain moment. Cannot point out the way to a certain place. Note: If he/she is constantly accompanied due to physical difficulties with walking, does he/she know where he/she is going?</i> | [] | [] | [] | [] | [] |

never seldom sometimes often very often

| | | | | | |
|--|-----|-----|-----|-----|-----|
| 9 Blames others for his/her difficulties <i>Attributes the cause of his/her problems to others (e.g. children, family, doctor).</i> | [] | [] | [] | [] | [] |
| 10 Moans and complains <i>Complains without cause.</i> | [] | [] | [] | [] | [] |
| 11 Is dejected or depressed <i>Feels down, blue.</i> | [] | [] | [] | [] | [] |
| 12 Is not interested in anything <i>Does not show interest in participating in activities in the home.</i> | [] | [] | [] | [] | [] |
| 13 Is suspicious and distrustful <i>Always looks for ulterior motives. Attributes bad intention to others (e.g. family, doctor).</i> | [] | [] | [] | [] | [] |
| 14 Needs to have an eye kept on him/her <i>Is not aware of how things are. Needs guidance for his/her own safety and health.</i> | [] | [] | [] | [] | [] |
| 15 Looks sloppy <i>Not well groomed, slovenly (physical appearance). E.g. clothing is sloppy in spite of help from the carer.</i> | [] | [] | [] | [] | [] |
| 16 Strays from the subject when you are in conversation with him/her <i>Cannot remain on one subject, goes from one subject to another, loses the thread of the story.</i> | [] | [] | [] | [] | [] |
| 17 Has memory difficulties <i>Is forgetful - makes appointments but forgets them again. Note: If he/she writes a note so as not to forget an appointment and as a result does not forget it, then he/she does not have difficulties remembering appointments.</i> | [] | [] | [] | [] | [] |
| 18 Is upset when little things go wrong <i>Looses his/her stride. Reacts in panic when everyday things go wrong.</i> | [] | [] | [] | [] | [] |

never seldom sometimes often very often

| | | | | | |
|--|-----|-----|-----|-----|-----|
| 19 Does not understand when you explain something <i>Cannot understand your meaning. Cannot follow what you are saying.</i> | [] | [] | [] | [] | [] |
| 20 Is demanding <i>Takes total control of people, will not let them give attention to others. Makes unreasonable demands. Is not open to reason. Will not let anything go.</i> | [] | [] | [] | [] | [] |
| 21 Is confused <i>Has lost touch with reality. Says or does things which do not altogether make sense.</i> | [] | [] | [] | [] | [] |
| 22 Has difficulties with making decisions (even with small things) <i>Is irresolute, indecisive, uncertain when making choices. Is slow in making choices. Lets others decide.</i> | [] | [] | [] | [] | [] |
| 23 Is drowsy during daytime <i>Is as though lost in a dream world. Is sleepy, is not awake and alert, nods off, is dreamy. (Taking a nap in the afternoon is not included).</i> | [] | [] | [] | [] | [] |
| 24 Is restless during the night <i>Wanders at night. Shuffles around his/her room. Calls often for assistance (correct calls for assistance, e.g. in case of illness etc are not included).</i> | [] | [] | [] | [] | [] |
| 25 Loses things <i>Cannot remember where he/she left things.</i> | [] | [] | [] | [] | [] |
| 26 Has to be encouraged to participate in activities <i>Does not take any initiative to take part in things. Has to be motivated to join in. (Has almost to be forced to take part).</i> <i>Note: This does not concern memory problems, so do not count memory problems which cause people to forget to take part in things.</i> | [] | [] | [] | [] | [] |

| | never | seldom | sometimes | often | very often |
|---|-------|--------|-----------|-------|------------|
| 27 Withdraws to his/her room <i>Deliberately withdraws from social activities.</i> | [] | [] | [] | [] | [] |
| 28 Is lonely <i>Feels alone and finds this very unpleasant.</i> | [] | [] | [] | [] | [] |
| 29 Has little interest in the surroundings <i>Shows little or no interest in what is happening around him/her (e.g. weather, season, world events). Note: Here the emphasis is on what is happening outside the home.</i> | [] | [] | [] | [] | [] |
| 30 Wanders (aimlessly) through the home or outside <i>Just walks to and fro. Is not going anywhere special, e.g. to visit someone.</i> | [] | [] | [] | [] | [] |
| 31 Makes remarks or gestures with sexual connotations <i>Makes intimate remarks to others. Demands undesired intimacy. This is experienced as undesired.</i> | [] | [] | [] | [] | [] |
| 32 Lets people know that he/she wants to end his/her life <i>Lets people know that he/she wants to kill him/herself by words or behaviour, for example, by storing sleeping tablets, refusing vital medicine or refusing to eat.</i> | [] | [] | [] | [] | [] |
| 33 Is physically aggressive to others <i>Hits, kicks, pinches others, i.e. concerns physical violence.</i> | [] | [] | [] | [] | [] |
| 34 Expresses him/herself by calling names, shouting or swearing <i>Tries verbally to hurt someone's feelings. Must be noticeable in words or other use of voice.</i> | [] | [] | [] | [] | [] |
| 35 Shows signs of over-indulgence in medicine or alcohol <i>He/she is stupefied through an excess of tranquillising medicine or alcohol. Must be noticeable in behaviour.</i> | [] | [] | [] | [] | [] |

The Behaviour Rating Scale for Psychological and Social Problems (BPS)

Cut off scores (Bronts 1993):

| Degree of impairment | cognition scale | mood scale | social contact scale |
|----------------------|-----------------|------------|----------------------|
| none | 0 | 0 | 0 |
| light | 1-10 | 1-4 | 1-4 |
| moderate | 11-20 | 5-12 | 5-9 |
| severe | 21-35 | 13-20 | 10-14 |
| very severe | 36-44 | 21-28 | 15-20 |

Cognition:

5, 7, 8, 14, 16, 17, 19, 21, 22, 25, 30

Mood

1, 3, 9, 10, 13, 18, 20

Social Contact

12, 26, 27, 28, 29

Appendix three

The Bristol Activities of Daily Living Scale (BADLS)

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another.

For each activity (Nos. 1-20), statements a – e refer to a different level of ability. Thinking of the last 2 weeks, tick the box that represents your relative's / friend's ability. Only 1 box should be ticked for each activity (if in doubt about which box to tick, chose the level of ability which represents their *average* performance over the last 2 weeks).

1. FOOD

Scoring

- | | | | |
|---|--|-----|---|
| a | Selects and prepares food as required | [] | 0 |
| b | Able to prepare food if ingredients set out | [] | 1 |
| c | Can prepare food if prompted step by step | [] | 2 |
| d | Unable to prepare food even with prompting and supervision | [] | 3 |
| e | Not applicable | [] | 0 |

2. EATING

- | | | |
|---|--|-----|
| a | Eats appropriately using correct cutlery | [] |
| b | Eats appropriately if food made manageable and/or uses spoon | [] |
| c | Uses fingers to eat food | [] |
| d | Needs to be fed | [] |
| e | Not applicable | [] |

3. DRINK

- | | | |
|---|--|-----|
| a | Selects and prepares drinks as required | [] |
| b | Can prepare drinks if ingredients left available | [] |
| c | Can prepare drinks if prompted step by step | [] |
| d | Unable to make a drink even with prompting and supervision | [] |
| e | Not applicable | [] |

4. DRINKING

- | | | |
|---|---|-----|
| a | Drinks appropriately | [] |
| b | Drinks appropriately with aids, beaker/straw etc | [] |
| c | Does not drink appropriately even with aids but attempts to | [] |
| d | Has to have drinks administered (fed) | [] |
| e | Not applicable | [] |

5. DRESSING

- | | | |
|---|---|-----|
| a | Selects appropriate clothing and dresses self | [] |
| b | Puts clothes on in wrong order and/or back to front and/or dirty clothing | [] |
| c | Unable to dress self but moves limbs to assist | [] |
| d | Unable to assist and requires total dressing | [] |
| e | Not applicable | [] |

6. HYGIENE

- | | | |
|---|--|-----|
| a | Washes regularly and independently | [] |
| b | Can wash self if given soap, flannel, towel, etc | [] |
| c | Can wash self if prompted and supervised | [] |
| d | Unable to wash self and needs full assistance | [] |
| e | Not applicable | [] |

7. TEETH

- | | | |
|---|---|-----|
| a | Cleans own teeth / dentures regularly and independently | [] |
| b | Cleans teeth / dentures if given appropriate items | [] |
| c | Requires some assistance, toothpaste on brush, brush to mouth etc | [] |
| d | Full assistance given | [] |
| e | Not applicable | [] |

8. BATH / SHOWER

- | | | |
|---|--|-----|
| a | Bathes regularly and independently | [] |
| b | Needs bath to be drawn / shower turned on but washes independently | [] |
| c | Needs supervision and prompting to wash | [] |
| d | Totally dependent, needs full assistance | [] |
| e | Not applicable | [] |

9. TOILET / COMMODE

- | | | |
|---|--|-----|
| a | Uses toilet appropriately when required | [] |
| b | Needs to be taken to the toilet and given assistance | [] |
| c | Incontinent of urine or faeces | [] |
| d | Incontinent of urine and faeces | [] |
| e | Not applicable | [] |

10. TRANSFERS

- | | | |
|---|---|-----|
| a | Can get in / out of chair unaided | [] |
| b | Can get into a chair but needs help to get out | [] |
| c | Needs help getting in and out of a chair | [] |
| d | Totally dependent on being put into and lifted from chair | [] |
| e | Not applicable | [] |

11. MOBILITY

- | | | |
|---|--|-----|
| a | Walks independently | [] |
| b | Walks with assistance, i.e. furniture, arm for support | [] |
| c | Uses aids to mobilise, i.e. frame, sticks etc | [] |
| d | Unable to walk | [] |
| e | Not applicable | [] |

12. ORIENTATION – TIME

- | | | |
|---|---|-----|
| a | Fully orientated to time / day / date etc | [] |
| b | Unaware of time / day but seems unconcerned | [] |
| c | Repeatedly asks the time / day / date | [] |
| d | Mixes up night and day | [] |
| e | Not applicable | [] |

13. ORIENTATION – SPACE

- | | | |
|---|--|-----|
| a | Fully orientated to surroundings | [] |
| b | Orientated to familiar surroundings only | [] |
| c | Gets lost in home, needs reminding where bathroom is etc | [] |
| d | Does not recognise home as own and attempts to leave | [] |
| e | Not applicable | [] |

14. COMMUNICATION

- | | | |
|---|--|-----|
| a | Able to hold appropriate conversation | [] |
| b | Shows understanding and attempts to respond verbally with gestures | [] |
| c | Can make self understood but difficulty understanding others | [] |
| d | Does not respond to or communicate with others | [] |
| e | Not applicable | [] |

15. TELEPHONE

- | | | |
|---|--|-----|
| a | Uses telephone appropriately, including obtaining correct number | [] |
| b | Uses telephone if number given verbally / visually or predialled | [] |
| c | Answers telephone but does not make calls | [] |
| d | Unable / unwilling to use telephone at all | [] |
| e | Not applicable | [] |

16. HOUSEWORK / GARDENING

- | | | |
|---|---|-----|
| a | Able to do housework / gardening to previous standard | [] |
| b | Able to do housework / gardening but not to previous standard | [] |
| c | Limited participation even with a lot of supervision | [] |
| d | Unwilling / unable to participate in previous activities | [] |
| e | Not applicable | [] |

17. SHOPPING

- | | | |
|---|---|-----|
| a | Shops to previous standard | [] |
| b | Only able to shop for 1 or 2 items with or without a list | [] |
| c | Unable to shop alone, but participates when accompanied | [] |
| d | Unable to participate in shopping even when accompanied | [] |
| e | Not applicable | [] |

18. FINANCES

- | | | |
|---|--|-----|
| a | Responsible for own finances at previous level | [] |
| b | Unable to write cheque but can sign name and recognises money values | [] |
| c | Can sign name but unable to recognise money values | [] |
| d | Unable to sign name or recognise money values | [] |
| e | Not applicable | [] |

19. GAMES / HOBBIES

- | | | |
|---|--|-----|
| a | Participates in pastimes / activities to previous standard | [] |
| b | Participates but needs instruction / supervision | [] |
| c | Reluctant to join in, very slow, needs coaxing | [] |
| d | No longer able or willing to join in | [] |
| e | Not applicable | [] |

20. TRANSPORT

- | | | |
|---|--|-----|
| a | Able to drive, cycle or use public transport independently | [] |
| b | Unable to drive but uses public transport or bikes etc | [] |
| c | Unable to use public transport alone | [] |
| d | Unable / unwilling to use transport even when accompanied | [] |
| e | Not applicable | [] |

Thank you for taking the time to complete this questionnaire.

Appendix four

Thematic analysis of biographies

Malignant Social Psychology / positive person work

Does the way we care help? (carer wonders)

When I could think about anything at all, I thought that the simplest facts about what had happened would never be clear: when her illness commenced, when she was first aware of it, whether the manner in which she had struggled with it delayed or altered its course in any way; whether the manner in which we cared for her and fought to keep her aware of her surroundings helped to slow its passage through her brain; (Ignatieff 1992) p. 170

Carer responsible for the person with dementia's quality of life

So, I wanted to make the most of the time we had together until he "graduated" from this earth and this life and moved onto the next and I would be responsible for filling that time.
(Seegmiller 2000) p. 6

Deception (even though good intentions)

Or sometimes saying, with a reassuring smile, 'Have you any idea how much I hate you?'
It sounds then as if I am making a reasonable point, and she seems to receive it in the same spirit.
(Bayley 1999) p. 81

Invalidation

I explained that he had been sleeping when we arrived and that more than likely he had been having another vivid dream. However, he was adamant that these visitors were real people and wouldn't be persuaded any differently.
(Ashman 2002) p. 30

Carer feels pwd feels betrayed

I'm sure he feels betrayed and that I'm the enemy.

(Seegmiller 2000) p. 123

**Person with dementia as not a person / Human vs not-human / object,
'us' vs 'them'**

In Marks and Spencer's my mother became, for a brief moment, a proper person again.

(Grant 1998) p. 218

Gradual loss of being human / a person

She was wondering who the 'I' was in her own sentences.

(Ignatieff 1992) p. 53

Child-like

Looking in on her as I potter about I am relieved to see her sitting intently, like a good child, watching the Sunday morning service.

(Bayley 1998) p. 180

Parent-child relationship

In her place is a bewildered infant who the world insists on treating as an adult with no one to protect her. My mother, my child.

(Grant 1998) p. 166

Carer treats the person with dementia as same person / still as an adult / human

Nothing that Iris could do, and nothing that could happen to her, could possibly make her any different.

(Bayley 1998) p. 148

Person with dementia develops strategies to deal with their difficulties

I used to think she was just falling apart. Now I think she has developed strategies of her own for dealing with this.

(Ignatieff 1992) p. 57

Others can learn from the person with dementia

Miranda nodded as she filled out the evening prescription sheet behind the nursing station. 'They tell us many things.' I liked the way Miranda talked about my mother and I said so.

(Ignatieff 1992) p. 111

Insight / awareness

Carer uncertain (and wants to know) about what is going on in the person with dementia's head / if they understand what remains / whether insight

They cannot share with others what they still formulate inside themselves. Does Iris speak, inside herself, of what is happening? How can I know? What is left is the terrible expectancy. 'When?' And 'I want....'

Is she still saying inside herself, like the blind man in Faulkner's novel, 'When are they going to let me out?'

(Bayley 1998) p. 172

Person with dementia still knows what's going on

My wife once said, 'Don't be hard on yourself. She doesn't feel a thing. The illness takes care of everything. It's worse for you'. Nothing could be farther from the truth. I know she has insight. I know she has counted up every one of her losses. She looks at herself and asks what kind of person she is becoming. The illness spares her nothing.

(Ignatieff 1992) p.49

Carer thinks person with dementia has some insight / sometimes

More than that, which makes the relation of memory and understanding so strangely unpredictable, she still seems able at times to identify an old joke reference.

(Bayley 1999) p.203

Person with dementia has lucid moments

Tonight when I put him to bed he called me by name, Judy, which he hasn't done for a long time and told me thank you and that he loved me. It was like the old Craig was in there.

(Seegmiller 2000) p.83

(and these surprise the carer)

Her coherence perturbs me. Normally now sentences trail off, become deadlocked – start again in another place. Only anxiety queries complete themselves, and this seems to be one.

(Bayley 1998) p. 163

(lucidity as terrible)

Twice Iris has said to Peter Conradi that she feels now that she is 'sailing into the darkness'. It was when he asked her, gently, about her writing. Such a phrase might be said to indicate the sort of inner knowledge that I had in mind. It seems to convey a terrible lucidity about what is going on.

(Bayley 1998) p. 179

Carer thinks person with dementia doesn't know what's going on

He glanced back at me from the window, 'I know what you think, but believe me, it's good that Mother doesn't know'.

(Ignatieff 1992) p. 145

or do they? – dilemma

In old days she used to weep quite openly, as if it were a form of demonstrable and demonstrated warmth and kindness. Now I find her doing it as if ashamedly, stopping as soon as she sees I have noticed. This is so unlike the past; but disturbing too in another way. It makes me feel she is secretly but fully conscious of what has happened to her, and wants to conceal it from me. Can she want to protect me from it?

(Bayley 1998) p. 178

Person with dementia no longer 'taking things in', 'failing to grasp'

It has become more obvious that this information is just not sinking in as Dad continues to ring at odd hours.

(Ashman 2002) p. 78

Person with dementia not in touch with reality / losing touch /different reality

For what our mother has said has unwittingly revealed how totally remote she is from reality.

(Grant 1998) p. 189

(and adamant their reality is real)

I explained that he had been sleeping when we arrived and that more than likely he had been having another vivid dream. However, he was adamant that these visitors were real people and wouldn't be persuaded any differently.

(Ashman 2002) p. 30

Reality as nightmare

And no outing can offer more escape from the nightmare of her present reality than shopping for clothes..

(Grant 1998) p. 3

Hopes the person with dementia doesn't know what's going on

The sense of someone's mind. Only an awareness of it; other minds are usually taken for granted. I wonder sometimes if Iris is secretly thinking: How can I escape? What am I to do? Has nothing replaced the play of her mind when she was writing, cogitating, living in her mind? I find myself devoutly hoping not.

(Bayley 1998) p. 158

Person with dementia and emotions / behaviour

Person with dementia has poor quality of life

You look around the yellow room and the walls and the ceiling and the linoleum and you think to yourself, 'What kind of life is this?'

(Ignatieff 1992) p. 158

Life passes person with dementia by

Time goes by without her. Great events more or less pass her by, first the General Election then something altogether more momentous. I go to pick her up for our Sunday expedition. I say, 'Did you watch Princess Diana's funeral yesterday?'

We're standing at the bus-stop. I watch her face. She is floating about in the deep emptiness of her mind to try to find something. Out of the corner of her eye she catches sight of a recollection and reaches out for it.

(Grant 1998) p. 247

Person with dementia lives only in present

'Your mother does not deal in the past or in the present but in the here and now..

(Grant 1998) p. 208

Present moment also forgotten

This moment, the one she is really living in, is lost from sight as soon as it happens.

(Grant 1998) p. 15

Even current emotions forgotten quickly

'She begins another sentence then breaks off. 'I don't remember what I was talking about'. She cries again, easy tears that stop as easily, for like cigarette smoke, the memory of her sorrow has disappeared into the air.

(Grant 1998) p. 151

**Person with dementia doesn't remember or understand therefore
protected from feelings / has no cares**

Then he said, 'At least she didn't know what happened. We can thank the illness for that'.

(Ignatieff 1992) p. 83

Person with dementia still has emotion/feeling

Even into the late stages of Alzheimer's, Craig continued to retain his emotions. He would appear happy, sad, surprised, fearful, worried, angry and depressed.

(Seegmiller 2000) p. xix

Rational reason for actions – not just due to the disease

'Just giving her the benefit of the doubt. Just assuming there might be some method in the madness'.

(Ignatieff 1992) p. 59

Emotions due to symptoms of dementia not the person

'I now know that the way she behaves, the crying, for example, is a product of chemical changes which are taking place in her brain,

(Grant 1998) p. 265

Person with dementia has mood changes

Her mood changes like a radio clicking to another station from sobbing violins to angry drums.

(Grant 1998) p. 164

Person with dementia as frightened

All the time now she looks frightened. I hold her hand, tell her I am here, and that she has nothing to worry about. But it makes no difference.

(Ignatieff 1992) p. 45

Person with dementia as confused / bewildered

He seemed so bewildered and said rather pathetically, 'I don't know what's the matter with me these days, Shirl. It seems as if I'm out of tune with the rest of the world'.

(Ashman 2002) p. 46

Confused by night and day

Again he was really confused and thought that it was morning and that he was just about to go to the shop for his newspapers.

(Ashman 2002) p. 39

Person with dementia as lonely/isolated/alone

Suddenly she says, 'I am alone', not piteously, but in the unemotional voice she used of old when facing up to disagreeable realities.

(Ignatieff 1992) p. 49

Person with dementia as agitated / anxious / upset / concerned / depressed

With Iris still sweetly and childishly asleep, still unafflicted with the compulsions of Alzheimer's, which will cause her on bad mornings, and most mornings are bad, to shed silent miserable tears, or to utter small anxious cries and queries on waking.

(Bayley 1999) p. 11

Person with dementia as suicidal

I stood there for some time waiting and then I heard Dad crying (whether in prayer to himself I do not know) 'Oh God, what have I done to deserve this – I don't know what is happening to me. I may as well throw myself in the river now and have done with it all'.

(Ashman 2002) p. 74

Person with dementia as annoyed / aggressive

He became quite aggressive and accused the Home Care worker of burning his slippers on the fire as he couldn't find them.

(Ashman 2002) p. 56

Person with dementia needing to feel safe

Normally, if more than one person was talking, she'd say, 'What? What's that? What are you saying? Don't leave me out'. But I think that was an aspect of paranoia rather than keen hearing, her brain intent on protecting itself by zeroing in on information it thought it might need, making a sweep of the surrounding area. But here, lulled by careful hands about her head, she feels safe. So she ignores any noises there might be in the room.

(Grant 1998) p. 255

Person with dementia as suffering

My brother went over and sat on the sofa. 'Mother can only suffer. She can't give her experience any meaning. That's the worst thing about it for her'.

(Ignatieff 1992) p. 144

Carer thinks person with dementia would like to escape

My favourite bit is the wild triumphant strain of Nun weiter denn, nur weiter, as he gives way to his impulse to go on, go farther, anywhere, anywhere to escape the madness in his mind. This must be why Iris stands at the front door, rattling the handle. Anywhere, anywhere, to get out of it all.

(Bayley 1999) p. 66

Person with dementia as attention seeking

Or has the whole incident been a superbly acted performance, a cry for help from a woman abandoned and deserted?

(Grant 1998) p. 186

Person with dementia as difficult

Even before we started Iris had become difficult.

(Bayley 1999) p. 260

Person with dementia as slower on the uptake, slowing down in processing

Her face lights up when her friends smile, and when they laugh, she joins in. If her laughter is sometimes a beat late, no one seems to notice.

(Ignatieff 1992) p. 45

Person with dementia as having lost skills

She remembers the summer nights when her father used to wrap her in a blanket and take her out to the edge of Otter Lake to see the stars. But she can't dice an onion. She can't boil a kettle of water. Any sustained course of action requires more concentration than she can muster. Cold curiosity leads me to ask her to set the table, just to see what will happen. She puts the knife where the fork ought to be, a plate with neither knife nor fork, and a spoon far off in the middle of the table. She looks bored with the result.

(Ignatieff 1992) p. 44

Person with dementia as unpredictable

And with Craig I never knew what was going to come out of his mouth anymore.

(Seegmiller 2000) p. 138

Person with dementia as happy

Obviously Dad was very happy and he said, 'Well, Shirl, that's restored my faith in human nature' and said that the Lord has answered prayer.

(Ashman 2002) p. 23

Person with dementia as changed vs not changed

Person with dementia as different vs same person

It breaks my heart to see the decline. I wish he could sometimes go quickly while he is still "Craig" – the person he was and would still like to be.

(Seegmiller 2000) p. 97

Person with dementia as a changed / different person

Iris gives up the struggle, but produces a frightful grimace, an expression wholly new and different from anything her face ever did in the past. It always unnerves me, and is becoming more frequent in other situations.

(Bayley 1998) p. 168

Person with dementia as a stranger

When she has to leave me to be in a home, a beautiful home no doubt, I shall visit her as a stranger. It will be like reading those letters to the men whom she was briefly engaged, just after the war. I could not recognise the handwriting, or the young woman who had written them.

(Bayley 1999) p. 244

Person with dementia still the same in some senses

In spite of this, her gestures, her smile, her voice remained unchanged. A blurred vision of her charm survived, together with hints of her sense of humour.

(Ignatieff 1992) p. 53

The relationship between the person with dementia and carer

Still same relationship together vs different

We can still talk as we did then. But it doesn't make any sense any more, on either side. I can't reply in the way I used to do then but only in the way she speaks to me now. I reply with the jokes or nonsense that still makes her laugh. So we are still part of each other. We can still talk as we did then. But it doesn't make any sense any more, on either side. I can't reply in the way I used to do then but only in the way she speaks to me now. I reply with the jokes or nonsense that still makes her laugh. So we are still part of each other.

(Bayley 1998) p. 162

Person with dementia and carer as closer

Life is no longer bringing the pair of us 'closer and closer apart', in the poet's tenderly ambiguous words. Every day we move closer and closer together. We could no do otherwise.

(Bayley 1998) p. 183

Person with dementia and carer can no longer share same things as before

All such memories release me none the less: release me into that inevitable selfish world of sights and sounds I can no longer share with her.

(Bayley 1999) p.254

Recognition

Recognition of others vs non-recognition

Suzanne helps me see things and put things into perspective. I've really been struggling lately. She said, "Mom, I don't know what we need to do, but we can't put dad in a home yet. He still knows everyone."

(Seegmiller 2000) p. 61

No longer recognising self

People kept asking me: does she recognise you? As if recognition is simple, binary, yes or no. Actually, she was simultaneously aware that she should recognise me and yet sometimes unable to do so.

(Ignatieff 1992) p. 163

Communication

Pointless (for various different reasons)

(asking questions)

The questions are pointless, since she can't remember the answers.

(Ignatieff 1992) p. 46

(visiting)

After the nurses led her back upstairs, I didn't want to take him back to my place so we went into the chapel room, where memorial services for former patients were held and he said, immediately, 'What's the point?'

'Of what?'

'Of visiting.'

'Why not?'

'Is there anything left?'

'How much do you need for it to be worthwhile?'

'I need something'.

(Ignatieff 1992) p. 158

(trying to communicate)

It is no use trying to tell Iris about these memories as I would once have done, no use trying out an idea or a thought on her. It upsets her; a bothered look can come over her face, but usually there is only vacancy and, with luck, a smile.

(Bayley 1999) p. 13

(taking him to Dr cos he wont understand the questions)

He's probably got whiplash but there is no use in taking him to the doctor because he's too confused by questions that people ask him. I don't know how bad his head really hurts or even how well he really sees anymore.

(Seegmiller 2000) p. 100

Person with dementia no longer understands words

I ask her to read a page to me, and she does so in a childlike singsong, without inflection, unaware that the words are forming into meanings.

(Ignatieff 1992) p. 47

Communicating with person with dementia is like communicating with foreigner

I remember that from the wartime, from yesterday as it seems, as now I try to speak more clearly, more forcefully. It's as if Iris were a very foreign sort of

foreigner, but with such a person one might successfully resort to pantomime, exaggerated gestures signifying bed – sleep. Closing eyes, putting a hand under one's head. Such gestures now would only alarm her?

(Bayley 1999) p. 242

Communicating with person with dementia is difficult / takes time

When it eventually 'got through' that is was very late in the night, Dad apologised for getting me out of bed and I said I would see him tomorrow at our usual time of 6.30pm.

(Ashman 2002) p. 31

Person with dementia is on a different planet / in a different place

I'm almost beginning to think he's comfortable out there as Suzanne said, "It's his world and he doesn't need to fit into our world".

(Seegmiller 2000) p. 114

Person with dementia is still trying to communicate

Now she cannot tell me she loves me, and I cannot tell her that I do. At least not in so many words. The other day in the car she laid a hand on my knee and said with emphasis, 'Susten poujin drom love poujin? Poujin susten?' I hastened to agree, and one word was clear. As soon as I could stop the car we kissed each other. She knew what she meant even when there is no meaning, and there was in that word...

(Bayley 1999) p. 240

Person with dementia relates well to children and animals

It didn't surprise me that Dad believed in the power of prayer but it did take me by surprise at the speed with which he latched onto the plight of a sick animal and showed such passionate concern.

For, to my amateur way of thinking, perhaps Dad can identify with a poor creature that is sick and cannot bring people to the understanding of what they are really feeling and to explain what is wrong. Who knows?

(Ashman 2002) p. 77

Carer has to decipher in order to communicate

Lunatic conversations by the hour, she looking at me, as if to say, 'Am I making sense?' And me encouraging her to go on, even though I didn't know what she was talking about. Her speech reminded me of a film I saw on television once about some travellers lost in the desert, who try to attract the attention of passing planes by reflecting the light of the sun with a piece of broken mirror.

(Ignatieff 1992) p. 157

Some memories still intact

Norm and Tricia visited him today. Craig remembers Norm – not his name. He smiles and must have a flickering of the trips we took together.

(Seegmiller 2000) p. 142

Person with dementia repeats

'It's like trying to tune into Channel Five', he says when he comes back. 'And when you do find it, all you get is repeats'.

(Grant 1998) p. 257

Social death

As good as dead

The eyes that do not see, the eyes that have no memory, the eyes that are dead. I had arrived at the moment, long foretold, hopelessly prepared for, when Mother took the step beyond her self and moved into the world of death with her eyes open.

(Ignatieff 1992) p. 165

Carer as alone (even though the person with dementia is there)

I almost feel guilty that he's there tonight when I'm home and I don't need to be anywhere. It feels good in a lot of ways but very strange to be alone even though I've been alone for at least two years now.

(Seegmiller 2000) p. 115

Already dead

He stroked the top of his right hand with his left, and said, not looking at me, but gazing at the floor, 'She's left me now. I wish I could go with her'.

(Ignatieff 1992) p. 73

Carer saying goodbye before the person with dementia was dead

It's like I said earlier, you bury them a little every day. I think more so in the beginning and then you let it go until the latter part of the disease. It's looking at it as being able to say a long good-bye and it's hard.

(Seegmiller 2000) p. 7

Person with dementia talked about in third person

My Iris is not yet a She, but inevitably she becomes more like one every day, even in my thoughts.

(Bayley 1999) p. 249

Use of past tense to describe person with dementia, even though they were still alive

How sorry I feel for this man who was once my father.

(Ashman 2002) p. 45

Between life and death

Every morning she wakes up a little farther from us.

(Ignatieff 1992) p. 49

Death as a relief / good thing

Tonight Suzanne admitted that she, too, has thought about death being sweet.

(Seegmiller 2000) p. 40

Person with dementia wanting to die

Friday he told me that he hated this disease and that he wanted to go live with Heavenly Father. I told him it wasn't that easy and that we would all like to go live with Heavenly Father.

(Seegmiller 2000) p. 67

Mind-body interaction

Mind as separate from body

It is as if her mind is miles away from her body, looking down on its ruin and absurdity.

(Ignatieff 1992) p. 47

Body present, mind/memory not

She's here with me, but her memory is on a boat that has had its moorings cut and is gone beyond the horizon.

(Grant 1998) p. 14

Mind somewhere else

He said that he couldn't remember and he furrowed his brow and said, 'I don't recall that, Shirl - it's as if my mind has gone into the next world or somewhere!'

(Ashman 2002) p. 93

Mind shutting down / declining

'But the circuits are going down. Every day I come in here and one more has gone. She could walk three months ago. She could eat her food three months ago. She could talk. Now the words are going and everything she says is blurred like the words in a kid's writing book left out in the rain.

(Ignatieff 1992) p. 158

Disease taking over the mind

Craig never goes to bed alone anymore. Just another thing that he is not himself. I suppose this is more of the disease as it takes over his mind.

(Seegmiller 2000) p. 15

Dementia and the self

Person with dementia as shell of / Ghost of former self

'She's like a shell,' Michele had said a couple of weeks earlier. 'With bits of her rattling around inside'.

(Grant 1998) p. 260

Person with dementia as leaving the self

She has left her self behind.

(Ignatieff 1992) p. 158

Dementia as an illness of self

It is pointless to go on and we both know it. The doctor looks at Mother's PET scans and sees a disease of memory function, with a stable name and a clear prognosis. I see an illness of selfhood, without a name or even a clear cause.

(Ignatieff 1992) p. 60

Self / identity vs no-self remaining, gradual loss of

The disease begins to turn its malign attention to the very heart of her self, as she struggles to hold her identity together.

(Grant 1998) p. 146

Metaphor and dementia

Terrible wilderness

We are wondering through the looking-glass now, my mother and I, where we wander in that terrible wilderness without landmarks, nothing to tell you that you passed here only moments before.

(Grant 1998) p. 8

Shrinking lump of meat

So nearly a century of private history with a cast if not of thousands then of dozens – enough to mount a Broadway musical – is reduced to a shrinking lump of meat weighing a pound or two through which electrical impulses pass.

(Grant 1998) p. 16

Permanently turned off at the mains

So nearly a century of private history with a cast if not of thousands then of dozens – enough to mount a Broadway musical – is reduced to a shrinking lump of meat weighing a pound or two through which electrical impulses pass. Certain areas of it are permanently turned off at the mains.

(Grant 1998) p. 16

Soft in the head

We all knew people who were senile, gone soft in the head, which was not a medical complaint but an inevitable punishment for living too long.

(Grant 1998) p. 131

Software in the computer is all muddled up

The software in the computer is all muddled up and sometimes she might be able to put it together, other times she might not.

(Grant 1998) p. 264

On a journey

I tell him that my father had said she was on a voyage away from us, and that there were times when we all wished we could follow her. She couldn't tell us what it was like, I say, but you can.

'a journey, yes'.

(Ignatieff 1992) p. 141

An insidious fog

Alzheimer's is in fact like an insidious fog, barely noticeable until everything around has disappeared. After that it is no longer possible to believe that a world outside fog exists.

(Bayley 1998) p. 151

Sailing into the darkness

Twice Iris has said to Peter Conradi that she feels now that she is 'sailing into the darkness'. It was when he asked her, gently, about her writing.

(Bayley 1998) p. 179

Before all the lights go out

The clear things Iris does sometimes come out with are intended for public consumption. They are social statements. They have the air of last remarks before all the lights go out.

(Bayley 1998) p. 180

As poor radio-telephone reception

I urge her imperiously and impotently to get back into bed. She does not ignore me, or pay no attention; she seems to be listening to a garbled message. On the Radio-Telephone in the army the operator would have been saying, 'I am not receiving you', or 'Receiving you Strength One'.

(Bayley 1999) p. 242

Dr Jekyll and Mr Hyde

Off Dad went with Gareth, with no trouble or grumbles at all – leaving Alwyn and myself staring at each other in disbelief of what we had just witnessed.

Talk about 'Dr Jekyll and Mr Hyde'!

(Ashman 2002) p. 102

Corridors of confusion in the mind

I understand, too, that Dad must be in pain as there are corridors of confusion running through his mind and I pray that the Lord will bring to his remembrance the times of long ago when he sat, as a child, under the ministry of the Gospel whilst at his mother's knee.

(Ashman 2002) p. 113

Dementia as madness

But how hard could that be to obtain when she is so obviously at risk and in need and all the other words that bureaucracies use to describe the frail, mad woman my mother is, with so little grip on reality?

(Grant 1998) p. 176

Vacant / vacuum / empty

It is no use trying to tell Iris about these memories as I would once have done, no use trying out an idea or a thought on her. It upsets her; a bothered look can come over her face, but usually there is only vacancy and, with luck, a smile.

(Bayley 1999) p. 13

Dementia as a dark place

Beyond the fear and the loss, she seems to say, there is a life of a sort here, at the dark edge where everything is crumbling, falling away, becoming indistinct.

(Ignatieff 1992) p. 49

Dementia as tragic

I guess after two years of watching the decline I want people to know how tragic it is and about the disease.

(Seegmiller 2000)

Dementia as stigma

I feel it very important to be honest and upfront so that people become aware of this terrible disease. It will never be out in the forefront if the disease is kept hidden and if we hide these individuals afflicted with the disease.

(Seegmiller 2000) p. xv

BUT

Dementia not as frightening as we imagine

In her life she managed to teach us what it was like, in this realm beyond speech. She had done what she could to take our fear of it away, to take it upon herself, so we would not be frightened when our turn came. It was as if she was always saying to us: Look, it is only this, only this. I have been there. Only this.

(Ignatieff 1992) p. 165

Dementia as loss

Dementia as something lost vs something remaining

'You keep telling me what has been lost, and I keep telling you something remains'.

(Ignatieff 1992) p. 58

lost dignity

You can choose life or you can choose consciousness, but as Mrs Adkins knew, the illness does not allow you both. If you do not act, as Mrs Adkins did, on the first signs of its presence within you, the illness will not even allow you the dignity of a choice.

(Ignatieff 1992) p. 187

Dementia as more than just a loss of memory

In spite of this, her gestures, her smile, her voice remained unchanged. A blurred version of her charm survived, together with hints of her sense of humour. She was suffering a disturbance of her soul, not just a loss of memory, yet she was still intact.

(Ignatieff 1992) p. 53

What is it like for the carer?

Carer as alone

Here we see a link with the theme of social death.

The horrid wish, almost a compulsion at some moments, to show the other how bad things are. Force her to share the knowledge, relieve what seems my isolation.

(Bayley 1998) p. 162

Much worse for the carer!

As a pastor, my heart goes out to those who find themselves in a similar situation, because this illness is often more traumatic for the carer than for the patient.

(Ashman 2002) p. xi

Person with dementia drives carer to violence / infuriates

When I get back the woman, a nice-looking person, is awake, and distraught, desperately trying to regain the handbag and other possessions which had been on the seat beside her. I take them from Iris and put them back, apologising again in a whisper. Iris says, 'So sorry', gives the woman a beautiful smile. I get Iris into a seat and give her a violent surreptitious punch on the arm by which I am holding her.

(Bayley 1998) p. 176

Others aren't aware of the difficulties

Some of Craig's friends thought I was embellishing how Craig was slipping because he could talk to them for a period of time and "looks" good; but they don't see him for long periods of time and see what I see and hear. I've decided also, they talk to Craig, but they don't really listen or they would know.

(Seegmiller 2000) p. 61

Person with dementia as having public and private images

In public, her façade is still intact. With enormous effort, she puts her old personality on public show. In private, however, the façade is giving way.

(Ignatieff 1992) p. 46

Appendix five

Mr and Mrs Woody

Visit 1, November 2000

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

At the Alzheimer's society lunch, Helen was talking whilst the raffle was being drawn, and Gilbert said, 'ssshhhhhh!' so that the raffle draw could take place.

In his daughter's shop there was a spread of different foods to try and he helped himself to various items.

The family have bought a tracker device so that Gilbert can walk round the village and they can still find him.

Initiating social contact

In the Alzheimer's meeting Gilbert did not approach anyone to initiate contact, but looked a little lost. However, when Gilbert and I were walking towards Maidstone high street he said 'hello!' to a man passing by who then stopped and chatted with him.

Warmth and affection

While we were in the shop Gilbert came up very close to me, stared into my eyes, and then 'parped' the end of my nose with his finger.

He also counted invisible buttons down the front of his daughter's t-shirt and she was fine about this, smiling and laughing.

Self Respect

I didn't observe any signs for this category. When food was spilt at lunchtime Patricia wiped it up while Gilbert sat still.

Being helpful

I didn't observe any signs for this category. Gilbert has difficulty with mobility and also some perceptual problems which may have made it difficult for him to help with some practical things. His daughter said that Gilbert was an engineer and that this was a part of his personality that had gone, that he always used to be fixing things. She said that at one stage she could help him to put a screw in if she told him where it was to go and she believed he still felt useful then.

Humour

Gilbert was often laughing and smiling. His family said that his sense of humour remains and that, for example, he likes to do impressions of Germans with his granddaughter. He also laughed when he got his foot tangled up in the car with the gear lever, showing no signs of tension.

Bodily relaxation

During my time observing Gilbert he was often both alert and relaxed. For example in the shop he wandered around happily, trying some of the samples of foods on offer. Although he was a large chap and had difficulty with mobility, he was always in a relaxed position wherever he was seated.

Creative self-expression

When I went to leave I shook Gilbert's hand, and he put his other hand on top and started jiggling our hands around and singing.

Showing pleasure or enjoyment

Gilbert showed many signs of enjoyment – of the lunch, '*much larger lunch!*', of his time in the shop, and when greeted by others – particularly his daughter.

Responding appropriately to others

When I stood up from having sat in a chair in the lounge for a while I rubbed my knee, and Gilbert said, 'stiff'.

Expressing appropriate emotions

Gilbert was generally very happy during the day. He was pleased when greeted by people, and showed this despite his failing powers of speech. He also showed his annoyance when the group leader, Helen, was chatting during the raffle draw by saying, 'ssshhhh!'. While Patricia was away on holiday his granddaughter said he had shown signs of sadness – he pulled her close and there were tears in his eyes.

Holding his own socially

In the Alzheimer's society meeting Gilbert looked lost and stood alone as no one was talking to him. However in the shop later in the day he obviously felt able to move around freely and do what he wanted despite the presence of other people.

Alertness

Gilbert spent a good proportion of his time alert to his surroundings. When we were driving to Maidstone he asked if we were going the right way. In the shop he was very alert and tried many different samples of food, and felt some of the toys available in the children's play area. He watched some of the film later in the day, but also dozed on and off.

Being active

Despite Gilbert's mobility problems he still moved around in the shop, taking care when going up the small flight of stairs (three) (with some help). Patricia did help him to eat some of his food, as he appeared to have a slight perceptual problem.

Being purposeful

When Gilbert and I were walking to the shop he often took the lead and walked in a purposeful way.

Indicators of ill-being

Depression or despair

Gilbert did not show any signs of depression during the observation.

Intense anger

Gilbert showed no signs of anger during the observation.

Grief

In terms of grief for lost status and abilities, Gilbert may show some signs as according to his granddaughter he sometimes says, '*I'm just a silly old man*'. Similarly when Patricia went on holiday recently his granddaughter said he pulled her close and there were tears in his eyes.

Anxiety

Whilst we were driving Gilbert occasionally said, '*are we going the right way?*' In the evening when Patricia went to the other side of the (large) kitchen he said, '*are you coming back?*'

When we had left the shop and were returning to the car we had to turn down a narrow alleyway. Gilbert clung onto the corner of the wall and I had to help him to release his grip so we could continue. Patricia says that he sometimes does this, she felt, for security.

Fear

Gilbert showed no signs of fear during the observation.

Boredom

Gilbert showed no signs of boredom during the observation. He fell asleep briefly while we were having coffee in the morning and then again during the car journey and while watching the video, but for no longer than the 'appropriate sleep period' as defined for residential settings in the DCM manual.

Physical discomfort / pain

Gilbert showed no signs of physical discomfort.

Bodily tension

Gilbert showed no signs of bodily tension.

Agitation

Gilbert showed no signs of agitation.

Apathy and withdrawal

Gilbert was happy to take part in the activities at the shop. Although he slept at times during the day this was within the 'appropriate sleep period' as defined for residential settings in the DCM manual.

Distress

Gilbert did not show signs of distress.

Cultural isolation

Gilbert is not treated as an outsider within the family. This was also the case at the shop where his daughter and son-in-law were happy for him to wander round and look at the items – he was very much included. However although the members of the Alzheimer's society had greeted Gilbert and helped him in he was the only one with dementia present, and at one point he was left standing alone whilst everyone else had sat down or were chatting in groups.

Difficulty withstanding powerful others

Gilbert showed no signs of difficulty withstanding powerful others.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 1 |
|---|---------|
| Making wishes known (non-destructively) | 2 |
| Initiating social contact | 1 |
| Warmth and affection | 2 |
| Self-respect | 0 |
| Being helpful | 0 |
| Humour | 2 |
| Bodily relaxation | 2 |
| Creative self-expression | 1 |
| Showing pleasure or enjoyment | 2 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 2 |
| Holding their own socially | 1 |
| Alertness, responsiveness | 2 |
| Being active | 1 |
| Being purposeful | 1 |
| Score | 20 |

TOTAL = 20/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 1 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 1 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 0 |
| Physical discomfort / pain | 0 |
| Bodily tension | 0 |
| Agitation | 0 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Score | 3 |

TOTAL = 3/26

Elements of Malignant Social Psychology

Banishment (mild)

When we went into the Alzheimer's society lunch, although Gilbert had been greeted and helped in by the others he was left standing alone whilst others talked together in groups or sat down for a cup of tea.

Invalidation (moderate)

When we arrived back home it was raining very hard and Gilbert didn't want to get out of the car. After being very calm and understanding all day, Patricia became rather frustrated and said, *'oh well you stay there then if you want to!'*

Positive Person Work

Relaxation

While Patricia and I were talking together in the Alzheimer's group meeting she sat with her hand on Gilbert's knee, allowing him to relax and have bodily contact with her.

Recognition & Collaboration

As soon as we arrived in the car park at the Alzheimer's society meeting, three friends of Gilbert came running up to say hello, and all three of them helped him to walk across the car park and into the building.

Facilitation

Gilbert had got his legs in a tangle in the car such that he had one leg on either side of the gear stick. Patricia helped to disentangle him by taking off his shoe so that he could manoeuvre his foot round. She was supportive throughout, calling him *'old love'*.

Recognition

We were walking up the high street towards his daughter's shop when she saw us and rushed outside to greet and hug Gilbert, *'ah Dad!'*

Similarly when we left the shop she rushed up the road after us to give her Dad a big hug goodbye.

Play

Gilbert noticed a small plastic dinosaur on the table in the children's area and showed it to me, running his finger along the outline of its spiny back.

Gilbert enthusiastically counted imaginary buttons down the front of his daughter's t-shirt while they both laughed.

Creation

When I went to leave I shook Gilbert's hand, and he put his other hand on top and started jiggling our hands around and singing.

Carer support for intact abilities

Although Gilbert could feed himself he had some difficulty as he appeared to have some perceptual problems. Patricia helped to feed him every now and then but this was not done in an interfering way, but in a supportive, facilitating way. Gilbert did not help with any of the household tasks during the observation day, so it was difficult to assess his abilities in this aspect. It would have been interesting to have asked Patricia to fill out an activities of daily living scale to find out more about his abilities.

Validation of emotion by carer

When Gilbert asked if we were going the right way during the car journey Patricia was very supportive and reassured him.

When we arrived back home it was raining very hard and Gilbert didn't want to get out of the car. After being very calm and understanding all day, Patricia became rather frustrated and said, *'oh well you stay there then if you want to!'*

Politeness strategies

During the raffle the group leader, Helen, started chatting during the draw causing people to be distracted from the main purpose. Gilbert brought the group back to order so that the person making the draw could continue by saying, *'ssshhhh!'* to Helen.

When we arrived at the shop in the afternoon, Gilbert was nearer than I to the door, but held it open and said, *'after you'*, despite his failing powers of speech.

Aspects of selfhood

In terms of his role as granddad, Gilbert is still held in high esteem by his grandchildren. Christopher, his grandson, described him as *'great fun'* & said that all of his friends would like to have an eccentric granddad like him. The family spoke of his great sense of humour, and his granddaughter said he liked to pretend to be a German with her, and march around. However his daughter Ann spoke of some of the loss of self she felt in her father. As an engineer during his working life he was always fixing things and that was the bit of his personality which had gone according to Ann. She said that at one stage she could help him to mend, for example, fences if she told him where to place the screws, but that this ability had since gone.

In terms of still feeling a valued member of his family, this aspect of self was much nurtured by his family. This was most strongly demonstrated in

the shop – a family business, but in a public setting. Here, during the shop's open day, Gilbert was able to wander around trying the foods and mixing with the public. His daughter and son-in-law went out of their way to make him feel as welcome and as included as possible.

Perception and social death

There was one expression of the 'loss of part of a person' who has dementia from his daughter Ann who said that as an engineer during his working life Gilbert was always fixing things and that was the *'bit of his personality which had gone'*. However Gilbert's role as grandfather seemed to be an important one, and one in which his grandchildren still very much valued him. Christopher, his grandson, described him as *'great fun'*. Similarly the manner in which he was included in the shop opening celebrations verified his continuing role as much loved father. It could be interpreted that most of his family view do not feel that a person with dementia 'ceases to be there' once they have cognitive deficits which restrict conventional communication.

Visit 2, May 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Having very limited speech, Gilbert had to rely on other forms of communication to express his wishes. When he felt unsafe on his feet, for example when walking across a boundary such as through a door, he would often refuse to go on and show his distress by saying, '*oi! oi! oi!*'

Initiating social contact

There were some instances of Gilbert initiating social contact.

On one of the newspapers there was a huge headline entitled '*don't panic*', but the word '*panic*' was hidden. Gilbert read out to me '*don't*' and said '*don't what?*' Later that afternoon when I was reading the sports page he asked me '*Who's Houlier?*' (*Liverpool F C's manager*).

Warmth and affection

Gilbert showed many signs of warmth and affection.

While I was walking around the garden with him I squeezed his hand and he returned the squeeze.

When any of the family greeted him he would smile warmly.

When Teresa had a joke with him his eyes lit up and he would laugh with her.

Self Respect

One morning while I was eating breakfast with Gilbert he burped, and then said '*excuse me*'.

Similarly, at the dinner table his friend Barry was telling a story which involved doing an impression which sounded like a raspberry. On hearing this Gilbert exclaimed, '*wah, wasn't me!*'

Being helpful

Gilbert did not show any signs of helping out during my stay.

Humour

Gilbert showed many signs of humour, even in adversity. For example, when walking with Patricia and myself nearby he caught his foot on a raised part of the path and fell over. After the initial shock he lay there and laughed.

Gilbert also laughed quite often when communicating with Teresa. She mentioned something about women in bikinis in joking with him and his eyes lit up and he had a laugh.

Bodily relaxation

Although Gilbert spent quite a bit of his time dozing there were occasions when he was sitting alert, yet relaxed in his body, for example whilst he was watching me do a jigsaw puzzle on the kitchen table.

Creative self-expression

Gilbert enjoyed humming along to tunes on the tape recorder. Patricia often played music whilst he was sitting in either the kitchen (tended to be more lively music) or in his reclining chair in the lounge (relaxing classical music). Gilbert also enjoyed dancing to Foster and Allan with Teresa.

Showing pleasure or enjoyment

Gilbert showed many signs of pleasure during my stay. For example whilst humming or dancing as detailed above, and also when in the company of family and friends he would smile and laugh.

Responding appropriately to others

I did not observe any signs for this category during my stay.

Expressing appropriate emotions

I asked Patricia if she felt Gilbert was ever frustrated. She replied that she didn't as he had always been a good natured person. However she said that he does show signs of anxiety when he is out of his usual environment, this usually manifests itself in him clinging to various structures. For example, last year they had visited a craft fair and he became anxious in the marquee, clinging to the poles.

Gilbert was also able to show happiness when laughing with friends or relatives.

Holding his own socially

I did not observe any signs for this category during my stay.

Alertness

Gilbert showed some signs of alertness during my stay. He responded to unexpected noises, for example when his friend Barry was telling a story and became suddenly and loudly animated Gilbert looked momentarily startled. He also read out two short extracts from headlines in the paper whilst I was reading it, suggesting that he took an interest in his surroundings.

Being active

Despite having problems with mobility, Gilbert would sometimes explore his immediate environment by reaching out for a newspaper or other items on the table. This action also highlighted his perceptual problems with proprioception.

Being purposeful

Gilbert did not show signs for this category during my stay.

Indicators of ill-being

Depression or despair

Gilbert did not show any signs for this category during my stay.

Intense anger

Gilbert did not show any signs for this category during my stay.

Grief

Gilbert did not show any signs for this category during my stay.

Anxiety

When Gilbert felt unsafe on his feet, for example when walking across a boundary such as through a door, he would often refuse to go on and show his distress by saying, '*oi! oi! oi!*'

Fear

Gilbert did not show any signs of an intense anxiety during my stay.

Boredom

I did not observe Gilbert being offered any form of activity, with the exception of listening to music. He did spend more time dozing whilst sitting in a chair, either inside or out in the garden, than during my last visit.

Physical discomfort / pain

Gilbert showed some signs of physical discomfort when he was helped out of a chair. Having had a hip replacement last year, and considering his fairly heaving build he may have some stiffness in his leg. In addition, although Patricia encourages him to walk twice a day, he does spend a large proportion of his time sitting down on chairs. At one point he was trying to shift his position in his chair in the lounge. I said, '*OK there?*' to which he replied, '*too hard*'.

Bodily tension

Gilbert only showed signs of bodily tension when he felt unsafe in walking around. He would grip onto nearby structures and adopt a rigid body position.

Agitation

Gilbert did not show any signs of agitation during my stay.

Apathy and withdrawal

Gilbert did not show any signs for this category during my stay.

Distress

Gilbert did not show any signs of persistent discomfort.

Cultural isolation

Patricia and Gilbert live next door to their daughter and her family. Their house is often busy with either friends or family. Gilbert is always included in these activities. However unless visitors actually direct their conversation to him he can, at times, lack engagement. His cultural isolation, although very minimal, would be based on his having dementia, and being much slower and more verbally limited in his communication.

Difficulty withstanding powerful others

I did not witness Gilbert in any environment which included a powerful other. His refusal to walk straight across some boundaries when he feels anxious may lead to conclude that he can withstand powerful others.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 2 |
|---|---------|
| Making wishes known (non-destructively) | 1 |
| Initiating social contact | 1 |
| Warmth and affection | 2 |
| Self-respect | 1 |
| Being helpful | 0 |
| Humour | 2 |
| Bodily relaxation | 1 |
| Creative self-expression | 2 |
| Showing pleasure or enjoyment | 2 |
| Responding appropriately to others | 0 |
| Expressing appropriate emotions | 2 |
| Holding their own socially | 0 |
| Alertness, responsiveness | 1 |
| Being active | 1 |
| Being purposeful | 0 |
| Score | 16 |

TOTAL = 16/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 2 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 1 |
| Bodily tension | 1 |
| Agitation | 0 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Score | 5 |

TOTAL = 5/26

Dementia Care Mapping (DCM)

Approximately 11 hours of DCM were carried out over the three days (5.5 hours, 3 hours and 2.5 hours respectively). Behaviour profiles showing the proportion of time spent in each category are shown graphically for each day, and then summarised in a three day graph. Similarly, graphs showing the well-being / ill-being values are given.

Tuesday

Mapping periods: 11.05-11.30, 11.40-15.45, 18.00-19.00

A interacting verbally or otherwise (with no other obvious activity)

When Patricia greeted Gilbert and talked to him he would sometimes reach a well-being level of +3.

B being socially involved, but passively

C being socially uninvolved, withdrawn

Some of the time Gilbert spent in category B may be coded as 'ambiguous B/C', even though no distress was evident. In this case B would be subject to the 30 minute deterioration rule and would 'downgrade' to a C after 30 minutes continuous ambiguous B. This did not happen during any of the mapping periods.

D unattended distress

There were no signs of category D during Tuesday.

E engaging in an expressive or creative activity

Although no category E was recorded during mapping, Gilbert did spend some time singing along to pub songs on tape whilst in the kitchen during a period which wasn't mapped.

F eating, drinking

Some category F was observed as I mapped during lunchtime today.

G **participating in a game**

H **participating in a craft activity**

I **activity prioritising the use of intellectual abilities**

Gilbert did not participate in any activities of this nature during Tuesday.

J **participating in exercise or physical sports**

Patricia made sure that Gilbert had a walk round outside at least twice a day. This was coded as K during mapping, but could also be considered as J, since Patricia was encouraging him to walk to try and prevent him from becoming even more immobile.

K **independent walking, standing or wheelchair-moving**

Although this code is entitled 'independent walking' it has been used to code the time Gilbert spent walking with Patricia and myself holding his hands.

L **performing work or work-like activity**

Gilbert did not perform any work-like activity during Tuesday.

M **engaging with media**

Part of Patricia and Gilbert's daily routine is to pour a drink at 17.55 and settle down to watch the six o'clock news. Gilbert watched a few minutes before dozing off in his chair.

N **sleeping, dozing**

Gilbert spent 44% of the mapping time sleeping. He dozed in the morning, afternoon and evening.

O **independently engaging in self-care**

Gilbert did not engage in any form of self-care during Tuesday.

P **receiving practical, physical or personal care**

Patricia would often perform some form of care for Gilbert during the day.

- R** **participating in a religious activity**
- S** **activity related to explicit sexual expression**
- T** **direct engagement of the senses**
- U** **communicating without receiving a response**
- W** **repetitive self-stimulation**

Gilbert did not engage in any of the above categories during Tuesday.

X episodes related to excretion

One time frame was recorded during mapping. This captured Patricia's gentle way of leading Gilbert to the toilet, usually after a walk.

Y talking to oneself, or an imagined person; hallucination

On two occasions Gilbert was observed to be talking to himself.

Z behaviours that fit no existing category

No extra behaviours were noted on Tuesday.

Wednesday

Mapping periods: 09.55-10.45, 14.10-15.40, 18.30-19.05

**A interacting verbally or otherwise
 (with no other obvious activity)**

No category A was noted during mapping.

B being socially involved, but passively

There were only two time frames of B type behaviour observed. Both were during a period of dozing in the afternoon.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Wednesday.

E engaging in an expressive or creative activity

Gilbert spent a quarter of the mapping time humming and tapping his fingers along to tapes of music. I was on my own with Gilbert for a few hours in the afternoon and played some more lively music than his usual classical, relaxing afternoon music. He did not spend as much time asleep during the afternoon as on the other days when relaxing music was played.

F eating, drinking

Only one time frame of eating/drinking was recorded during mapping. This is because I did not map during meal times today.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Gilbert did not participate in any activities of this nature during Wednesday.

J participating in exercise or physical sports

K independent walking, standing or wheelchair-moving

Although no J or K type behaviour is recorded today Patricia walked Gilbert around a couple of times today, outside of the mapping periods.

L performing work or work-like activity

Gilbert did not perform any work-like activity during Wednesday.

M engaging with media

As usual, Gilbert watched a small amount of the six o'clock news, but this was outside the mapping period.

N sleeping, dozing

Gilbert spent 43% of the mapping time sleeping. He dozed in the morning, afternoon and evening. The cut off period for 'appropriate sleep'

was exceeded and hence his WIB value decreased from +1 to –1 and then to –3.

O independently engaging in self-care

Gilbert did not engage in any form of self-care during Wednesday.

P receiving practical, physical or personal care

Although only one time frame was recorded as P during the mapping periods, in the morning when Patricia shaved Gilbert, he also had his hair cut after lunch by a mobile hairdresser.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

U communicating without receiving a response

W repetitive self-stimulation

Gilbert did not engage in any of the above categories during Wednesday.

X episodes related to excretion

No category X behaviours were observed during mapping.

Y talking to oneself, or an imagined person; hallucination

Gilbert did not talk to himself during Wednesday.

Z behaviours that fit no existing category

No extra behaviours were noted during Wednesday.

Thursday

Mapping periods: 14.00-16.05, 17.15-17.40

**A interacting verbally or otherwise
(with no other obvious activity)**

No category A was noted during mapping.

B being socially involved, but passively

Two time frames of B were noted during mapping.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Thursday.

E engaging in an expressive or creative activity

Gilbert danced briefly with Teresa to a Foster and Allan tape. He was in a high state of well-being.

F eating, drinking

I did not map during mealtimes today.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Gilbert did not participate in any activities of this nature during Thursday. However, Patricia had given me a jigsaw to complete and whilst I was doing this on the kitchen table Gilbert occasionally reached out for pieces to touch.

J participating in exercise or physical sports

K independent walking, standing or wheelchair-moving

Again, although no J type behaviour is recorded today, Gilbert walked round – this time with Teresa. This was recorded as K.

L performing work or work-like activity

Gilbert did not perform any work-like activity during Thursday.

M engaging with media

As usual Gilbert watched a small amount of the six o'clock news, but this was outside the mapping period.

N sleeping, dozing

Gilbert spent 60% of the mapping time asleep. However the shorter mapping periods must be noted. Over the course of the day he didn't doze any more than on the other two days.

O independently engaging in self-care

Gilbert did not engage in any form of self-care during Thursday.

P receiving practical, physical or personal care

Patricia would often perform some form of care for Gilbert during the day, although no time frames are recorded during the mapping period.

R participating in a religious activity

Gilbert did not engage in any religious activity during Thursday.

S activity related to explicit sexual expression

Although no behaviours were coded as S during the mapping period, Teresa was joking with Gilbert about women and bikinis. His eyes lit up and he laughed. She also held his hand under the table and joked in a hushed voice '*what will we do if Patricia sees us?!*' Gilbert responded to her speaking also in a hushed voice.

T direct engagement of the senses

U communicating without receiving a response

W repetitive self-stimulation

Gilbert did not engage in any of the above categories during Thursday.

X episodes related to excretion

No category X behaviours were observed during mapping.

Y talking to oneself, or an imagined person; hallucination

Gilbert did not talk to himself during Thursday.

Z behaviours that fit no existing category

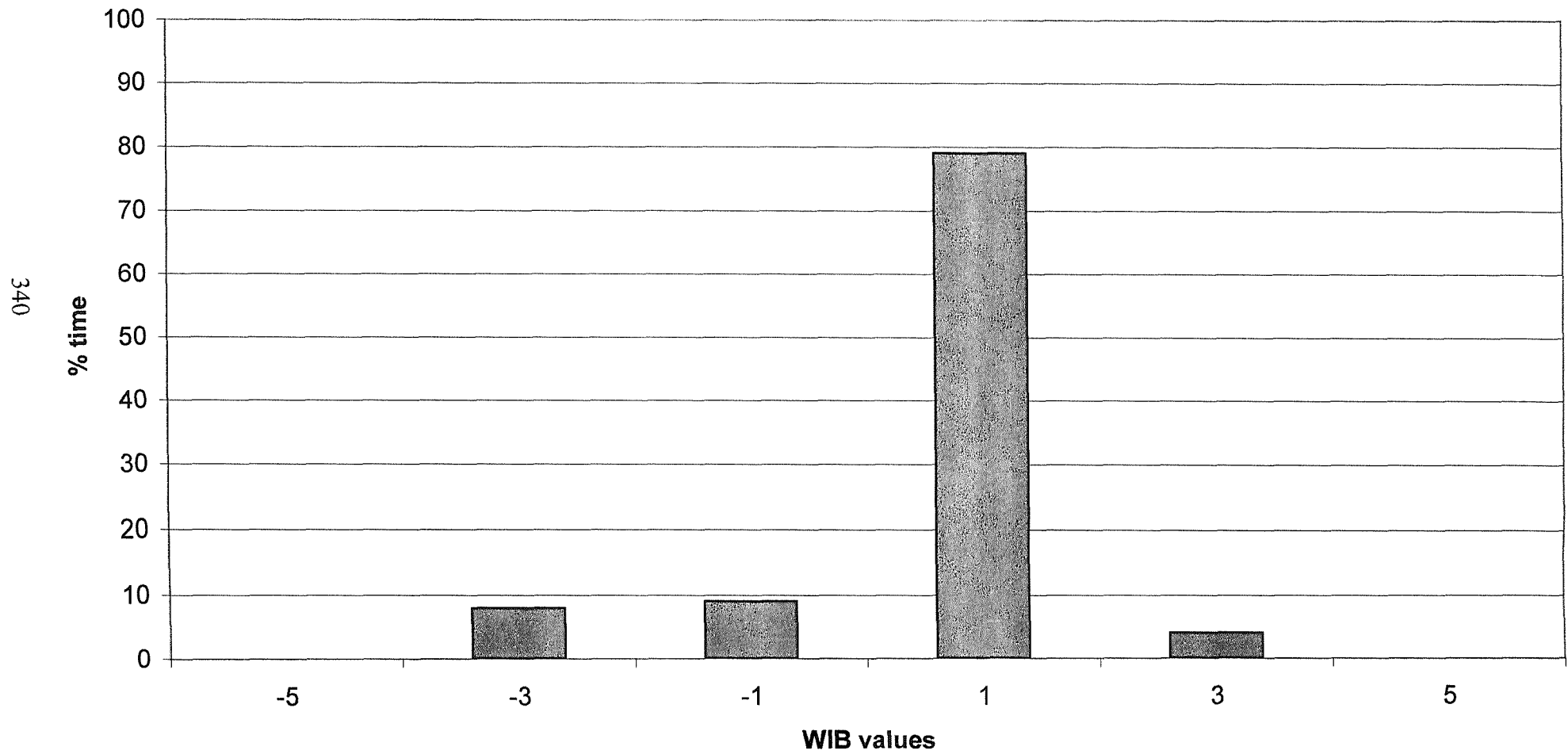
No extra behaviours were noted during Thursday.

WIB values

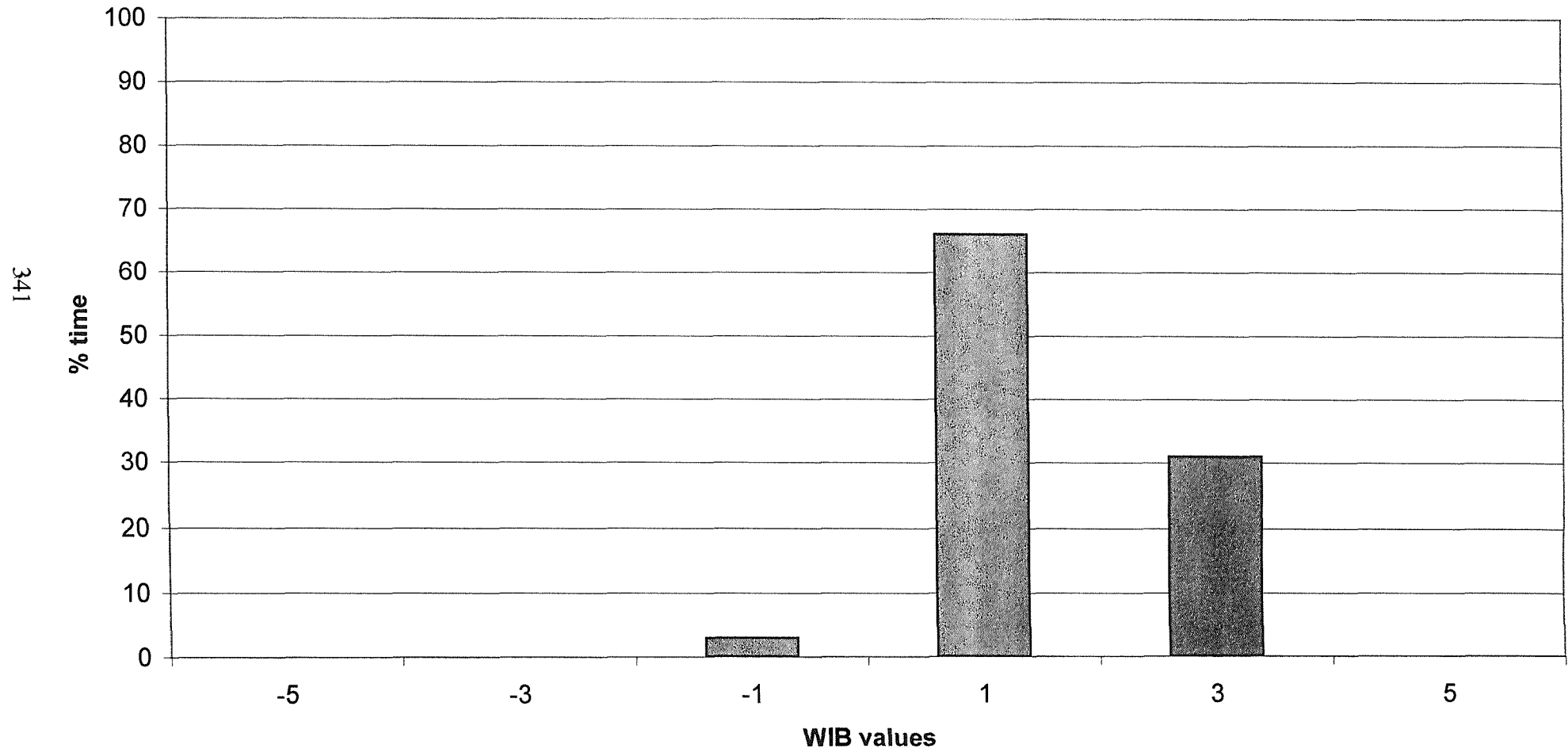
| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|-------|--------|--------|--------|----------|---------|--------|
| Tues | 0 (0) | 5 (8) | 6 (9) | 52 (79) | 3 (4) | 0 (0) |
| Wed | 0 (0) | 0 (0) | 1 (3) | 23 (66) | 11 (31) | 0 (0) |
| Thurs | 0 (0) | 0 (0) | 0 (0) | 26 (90) | 3 (10) | 0 (0) |
| Total | 0 (0) | 5 (4) | 7 (5) | 101 (78) | 17 (13) | 0 (0) |

| | Tuesday | Wednesday | Thursday | 3 days |
|----------------------|---------|-----------|----------|--------|
| Σ WIB scores | +40 | +55 | +35 | +130 |
| Σ time frames | 66 | 35 | 29 | 130 |
| WIB value | +0.6 | +1.6 | +1.2 | +1.0 |

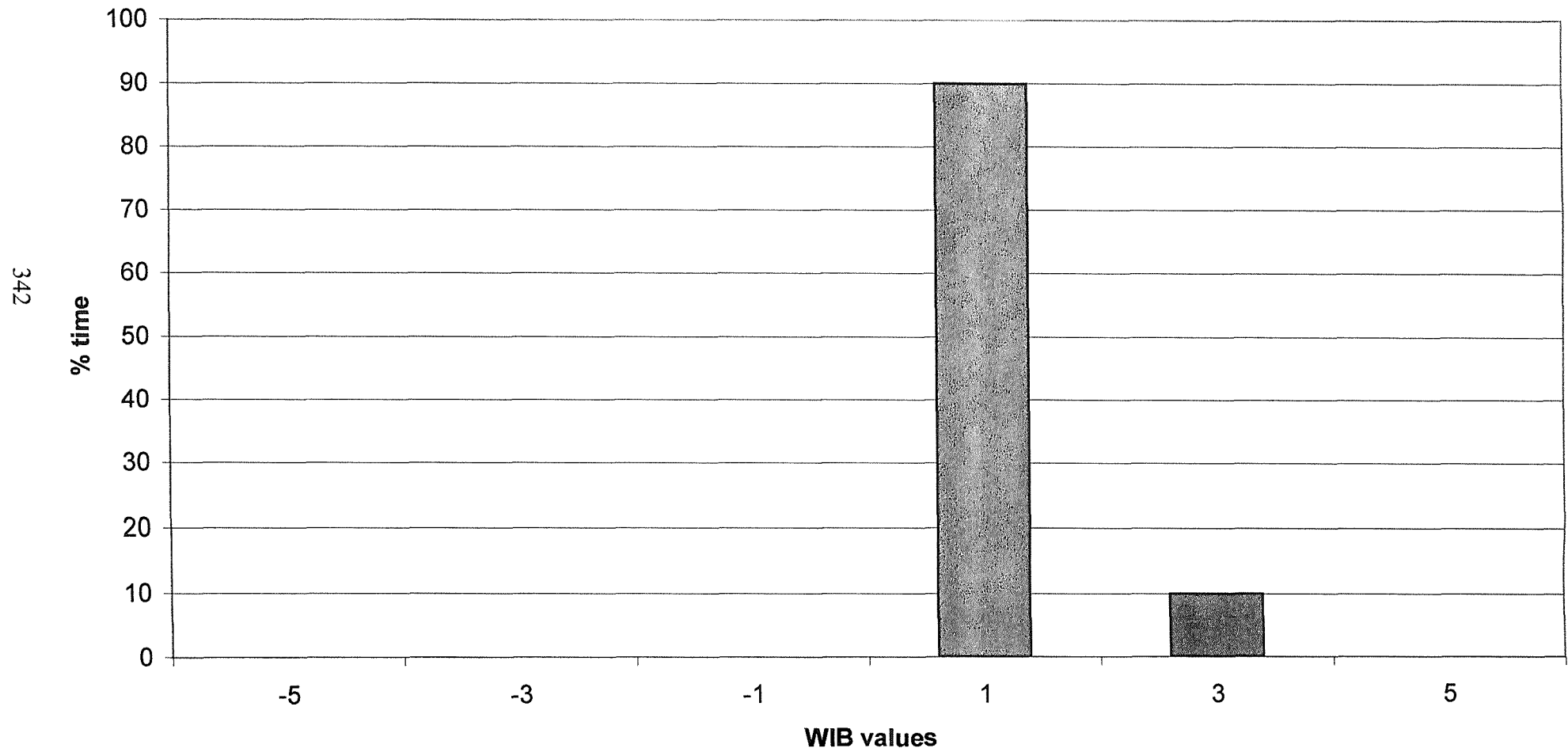
Gilbert
WIB Profile
Tuesday (Visit 2, May 2001)



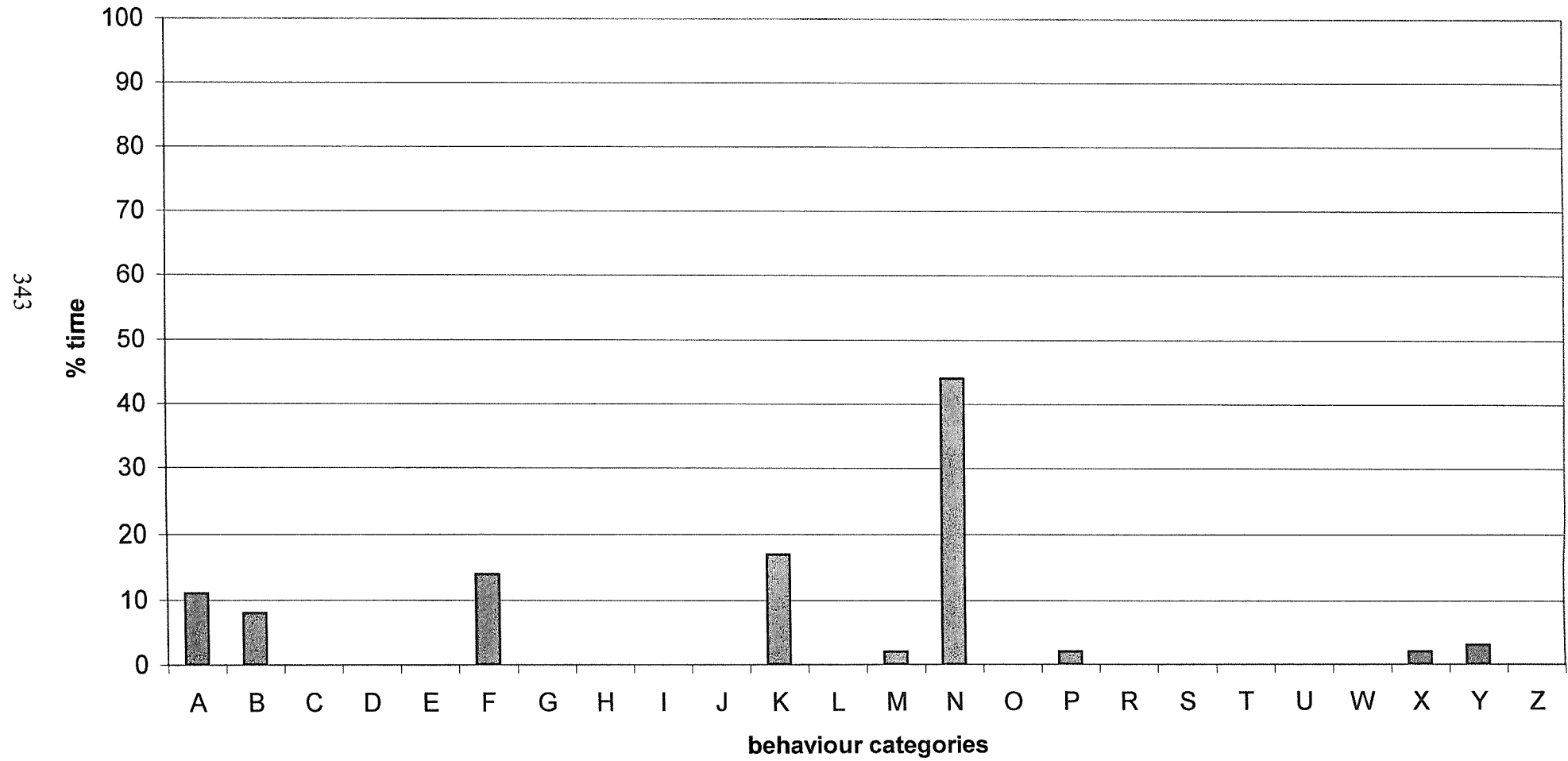
Gilbert
WIB Profile
Wednesday (Visit 2, May 2001)



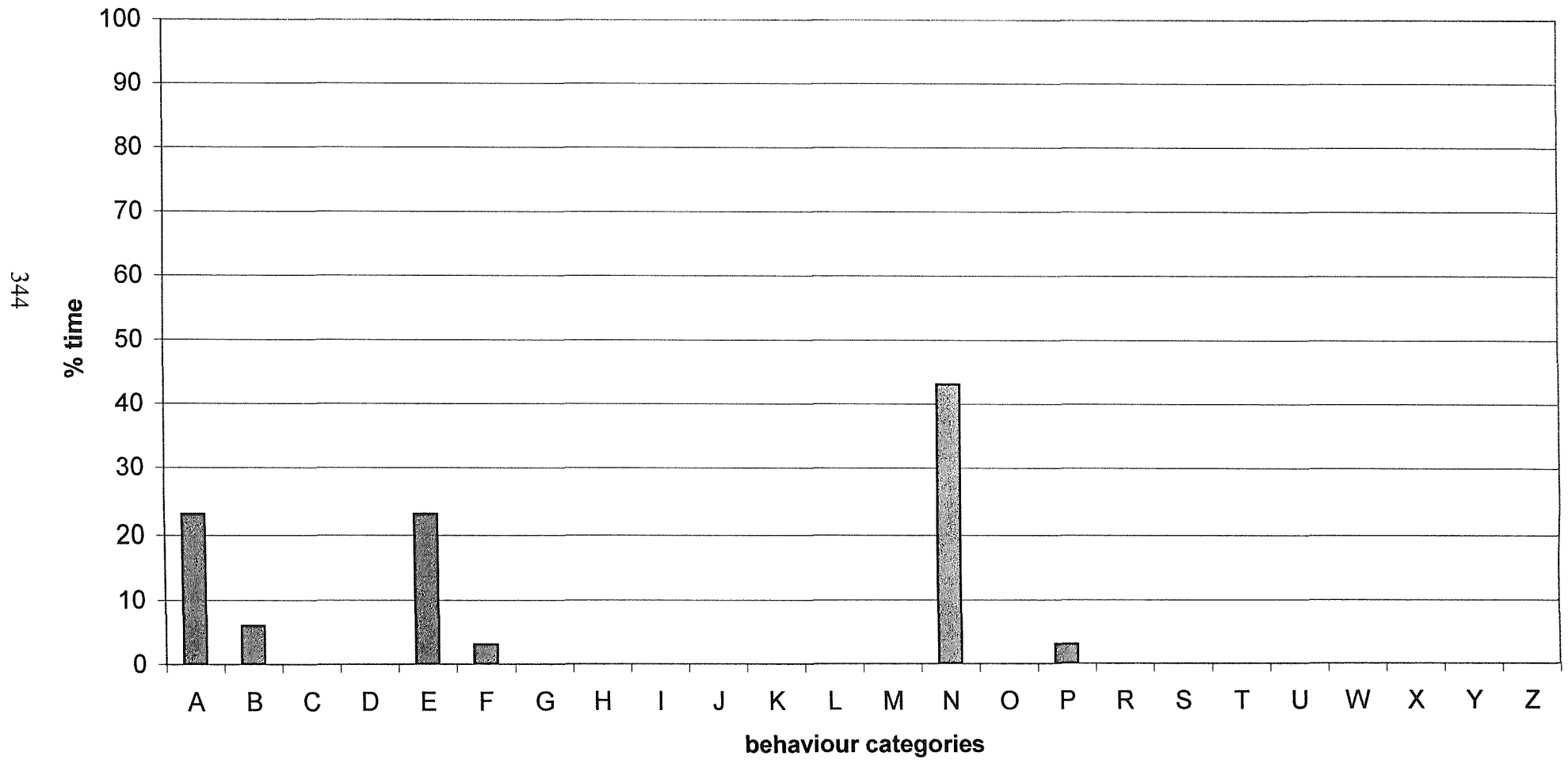
Gilbert
WIB Profile
Thursday (Visit 2, May 2001)



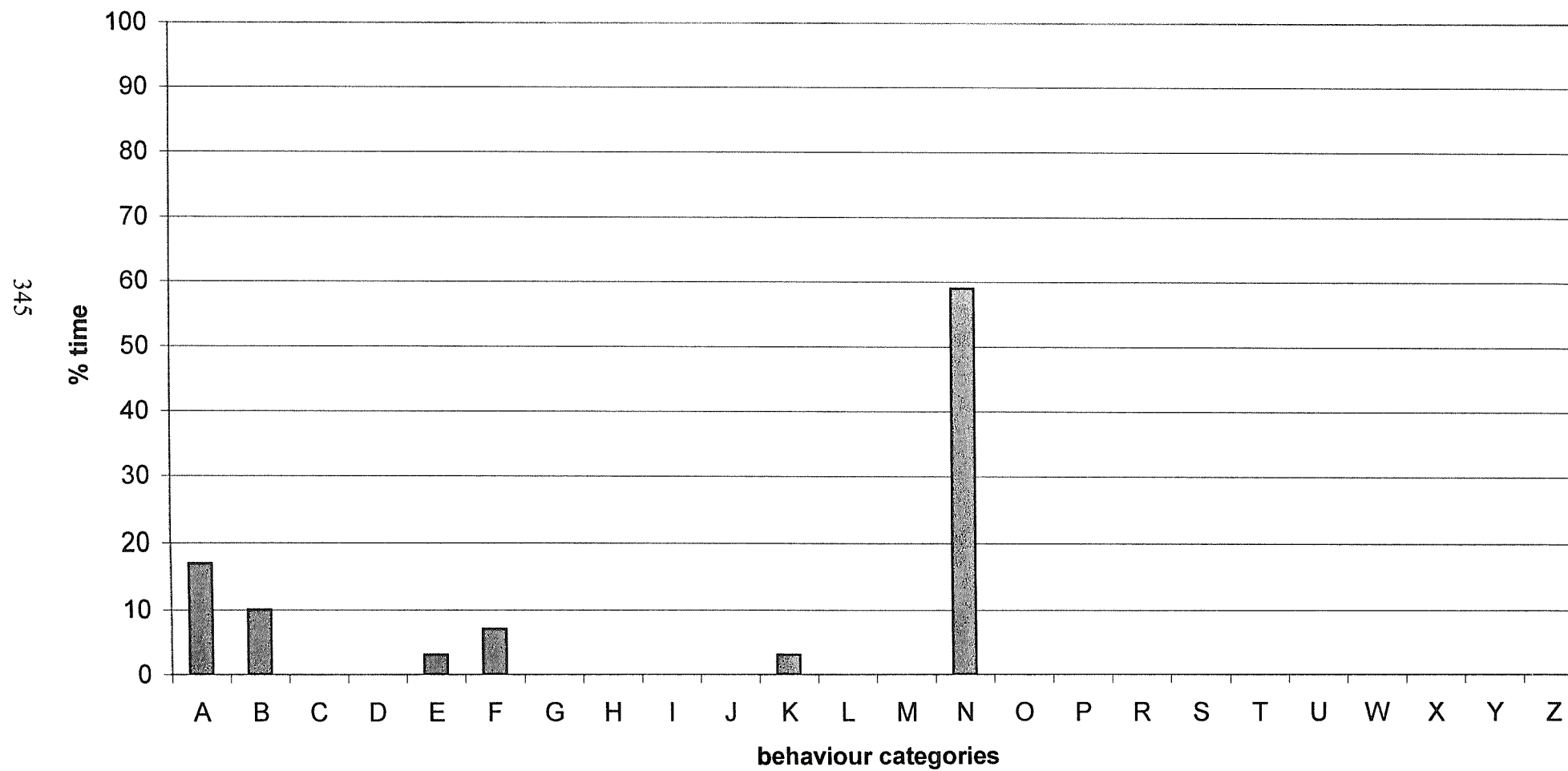
Gilbert
Behaviour Profile
Tuesday (Visit 2, May 2001)



Gilbert
Behaviour Profile
Wednesday (Visit 2, May 2001)



Gilbert
Behaviour Profile
Thursday (Visit 2, May 2001)



Behaviour Category Grid

Gilbert, Visit 2, May 2001

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |
|--------|----|----|---|---|----|----|---|---|---|---|----|---|---|----|---|---|---|---|---|---|---|---|---|---|
| Tue | 7 | 5 | 0 | 0 | 0 | 9 | 0 | 0 | 0 | 0 | 11 | 0 | 1 | 29 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 2 | 0 |
| Tue,% | 11 | 8 | 0 | 0 | 0 | 14 | 0 | 0 | 0 | 0 | 17 | 0 | 2 | 44 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 2 | 3 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Wed | 8 | 2 | 0 | 0 | 8 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 15 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Wed,% | 23 | 6 | 0 | 0 | 23 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 43 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Thur | 5 | 3 | 0 | 0 | 1 | 2 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 17 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Thur,% | 17 | 10 | 0 | 0 | 3 | 7 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 59 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| TOTAL | 20 | 10 | 0 | 0 | 9 | 12 | 0 | 0 | 0 | 0 | 12 | 0 | 1 | 61 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 1 | 2 | 0 |
| % | 15 | 8 | 0 | 0 | 7 | 9 | 0 | 0 | 0 | 0 | 9 | 0 | 1 | 47 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 1 | 2 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |

Elements of Malignant Social Psychology

Outpacing (moderate)

Gilbert's mental and physical difficulties mean that he is much slower than the people he lives with, both in cognition and movement. This disability lead to some episodes of outpacing.

Patricia encourages Gilbert to go for a walk at least twice a day. Since he appears to feel very unsteady on his feet and also has perceptual problems which mean he does not feel safe crossing boundaries such as doors, he can be very slow and at times can cling onto the surrounding structures such as door frames. Patricia finds this frustrating and tends to 'lead' Gilbert along by pulling him, rather than walking by his side.

The whole family, Gilbert, Patricia, their daughter and her husband and three children now eat dinner together in the evening. Such a large family can generate a lot of discussion about the day's events. Gilbert just looks on, as most of the conversation is not directed at him.

Positive Person Work

Recognition

When the grandchildren come round to Patricia and Gilbert's part of the farm for dinner they always come into the lounge to say hello to Gilbert in his chair, and help him through to dinner.

Collaboration

When the grandchildren come and say hello to Gilbert as above, he is often sitting in his chair with a drink and a few crisps. They all ask if he would like a drink and help him to sip it. Similarly they feed him crisps very gently.

Play

Patricia often played tapes which Gilbert would hum along to, or tap his fingers in time to the music. Similarly, Teresa would dance with him on occasions.

Teresa had a good rapport with Gilbert and they would often joke together, with him also talking in a hushed voice if she did. He very much enjoyed time with Teresa.

Carer support for intact abilities

Gilbert's intact abilities were very limited. However where possible, Patricia encouraged him to use these – even at the suggestion of risk by others. For example, Teresa told me that Gilbert was found by one of the workers laughing on his back in one of the fields recently when Patricia had let him walk unaided. I felt Teresa thought that this was very risky.

In addition although Patricia would feed Gilbert at meal times, if he started to help himself she would not interfere, even if he was using his fingers with food usually eaten with utensils, although she may make a comment to me such as *'ah we're using our fingers are we?!'* as if she were slightly embarrassed. Alone, I imagine, she would not mind at all.

Validation of emotion by carer

On the few occasions that Gilbert showed signs of anxiety during my stay, usually while walking through the back door which involved lifting his feet over a step, Patricia was supportive and reassuring. However, she still encouraged him to go through the door, even if he didn't want to, hence also keeping his remaining abilities going.

Patricia also spoke of how frightening and confusing it must be for him when he wakes up in the morning and doesn't know where he is. Like a 'fog' she described it.

Politeness strategies

Despite his very limited speech, after he had burped Gilbert said '*excuse me*'. This would either be viewed as a politeness strategy or as an automatic turn of phrase, still intact.

Similarly, at the dinner table his friend Barry was telling a story which involved doing an impression which sounded like a raspberry. On hearing this Gilbert exclaimed, '*wah, wasn't me!*'

Aspects of selfhood

Gilbert's mobility, speech and other cognitive difficulties necessitate that other member's of his family have to collaborate to help keep some aspects of his self intact. I have never observed (at either visit) Gilbert doing any kind of work in the household. Ann told me at the first visit that he used to be a brilliant engineer and hence did a lot of the household repairs and maintenance type chores. His mobility and cognitive problems prevent him from keeping this aspect of his self alive. However, he is still treated by the rest of the family as 'head of the family' and sits at the head of the table for dinner.

During the first morning of my stay, Gilbert walked with Patricia and myself round the outside of their house to where the swimming pool and vegetable patches were. When we returned Patricia went in to prepare the lunch and gave Gilbert his stick so he could walk round unaided with me. However, I held onto his hand as we walked slowly around the yard. At one point he stopped opposite their large French windows which led to

the dinning room. The curtains were drawn and I could see our figures reflected in the glass. Gilbert also appeared to notice this, and lifted our hands, watching them reflected in the window, as if to check if it was a reflection. He stood there for some time looking at our reflected selves as a young child would early in development.

Perception and social death

One evening while Gilbert was sleeping I asked Patricia if she thought he was ever frustrated. She replied that she didn't as he had always been a good natured person. However she knew that he became anxious in different environments, and also said that sometimes when he wakes up in the morning he doesn't know where he is. She said that it must be very frightening and confusing '*like being in a fog*' all the time, as she termed it. This very much reminded me of Tom Kitwood's passages (p. 77, 1997) where he attempts to describe what it may be like to have dementia, in which he also uses the metaphor of a fog.

She then spoke of how she is writing Gilbert's story so that his grandchildren that do not remember what he was like before his illness can read about the kind of man he was earlier in his life. She said that writing this story had made her feel sad because it made her realise what a great mind he had before the illness took over. She gave me the story as written so far to read.

The Bristol Activities of Daily Living (BADLS)

Scores:

| | |
|-----------------------------|----|
| Completed by Patricia Woody | 52 |
| Completed by Alison Carr | 50 |

**The Behaviour Rating Scale for Psychological and Social Problems
(BPS)**

| | cognition/ | | mood | | social contact | | total |
|-------|------------|----------------|------|-------|----------------|----------------|--------|
| Woody | 39/44 | very severe | 1/28 | light | 15/20 | very severe | 67/140 |
| Carr | 37/44 | very severe | 1/28 | light | 9/20 | moderate | 61/140 |

Visit 3, October 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

When Gilbert is out in his wheelchair he will say 'aw – oh shucks!' if he is taken over a bump and finds this uncomfortable. Similarly if he is being lifted with the hoist and finds this uncomfortable he will say 'shucks!' and Patricia will slow the process down.

Initiating social contact

Whilst I was sitting with Gilbert in the morning he looked at my newspaper and exclaimed 'look at that chap!'. In the car on the way back from Bluewater he pointed out where he has lunch sometimes to Patricia.

Warmth and affection

Gilbert smiles a lot when Patricia is talking to him, or when she returns and he sees her. Similarly when friends greet him.

Self Respect

Gilbert yawned whilst I sat with him during his afternoon sleep and he said 'oh excuse me!'

Being helpful

When being lifted or moved Gilbert would always try to help by moving his hands or legs where indicated.

Humour

Gilbert is a good natured person, and has always been according to his family. During my visit he would laugh from time to time, for example when congarating to bed with Patricia and Polly.

Bodily relaxation

When helped into his reclining chair Gilbert shows clear signs of bodily relaxation and is able to sleep in this position.

Creative self-expression

Gilbert enjoys Foster and Allen tapes and will tap his fingers or hum along to the tunes.

Showing pleasure or enjoyment

Gilbert clearly shows pleasure on meeting / greeting familiar faces. His pleasure comes from interactions with others, whether social or being helped with physical care.

Responding appropriately to others

Gilbert would say 'hello' when others said 'hello' to him.

Expressing appropriate emotions

Gilbert expresses his delight at seeing his relatives and friends, and also shows his discomfort 'oh shucks!' when going over a bump in the road in his wheelchair.

Holding his own socially

Whist I was reading the newspaper Gilbert made some comments to me about it's content, for example, 'look at that chap!' referring to a forlorn Gerry Francis who had just been sacked from Birmingham city.

Alertness

Gilbert spends some time dozing throughout the day, for example at the Alzheimer's society lunch. He remains alert when stimulated, for example when I chatted to him at the lunch.

Being active

Gilbert's mobility had deteriorated since my last visit, six months ago. However since Patricia has bought the adapted car which takes his

wheelchair in the back (he is still in it and strapped in so he can see out of the roof window) he has resumed some of the activities, such as lunches out, that he had been missing.

Being purposeful

Gilbert did not show signs for this category during my stay, he tends to take the lead from others.

Indicators of ill-being

Depression or despair

Gilbert did not show any signs for this category during my stay.

Intense anger

Gilbert did not show any signs for this category during my stay.

Grief

Gilbert did not show any signs for this category during my stay.

Anxiety

Gilbert shows some signs of anxiety when being moved in his wheelchair over bumps 'oh shucks!' or when being lifted in the hoist.

Fear

Gilbert did not show any signs for this category during my stay.

Boredom

Gilbert can fall asleep if not stimulated, and this could be interpreted as a sign of boredom.

Physical discomfort / pain

Gilbert did not show any signs for this category during my stay.

Bodily tension

When being moved over bumps or up ramps or steps in his wheelchair, or being lifted in the hoist, Gilbert clings on tightly showing the whites of his knuckles.

Agitation

Gilbert did not show any signs for this category during my stay.

Apathy and withdrawal

Gilbert did not show any signs for this category during my stay.

Distress

Gilbert did not show any signs for this category during my stay.

Cultural isolation

At both the Alzheimer's society lunch and at family mealtimes, although Gilbert is present, the pace of talking is quite fast and not always directed at him, so he looks on ahead, slightly excluded.

Difficulty withstanding powerful others

Gilbert did not show any signs for this category during my stay.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 3 |
|---|---------|
| Making wishes known (non-destructively) | 1 |
| Initiating social contact | 1 |
| Warmth and affection | 2 |
| Self-respect | 1 |
| Being helpful | 1 |
| Humour | 1 |
| Bodily relaxation | 2 |
| Creative self-expression | 1 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 1 |
| Alertness, responsiveness | 1 |
| Being active | 0 |
| Being purposeful | 0 |
| Score | 15 |

TOTAL = 15/30

III-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 3 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 0 |
| Bodily tension | 1 |
| Agitation | 0 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Score | 4 |

TOTAL = 4/26

Dementia Care Mapping (DCM)

Approximately 12 hours of DCM were carried out over the three days (4 hours, 6.5 hours and 1.5 hours respectively). Behaviour profiles showing the proportion of time spent in each category are shown graphically for each day, and then summarised in a three day graph. Similarly, graphs showing the well-being / ill-being values are given.

Monday

Mapping periods: 15.05-17.05, 20.50-22.40

A interacting verbally or otherwise (with no other obvious activity)

During his usual afternoon sleep he woke and Patricia said '*hello*', he replied '*hello*'.

B being socially involved, but passively

There was only one recorded B during the mapping. This occurred when Gilbert woke from his afternoon sleep, looked around and then returned to sleep.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Monday

E engaging in an expressive or creative activity

Although there were no recorded E categories, on the way to bed Polly, Patricia and Gilbert did the conga!

F eating, drinking

Category 'F' was observed whilst Gilbert was drinking a cup of tea in the afternoon.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Gilbert did not participate in any activities of this nature during Monday.

J participating in exercise or physical sports

The only time Gilbert stretched his legs was when he was helped to the toilet and to bed.

K independent walking, standing or wheelchair-moving

Gilbert is no-longer able to walk or stand independently.

L performing work or work-like activity

Gilbert did not carry out any work like activity during Monday.

M engaging with media

Gilbert watched some television during the evening, whilst dozing in between viewing.

N sleeping, dozing

Gilbert slept during the afternoon for an hour and a half ('appropriate' sleep limits one and a half hours). He also dozed in the evening, but since this was after the cut off time of being up for over ten hours (after 7pm), this was not subject to the degradation rule.

O independently engaging in self-care

Gilbert did not engage in any form of self-care during Monday.

P receiving practical, physical or personal care

Episodes of physical care were observed during the mapping period, and occasionally lifted Gilbert's well-being levels from +1 to +3, for example the 'conga' to bed.

- R** participating in a religious activity
- S** activity related to explicit sexual expression
- T** direct engagement of the senses
- U** communicating without receiving a response
- W** repetitive self-stimulation

Gilbert did not engage in any of the above categories during Monday.

X episodes related to excretion

Gilbert was helped to the toilet by Patricia on one occasion during the mapping period.

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

Gilbert did not engage in any of the above categories during Monday.

Tuesday

Mapping periods: 09.25-09.40, 13.40-18.10, 21.00-22.35

**A interacting verbally or otherwise
(with no other obvious activity)**

One A was recorded during a mapping period, and this referred to an interaction between Gilbert and Sally as she left after dinner and said goodbye to him.

B being socially involved, but passively

During the afternoon Gilbert spent some time in 'B' whilst sitting in his chair before his afternoon sleep. Also in the evening between nine and ten Gilbert spent much time in 'B' whilst sitting in his chair, before watching the news.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Tuesday.

E engaging in an expressive or creative activity

There were no signs of category E during Tuesday.

F eating, drinking

Category F was recorded during a mapping period as Gilbert was finishing his breakfast.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Gilbert did not engage in the above categories during Tuesday.

J participating in exercise or physical sports

Before we went out for lunch Patricia helped Gilbert to walk slowly round the tree outside the house, to help stretch his legs.

K independent walking, standing or wheelchair-moving

Gilbert is no-longer able to walk or stand independently.

L performing work or work-like activity

Gilbert did not carry out any work like activity during Tuesday.

M engaging with media

Gilbert watched 'Porridge' in the evening during a mapping period.

N sleeping, dozing

Gilbert spent nearly 60% of the total mapping time asleep today. This was from when we returned from lunch until before dinner, and hence degrades into WIB values of -1, -3 and finally -5. I also noticed that he would have slept during some of the lunch when no-one was talking to him, but I chatted to him and he stayed awake.

O independently engaging in self-care

Gilbert did not engage in any form of self-care during Tuesday.

P receiving practical, physical or personal care

A couple of instances of physical care occurred during the mapping periods. Again one of these raised his well-being level from +1 to +3, because of the interaction.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

Gilbert did not engage in any of the above categories during Tuesday.

U communicating without receiving a response

During the mapping period between nine and ten in the evening Gilbert twice tried to interact with others but nobody responded.

W repetitive self-stimulation

Gilbert did not engage in any form of self-stimulation today.

X episodes related to excretion

No episodes of this kind took place during a mapping period.

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

Gilbert did not engage in any of the above categories during Tuesday.

Wednesday

Mapping periods: 10.15-10.45, 14.35-15.35

**A interacting verbally or otherwise
(with no other obvious activity)**

Gilbert had a period of interaction with the carer, Roz, during the morning.

B being socially involved, but passively

Gilbert spent some time in a state of B when waking up from his afternoon sleep.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Wednesday.

E engaging in an expressive or creative activity

Although no 'E's were noted during a mapping period, Gilbert did spend some time listening to Foster and Allan tapes in the morning.

F eating, drinking

No mapping period took place during eating or drinking episodes.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Gilbert did not engage in the above categories during Wednesday.

J participating in exercise or physical sports

Gilbert did not have any exercise during the time I was with him on Wednesday.

K independent walking, standing or wheelchair-moving

Gilbert is no-longer able to walk or stand independently.

L performing work or work-like activity

Gilbert did not carry out any work like activity during Wednesday.

M engaging with media

Gilbert did not engage with the media during the time I was with him on Wednesday, but he tends to do this in the evening, and I left after tea in the afternoon.

N sleeping, dozing

Gilbert spent some time sleeping in the afternoon after lunch.

O independently engaging in self-care

Gilbert did not engage in any form of self-care during Tuesday.

P receiving practical, physical or personal care

The one episode of physical care noted during a mapping period was carried out by Roz and raised Gilbert's well-being from +1 to +3.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

U communicating without receiving a response

W repetitive self-stimulation

Gilbert did not engage in the above categories during Wednesday.

X episodes related to excretion

No episodes were noted during the mapping periods.

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

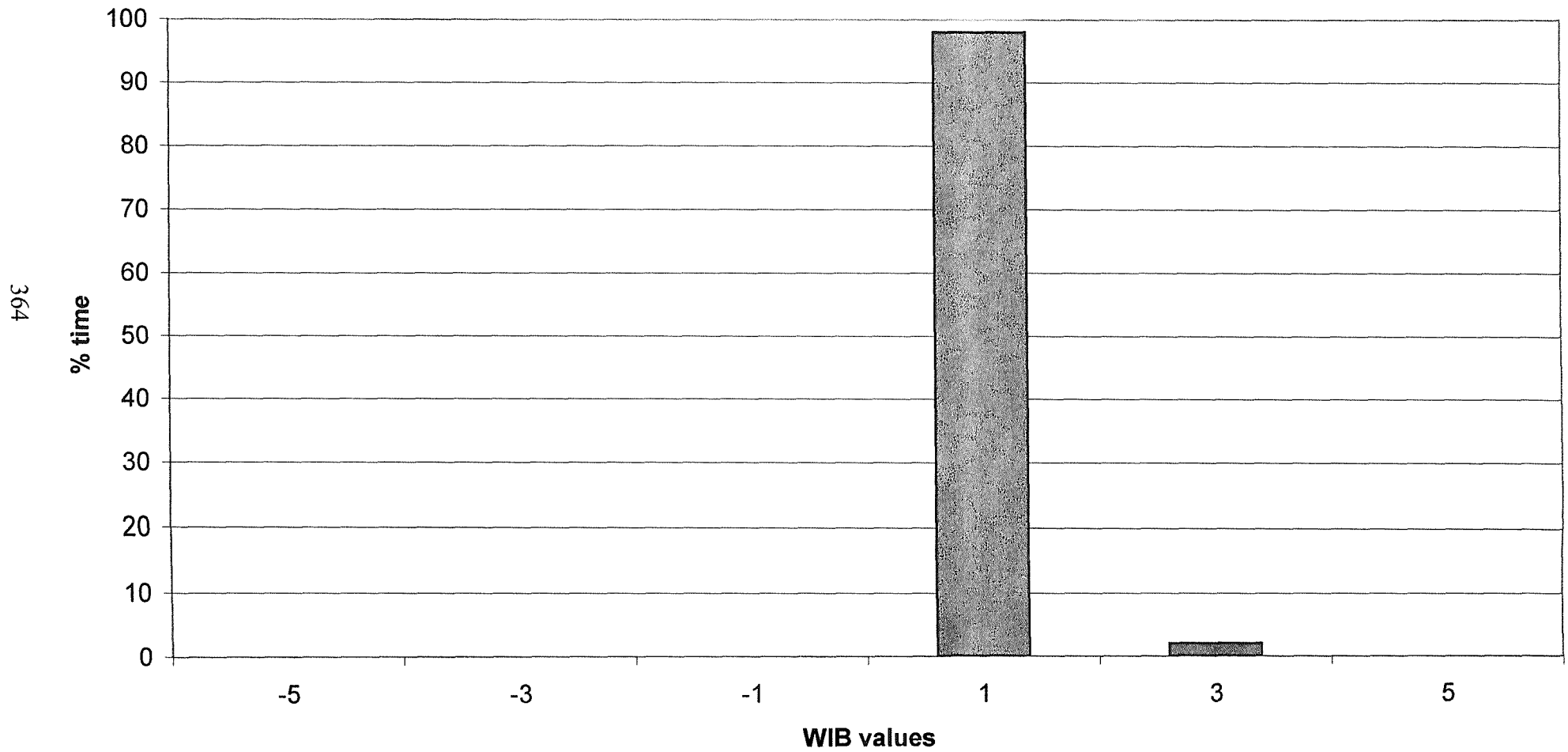
Gilbert did not engage in the above categories during Wednesday.

WIB values

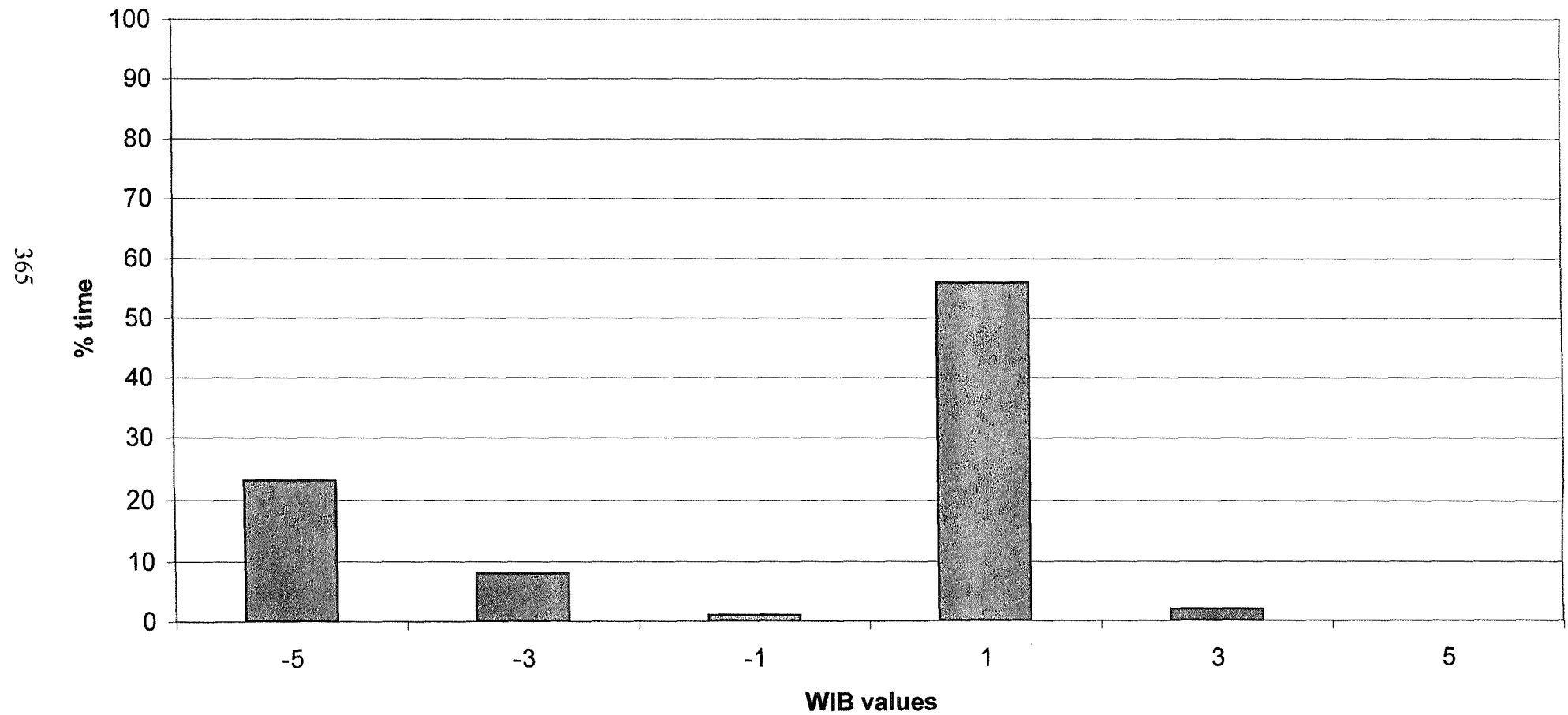
| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|-------|---------|--------|--------|----------|--------|--------|
| Mon | 0 (0) | 0 (0) | 0 (0) | 40 (98) | 1 (2) | 0 (0) |
| Tues | 18 (23) | 6 (8) | 8 (10) | 43 (56) | 2 (2) | 0 (0) |
| Wed | 0 (0) | 0 (0) | 0 (0) | 17 (85) | 3 (15) | 0 (0) |
| Total | 18 (13) | 6 (4) | 8 (6) | 100 (72) | 6 (4) | 0 (0) |

| | Monday | Tuesday | Wednesday | 3 days |
|---------------|--------|---------|-----------|--------|
| Σ WIB scores | +43 | -67 | +26 | -8 |
| Σ time frames | 41 | 77 | 20 | 138 |
| WIB value | +1.0 | -0.9 | +1.3 | 0.0 |

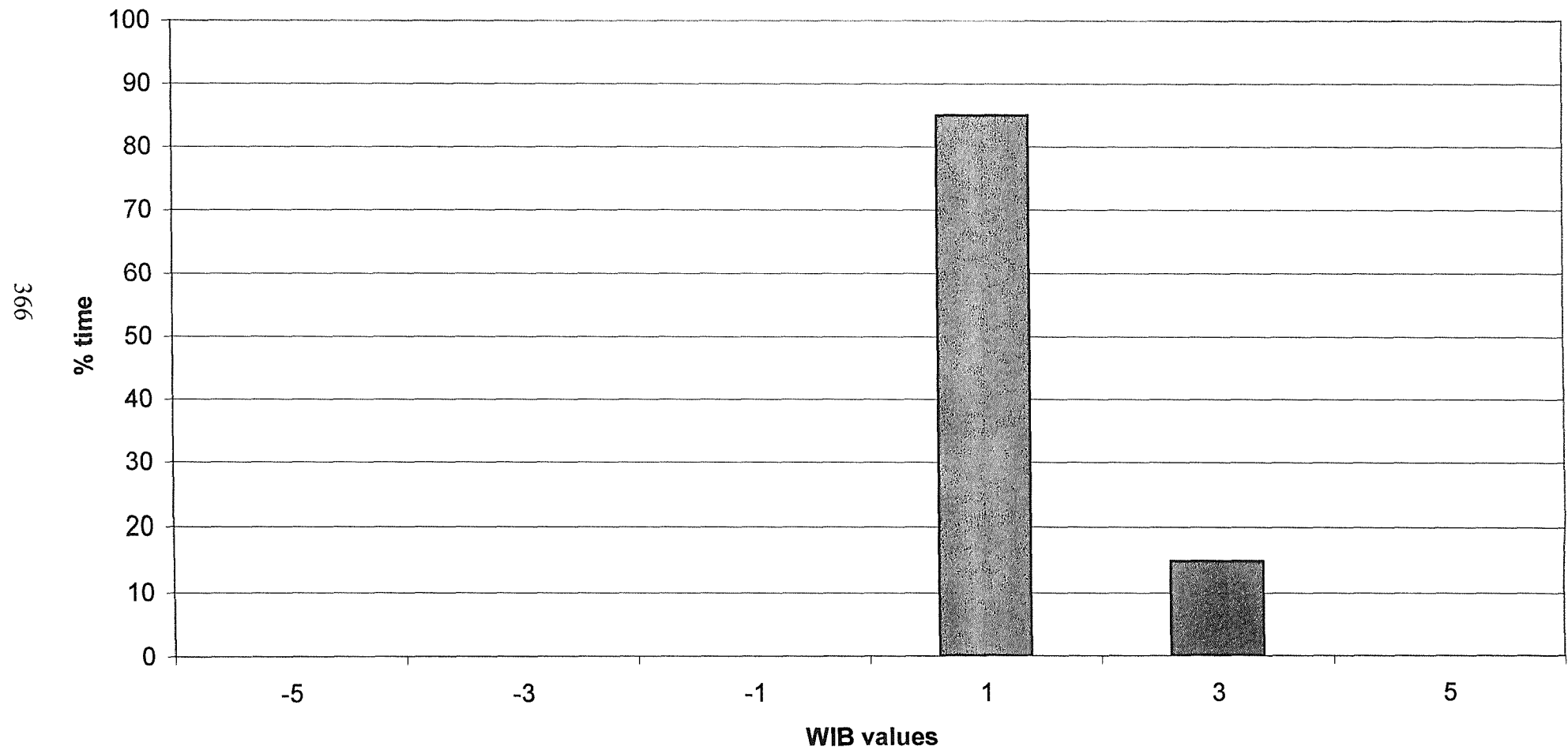
Gilbert
WIB Profile
Monday (Visit 3, Oct 2001)



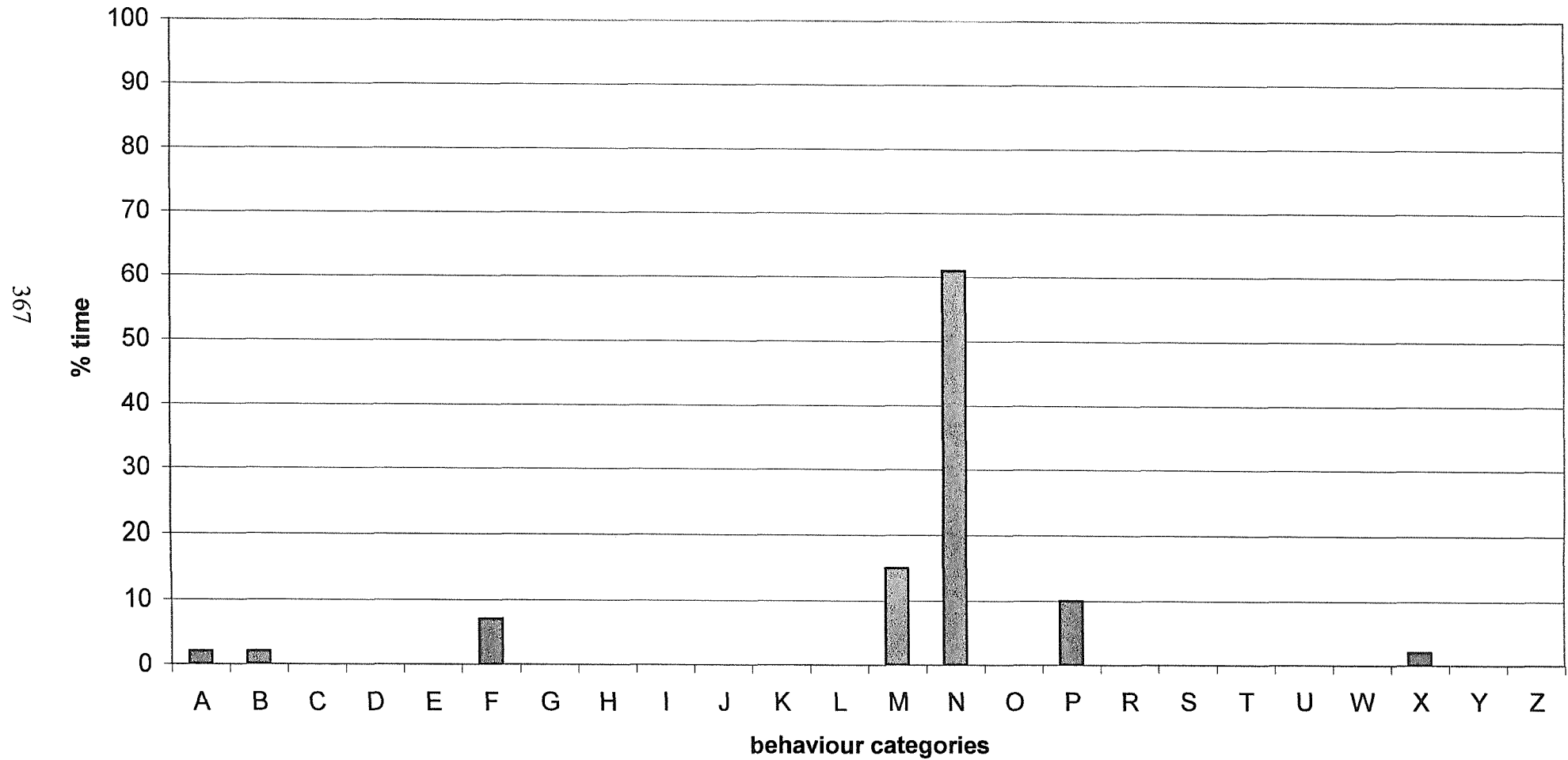
Gilbert
WIB Profile
Tuesday (Visit 3, Oct 2001)



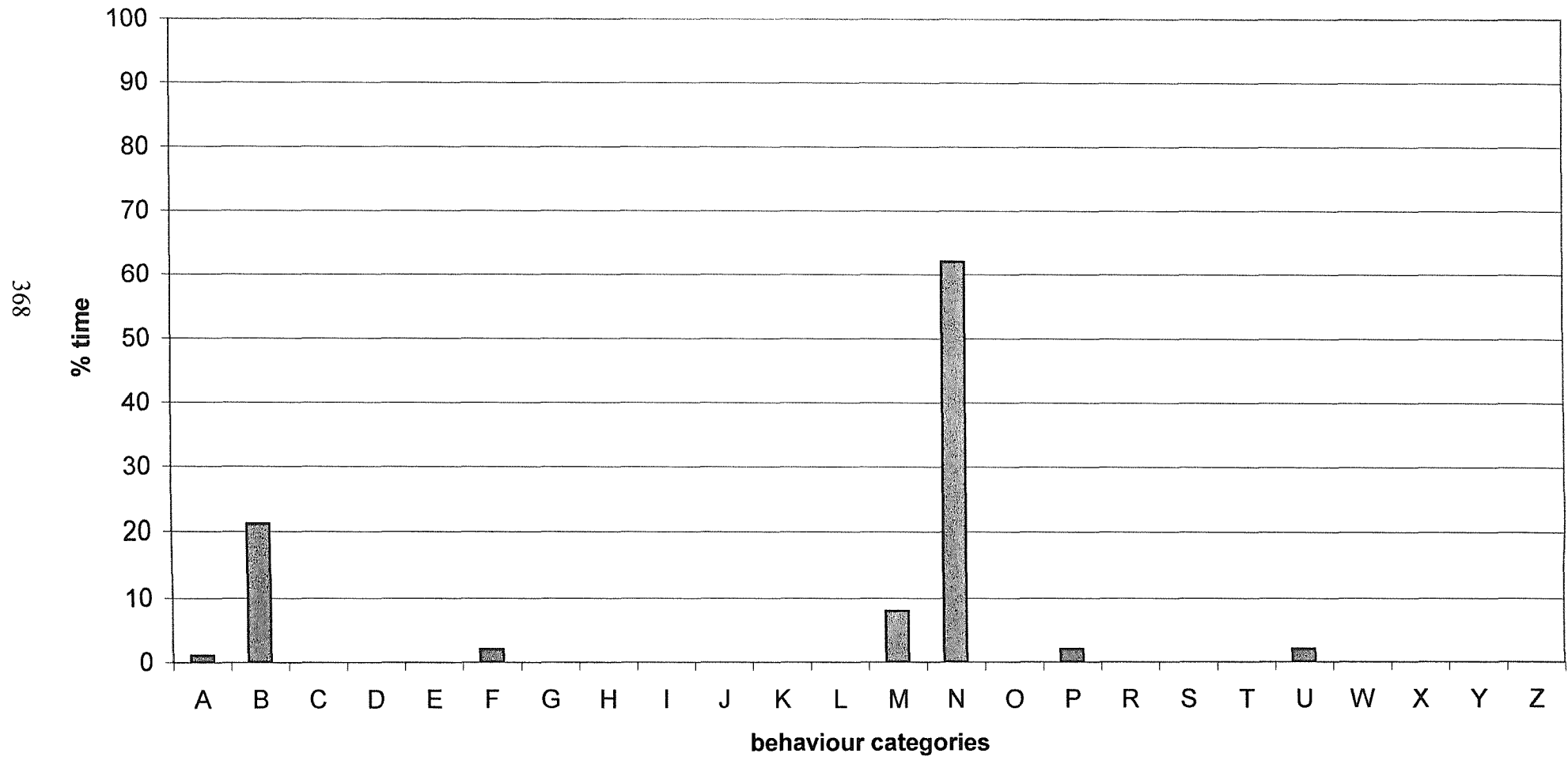
Gilbert
WIB Profile
Wednesday (Visit 3, Oct 2001)



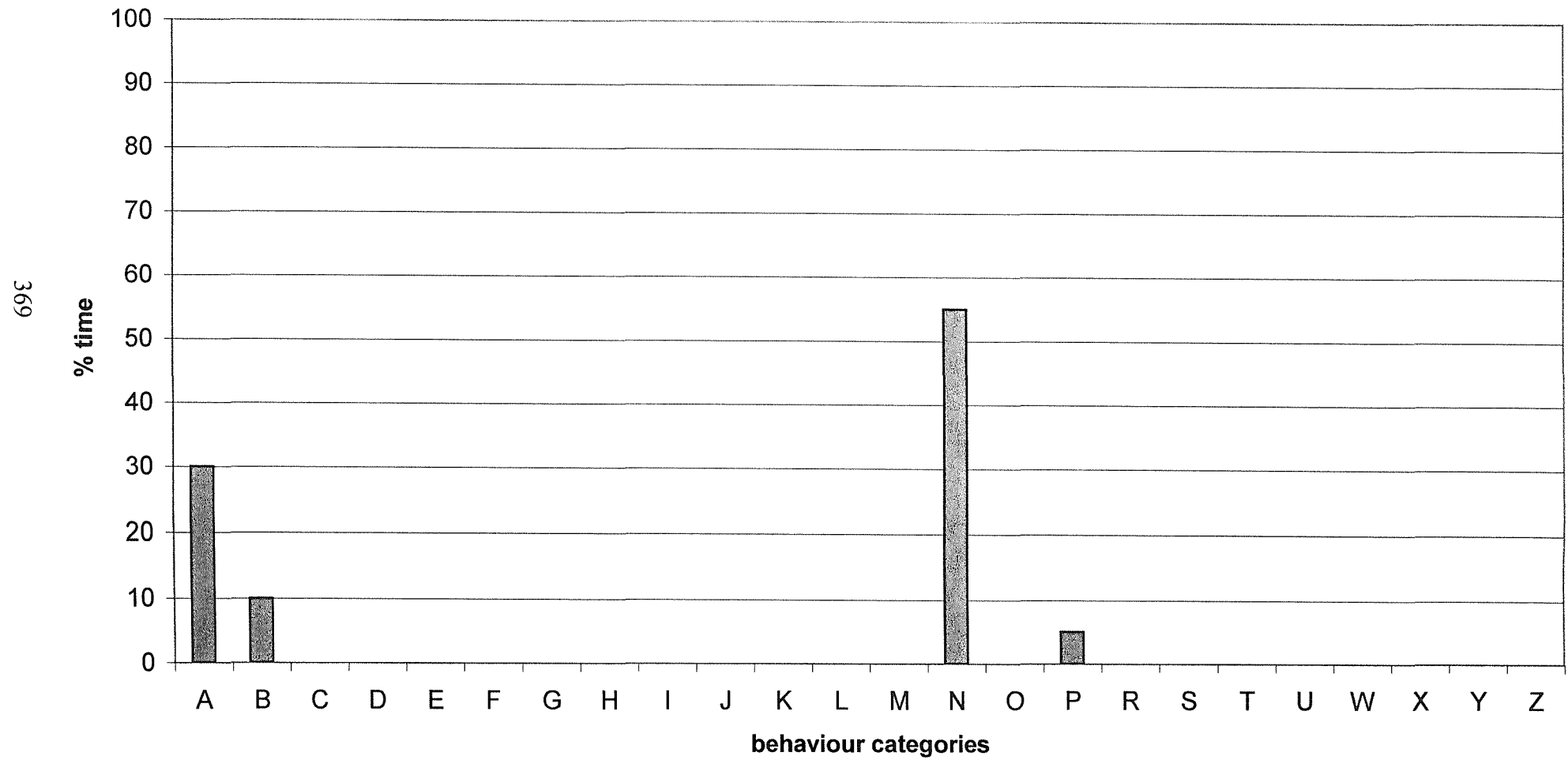
Gilbert
Behaviour Profile
Monday (Visit 3, Oct 2001)



Gilbert
Behaviour Profile
Tuesday (Visit 3, Oct 2001)



Gilbert
Behaviour Profile
Wednesday (Visit 3, Oct 2001)



Behaviour Category Grid

Gilbert, Visit 3, Oct 2001

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |
|-------|----|----|---|---|---|---|---|---|---|---|---|---|----|----|---|----|---|---|---|---|---|---|---|---|
| Mon | 1 | 1 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 6 | 25 | 0 | 4 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 |
| Mon,% | 2 | 2 | 0 | 0 | 0 | 7 | 0 | 0 | 0 | 0 | 0 | 0 | 15 | 61 | 0 | 10 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Tue | 1 | 16 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 6 | 48 | 0 | 2 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 |
| Tue,% | 1 | 21 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 8 | 62 | 0 | 2 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Wed | 6 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 11 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Wed,% | 30 | 10 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 55 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| TOTAL | 8 | 19 | 0 | 0 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 12 | 84 | 0 | 7 | 0 | 0 | 0 | 2 | 0 | 1 | 0 | 0 |
| % | 6 | 14 | 0 | 0 | 0 | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 9 | 61 | 0 | 5 | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |

Elements of Malignant Social Psychology

Objectification (moderate)

When the grandchildren came round to Gilbert and Patricia's for dinner they went in and said hello to Gilbert. His granddaughter moved him to the table without telling him where she was taking him or why. However when she had got him to the table she put an apron on him and talked him through the process.

Outpacing (mild)

When Polly came round to help her mother to get Gilbert ready for bed he was asleep in the chair. They washed his face and brushed his teeth, and he was partially awake, but then they operated the chair lift and he seemed rather unsteady on his feet. I felt he hadn't been given enough time to 'come to'.

Ignoring (mild)

At the dinner table there are usually many people present and everyone exchanges experiences from their day. Gilbert is present but I felt that the talk was going on around him rather than being directed to him for the most part. However he seems content to be part of the group. This also occurred at the Alzheimer's society lunch. Gilbert was the only person with dementia present and the carers use this time to exchange stories and experiences. I felt Gilbert was left out of the conversation. However, Patricia left me with Gilbert and probably enjoyed some time to chat with her friends. This may be one of the limitations of the observation method, in that the carer may usually act differently and stay with their relative with dementia, but because the observer is present use this opportunity for some freedom. This is most understandable.

Mockery (severe)

At the dinner table Gilbert said something which did not make sense and his granddaughter replied 'yes' and then muttered under her breath '*I haven't heard that one before*', I could hear her say this and I was the same distance away from her as Gilbert was.

Positive Person Work**Recognition**

On arriving for dinner each relative would greet Gilbert.

Play

When helping Gilbert through the hall to bed Patricia and Polly danced the conga with him!

Facilitation

Patricia's ingenuity and perseverance in finding a converted van and wheelchair have enabled Gilbert to regain some of his previous activities.

Caregiver support for intact abilities

Gilbert's intact abilities are now very limited, but where possible Patricia helps him to use them. For example, when feeding him she will place food in a spoon and then steadies his hand together with hers in lifting it to his mouth. Gilbert is still able to walk a little, but not unaided. He is a very large gentleman and could easily fall. However, Patricia does try to get him to walk with her from time to time so as to give his legs a little exercise. It would be much easier for her to use the hoist all the time (and perhaps less risky).

Validation of emotion by caregiver

Patricia is happy when Gilbert greets her joyfully, and when he shows signs of anxiety at being moved she reassures him.

Politeness strategies

When Gilbert and I were together in the lounge one afternoon he had been asleep and shortly after he had woken up he yawned and exclaimed *'oh excuse me!'*

Aspects of selfhood

At the last visit Gilbert's declining mobility meant that he was not able to go out and about as he used to. This was obviously part of his 'self' which had suffered. However, ingenious as ever Patricia had purchased a wheelchair and a van which took the wheelchair, with Gilbert in it, in the back. This enabled him to rejoin some of his activities such as the Alzheimer's society lunch and shopping with Patricia in Bluewater. I felt this had enabled an important part of his self to be maintained.

Perception and social death

Polly talked to me about her father and how his personality seems to have remained the same throughout his illness. She felt that this was because he has vascular dementia. When discussing how he is still very much part of the family gatherings Polly replied that she didn't know *'how much of it he takes in, if anything'*. The element of uncertainty was there, a suggestion that he *might*.

The Bristol Activities of Daily Living (BADLS)

Scores:

Completed by Patricia Woody 52

Completed by Alison Carr 53

The Behaviour Rating Scale for Psychological and Social Problems (BPS)

| | cognition/ | | mood | | social contact | | total |
|-------|------------|-------------|------|-------|----------------|--------|--------|
| Woody | 40/44 | very severe | 1/28 | light | 12/20 | severe | 71/140 |
| Carr | 32/44 | severe | 0/28 | none | 12/20 | Severe | 53/140 |

Visit 4, May 2002

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Following a fall from his wheelchair, Kate has advised Patricia to try to manoeuvre him backwards over ramps and bumps. I think Patricia had been wheeling him forwards so as to allow him to see where he was going. However, whilst he was wheeled backwards over some difficult steps into Tom's house he became anxious, exclaiming '*shucks!*'

Initiating social contact

On Saturday when I was wheeling Gilbert around the May Fair he noticed an old friend and shouted '*wah wah!*' showing he recognised him, and was clearly happy to see his friend.

Warmth and affection

Gilbert returns affection when people greet him, and shows his pleasure in meeting people he recognises.

Self Respect

Gilbert did not show any signs for this category during my stay.

Being helpful

Gilbert did not show any signs for this category during my stay.

Humour

Gilbert did not show any signs for this category during my stay.

Bodily relaxation

Gilbert shows clear signs of bodily relaxation in his favourite chair where he sleeps in the afternoon.

Creative self-expression

Gilbert did not show any signs for this category during my stay.

Showing pleasure or enjoyment

Gilbert showed clear signs of pleasure on Patricia returning from the shops, and also on recognising an old friend when at the May fair.

Responding appropriately to others

Gilbert responds by showing joy at being greeted by his family and friends.

Expressing appropriate emotions

Gilbert is able to show joy when pleased to see someone, and also anxiety when he feels unsafe when being manoeuvred in his wheelchair. He also cried on two occasions during the morning whilst sitting with Kate, but it was not clear why.

Holding his own socially

Gilbert did not show any signs for this category during my stay.

Alertness

Gilbert has a tendency to doze off a large proportion of the time.

Being active

Gilbert is not very mobile, and cannot walk without support from at least two others. He was helped to walk round a tree outside the back door.

Being purposeful

Gilbert clearly shouted out 'wah wah!' when spotting an old friend whilst I was taking him round the fair in his chair.

Indicators of ill-being

Depression or despair

Gilbert appeared weepy twice briefly one morning during my visit when in the presence of Kate, the carer.

Intense anger

Gilbert did not show any signs for this category during my stay.

Grief

Gilbert did not show any signs for this category during my stay.

Anxiety

Gilbert looked very anxious when being manoeuvred backwards in his wheelchair.

Fear

Gilbert did not show any signs for this category during my stay.

Boredom

Gilbert did not show any signs for this category during my stay.

Physical discomfort / pain

Gilbert did not show any signs for this category during my stay.

Bodily tension

Gilbert shows signs of tension when being moved backwards in his wheelchair.

Agitation

Gilbert did not show any signs for this category during my stay.

Apathy and withdrawal

Gilbert did not show any signs for this category during my stay.

Distress

Gilbert did not show any signs for this category during my stay.

Cultural isolation

Gilbert's increased mobility problems make for difficulties in physically getting him into some houses. Although his family's houses have ramps, some of the neighbours do not and so he was physically excluded from the household.

Difficulty withstanding powerful others

Gilbert did not show any signs for this category during my stay.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 4 |
|---|---------|
| Making wishes known (non-destructively) | 1 |
| Initiating social contact | 1 |
| Warmth and affection | 1 |
| Self-respect | 0 |
| Being helpful | 0 |
| Humour | 0 |
| Bodily relaxation | 1 |
| Creative self-expression | 0 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 0 |
| Alertness, responsiveness | 1 |
| Being active | 0 |
| Being purposeful | 1 |
| Score | 9 |

TOTAL = 9/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 4 |
|---|---------|
| Depression or despair | 1 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 0 |
| Physical discomfort / pain | 0 |
| Bodily tension | 1 |
| Agitation | 0 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Score | 4 |

TOTAL =4 /26

Dementia Care Mapping (DCM)

Approximately two hours of DCM were carried out during the visit. This was a two day visit (as we both had many other events in May, for example Patricia had relatives visiting from Australia). The mapping was carried out on the first day of the visit only.

Friday

Mapping periods: 14.30-16.40, 17.55-18.30

A interacting verbally or otherwise (with no other obvious activity)

Although only one period of A was noted during the mapping Gilbert spends some time in the company of people interacting. For example the new carer, Kate, *'can talk the hind legs off an elephant!'* according to Patricia. She also felt that this chatting can wear Gilbert out, as he usually sleeps well after Kate has been round.

B being socially involved, but passively

As before, Gilbert spends a lot of his time dozing on and off throughout the day. This dozing is in dispersed with periods of B.

C being socially uninvolved, withdrawn

D unattended distress

E engaging in an expressive or creative activity

None of the above categories were observed during mapping.

F eating, drinking

Gilbert ate some hula-hoops and was helped with his drink during the six o'clock news,

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

J participating in exercise or physical sports

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

None of the above categories were observed during mapping.

M engaging with media

Gilbert spent some of the mapping time watching the news on television.

N sleeping, dozing

Gilbert spent the largest proportion of his time during mapping asleep. He slept for almost two hours in the afternoon, so the final period of sleep was subject to the degradation rule and his well-being fell to -1. He also dozed on and off during the morning whilst I was not mapping.

O independently engaging in self-care

Gilbert did not engage in self care during the visit.

P receiving practical, physical or personal care

No periods of physical care were noted during mapping, but on a number of occasions Patricia or Kate helped Gilbert in a physical way.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

U communicating without receiving a response

W repetitive self-stimulation

X episodes related to excretion

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

None of the above categories were observed during mapping.

WIB values

| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|--------|--------|--------|--------|---------|--------|--------|
| Friday | 0 (0) | 0 (0) | 5 (14) | 30 (86) | 0 (0) | 0 (0) |

| | |
|----------------------|--------|
| | Friday |
| Σ WIB scores | +25 |
| Σ time frames | 35 |
| WIB value | +0.8 |

Gilbert, Visit 4, May 2002

[illegible]

Elements of Malignant Social Psychology

Imposition (moderate)

The dilemma over securing Gilbert into his wheelchair could fit into this category. Patricia prefers to wheel him in a forwards direction and not to strap him into the chair. However a fall from his chair when Patricia was wheeling him down a small incline outside the house lead the carer to recommend that she wheels the chair backwards and straps him in. Gilbert clearly does not like being manoeuvred backwards and shows his concern '*wah wah!*'. This could be seen as an element of imposition.

Banishment (moderate)

Gilbert's increased mobility problems make for difficulties in physically getting him into some houses. Although his family's houses have ramps, some of the neighbours do not and so he was physically excluded from the household.

Positive Person Work

Holding and validation

Gilbert cried twice in Kate's presence and both times she comforted him and cuddled him. Here she was validating his sad mood and accepting it – rather than trying to 'jolly him along'. She also provided a safe psychological space where he could show his emotions freely.

Recognition and validation

On entering the room Patricia would always greet Gilbert '*hello darling!*' On one occasion she entered the room after receiving a call from her neighbour to say that a fellow neighbour had died. Patricia told Gilbert the sad news in an adult and un-patronising way, making the assumption that

he could understand, and would want to know this news. In other words treating him as a person still.

Carer support for intact abilities

Gilbert's increasing mobility problems have lead to a dilemma for Patricia. She used to wheel him around in a forward position so he could see where he was going. However, he had fallen out of the chair whilst going down a slope near to the house so Kate, one of the carers, had advised her to travel backwards, and to strap Gilbert into the chair. This made Gilbert anxious but safer.

He is no longer able to feed himself, except for finger foods, and Patricia made sure he had some hula-hoops beside his evening drink.

Validation of emotion by carer

When Gilbert appeared weepy on a couple of occasions the carer, Kate, comforted him. When moving Gilbert Patricia is aware that he may become anxious and so talks him through what she is doing, for example, *'I'm going to shut the door now'* when getting him in his chair into the back of the converted car.

Politeness strategies

Gilbert is no longer able to lift a glass or cup to drink by himself. He and Patricia always have a drink at 17.55. I gave him a sip of his drink and he said *'thank you'*.

Aspects of selfhood

Gilbert is still included in the family gatherings even though having lunch at his son Tom's means a difficult manoeuvring of his wheel chair through the French windows (it took three of us). However when Patricia and I were out with Gilbert in his wheelchair delivering invitations to the Golden Jubilee do he had to remain outside as access to some houses was very difficult. I stayed with him but wonder what Patricia would have done if I hadn't have been there. Gilbert seems content to be out and about in his chair.

Perception and social death

The episode described earlier, in which Patricia tells Gilbert about their neighbour's death speaks volumes about her perception of what it may be like to have dementia. In telling him the news she treated him as an adult who would both understand and want to know the information. He did not show any emotion on hearing the news, but this is evidence to support the view that Patricia feels Gilbert is still a person and should still be treated the same way, despite his communication difficulties.

The Bristol Activities of Daily Living (BADLS)

Scores:

| | |
|-----------------------------|----|
| Completed by Patricia Woody | 55 |
| Completed by Alison Carr | 54 |

**The Behaviour Rating Scale for Psychological and Social Problems
(BPS)**

| | cognition/ | | mood | | social contact | | total |
|-------|------------|----------------|------|-------|----------------|--------|--------|
| Woody | 36/44 | very severe | 1/28 | light | 14/20 | severe | 62/140 |
| Carr | 37/44 | Very severe | 0/28 | none | 15/20 | severe | 69/140 |

Appendix six

Mr and Mrs Dudley

Visit 1, September 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Having very limited speech, Neil had to rely on other forms of communication to express his wishes. Claire told me that he would always reply 'yes' regardless of what the questions was. She saw this as a '*mental shortcut so he didn't have to make a decision*', and said that it had proved difficult when he was in hospital as the junior house doctor would ask '*does it hurt here? And here?*' and Neil would reply 'yes' each time. *He had all the diseases in the book!* she said.

Initiating social contact

Again due to his lack of speech I did not observe Neil initiating contact verbally. However I did notice one occasion where he initiated social contact by eye contact during my stay.

Warmth and affection

Albeit very occasionally, Neil would smile warmly when greeted by people he knew. For example at the residential home when he was greeted by the owner he beamed widely.

Self Respect

I had initially noted that Neil wiped crumbs off his chair and had wondered if this was a sign of self respect. However I later observed him wiping or cleaning up crumbs from his plate or chair in a very repetitive, almost

‘stuck in a groove’ way. This is a good example of how longer observations allows for more clarity in interpretation of behaviour.

Being helpful

Neil was always helpful when Claire was carrying out care. Their teamwork was impressive. She would allow him to do what he could by gentle prompting and assistance and he would always do what she suggested.

Humour

I did not observe any signs of humour from Neil during my stay.

Bodily relaxation

Although he spent a lot of time in his chair due to his mobility problems, Neil always seemed relaxed in posture.

Creative self-expression

Neil joined in with a painting and drawing session at Homemead, cutting out shapes very carefully, despite not being able to apply a lot of pressure to the scissors with his hand.

Showing pleasure or enjoyment

Neil showed obvious signs of pleasure on occasion, for example when greeted by people. During the England vs Albania match he cheered both times when England scored.

Responding appropriately to others

In terms of helping Claire to assist in care activities Neil could be said to be responding appropriately. He also replied ‘cheers’ when I raised my glass of wine and said ‘cheers’ on the second evening.

Expressing appropriate emotions

Neil expressed few emotions but did smile on greeting others, and as above, showed joy when England scored goals.

Holding his own socially

Neil did not initiate social contact but when prompted to take part in a game of dominoes he did compete, but often required prompting, for example when taking turns and where to place the domino – although he could spot which domino should be put down.

Alertness

Despite his quietness Neil remained alert during activities, such as watching television and playing games at the day centres.

Being active

Neil could be said to be active in as much as he would carry out tasks and activities but needed prompting.

Being purposeful

Neil did not show any signs for this category during my stay.

Indicators of ill-being

Depression or despair

Neil did not show any signs for this category during my stay.

Intense anger

Neil did not show any signs for this category during my stay.

Grief

Neil did not show any signs for this category during my stay.

Anxiety

Neil did not show any signs for this category during my stay.

Fear

Neil did not show any signs for this category during my stay.

Boredom

Neil did not show any signs for this category during my stay.

Physical discomfort / pain

Neil did not show any signs for this category during my stay.

Bodily tension

Neil did not show any signs for this category during my stay.

Agitation

Neil did not show any signs for this category during my stay.

Apathy and withdrawal

I felt it difficult to decide if a score of one should be placed under this category or under boredom. The event which I noted was when Neil was at the day centre and present during a quiz. Due to his lack of speech he was not questioned during the activity and sat quietly, not making much eye contact.

Distress

Neil did not show any signs for this category during my stay.

Cultural isolation

Due to Neil being younger than most of the day centre and residential home clients, and having reached a high standard of achievement in his career I felt he was to some extent isolated. This had been made worse by his diminishing speech since, according to a carer at the residential home, he used to be able to talk about his work.

Difficulty withstanding powerful others

Neil did not show any signs for this category during my stay.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 1 |
|------------------------------------|---------|
| Making wishes known | 0 |
| Initiating social contact | 1 |
| Warmth and affection | 1 |
| Self-respect | 0 |
| Being helpful | 2 |
| Humour | 0 |
| Bodily relaxation | 1 |
| Creative self-expression | 1 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 0 |
| Alertness, responsiveness | 1 |
| Being active | 1 |
| Being purposeful | 0 |
| Total | 11 |

TOTAL = 11/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 1 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 0 |
| Fear | 0 |
| Boredom | 0 |
| Physical discomfort / pain | 0 |
| Bodily tension | 0 |
| Agitation | 0 |
| Apathy and withdrawal | 1 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Total | 2 |

TOTAL = 2/26

Dementia Care Mapping (DCM)

Approximately 14 hours of DCM were carried out over the three days (7 hours, 4.5 hours and 3 hours respectively). Behaviour profiles showing

the proportion of time spent in each category are shown graphically for each day, and then summarised in a three day graph. Similarly, graphs showing the well-being / ill-being values are given.

Wednesday

Mapping periods: 08.45-09.35, 11.00-11.30, 12.20-13.35, 14.00-14.40, 15.00-15.30, 16.45-18.20, 20.00-21.50

A interacting verbally or otherwise (with no other obvious activity)

Only one period of A was noted during mapping. However, Neil has very limited speech and this seems to discourage some of the day centre carers from talking to him for longer periods than to ask him a question.

B being socially involved, but passively

When Neil was sitting in a chair he would usually be involved in either reading the paper or watching the television. However there were a few periods of passive sitting noted during the mapping time.

C being socially uninvolved, withdrawn

There were no signs of category C during Wednesday.

D unattended distress

There were no signs of category D during Wednesday.

E engaging in an expressive or creative activity

Neil would occasionally join in with a song on the tape and hence two periods of E have been observed during mapping. These were often accompanied by a +3 WIB state.

F eating, drinking

Approximately 15% of the mapping time was spent either eating or drinking.

G participating in a game

Neil was involved in a game of beetle drive in the afternoon at the day centre. There were some +3 WIB moments during this activity.

H participating in a craft activity

Before lunch Neil joined in with a painting / drawing and cutting out activity at the day centre.

I activity prioritising the use of intellectual abilities

No observations of category I were noted on Wednesday. Neil would read the paper on other days but had to get ready for the day centre today.

J participating in exercise or physical sports

Neil took part in the gentle physical exercises at the day centre.

K independent walking, standing or wheelchair-moving

No observations of category K were noted today. Neil usually requires assistance with mobility.

L performing work or work-like activity

One period of L was observed today when Neil was brushing crumbs from his seat. However it must be noted that this could also be categorised as W as the action was quite repetitive.

M engaging with media

Almost half of the mapping time was spent in category M, with Neil watching the television when he came home from the day centre while Claire prepared the evening meal and then later to watch the England vs Albania game.

N sleeping, dozing

Neil spent a short period of time dozing before lunch at the day centre. He did not sleep during the day outside the mapping times.

O independently engaging in self-care

A couple of periods of self care were noted when Neil shaved and brushed his teeth with some prompting from Claire.

P receiving practical, physical or personal care

A couple of periods of care were noted during mapping, however Neil requires help with personal care, such as toileting.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

U communicating without receiving a response

W repetitive self-stimulation

Neil did not engage in any of the above categories during Wednesday.

X episodes related to excretion

One episode of toileting was noted during mapping at the day centre.

Y talking to oneself, or an imagined person; hallucination

Neil did not engage in category Y during Wednesday.

Z behaviours that fit no existing category

No extra behaviours were noted on Wednesday.

Thursday

Mapping periods: 08.50-10.35, 13.30-14.30, 16.30-17.30, 20.00-21.00

**A interacting verbally or otherwise
(with no other obvious activity)**

No category A was noted during mapping.

B being socially involved, but passively

Neil was in his own home today and spent almost 20% of the mapping time in a state of B. This was either before a nap or before watching television.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Thursday.

E engaging in an expressive or creative activity

Neil sung on one occasion in the morning. He also sung along to some of the theme tunes on television today, but these have been coded as M because the singing was brief, however it did lift his well-being to +3 during these episodes.

F eating, drinking

Just over 10% of the mapping time was spent eating or drinking today.

G participating in a game

H participating in a craft activity

Neil did not engage in category G or H today.

I activity prioritising the use of intellectual abilities

Neil spent about 30 minutes reading the newspaper in the morning.

J participating in exercise or physical sports

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

Neil did not engage in categories J K or L today.

M engaging with media

About 35% of the mapping time was spent watching television.

N sleeping, dozing

Neil had a nap after lunch today for about 35 minutes.

O independently engaging in self-care

No periods of own care were noted during mapping but Neil does shave and brush his own teeth with prompting from Claire.

P receiving practical, physical or personal care

Approximately 10% of the mapping time today was spent with Neil receiving personal care, for example dressing.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

U communicating without receiving a response

None of the above categories were noted today.

W repetitive self-stimulation

Although there was no category W noted during mapping Neil did engage in repetitive wiping of a small section of the table and brushing away crumbs at other times today.

X episodes related to excretion

Y talking to oneself, or an imagined person; hallucination

None of the above categories were noted during mapping.

Z behaviours that fit no existing category

No extra behaviours were noted during Thursday.

Friday

Mapping periods: 08.50-09.55, 10.20-10.50, 13.45-15.30,

A interacting verbally or otherwise (with no other obvious activity)

One period of category A was noted during mapping.

B being socially involved, but passively

Neil spent a few periods in category B during mapping.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Friday.

E engaging in an expressive or creative activity

No episodes of E were noted today.

F eating, drinking

Just over 20% of the total mapping time was spent eating or drinking.

G participating in a game

Neil played dominoes during the afternoon at the residential home, amounting to 25% of the total mapping time.

H participating in a craft activity

I activity prioritising the use of intellectual abilities

J participating in exercise or physical sports

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

None of the above activities were noted today.

M engaging with media

After lunch at the residential home Neil spent a short time looking at a magazine.

N sleeping, dozing

After looking at the magazine Neil had a short nap.

O independently engaging in self-care

Neil was observed brushing his teeth and shaving with prompting from Claire during the mapping period today.

P receiving practical, physical or personal care

Just over 10% of the total mapping time was spent with personal care.

R participating in a religious activity**S activity related to explicit sexual expression****T direct engagement of the senses****U communicating without receiving a response**

Neil did not engage in any of the above categories during Friday.

W repetitive self-stimulation

There was one period of W noted at the residential home when Neil was repetitively wiping his plate after lunch.

X episodes related to excretion**Y talking to oneself, or an imagined person; hallucination**

No periods of X or Y were noted.

Z behaviours that fit no existing category

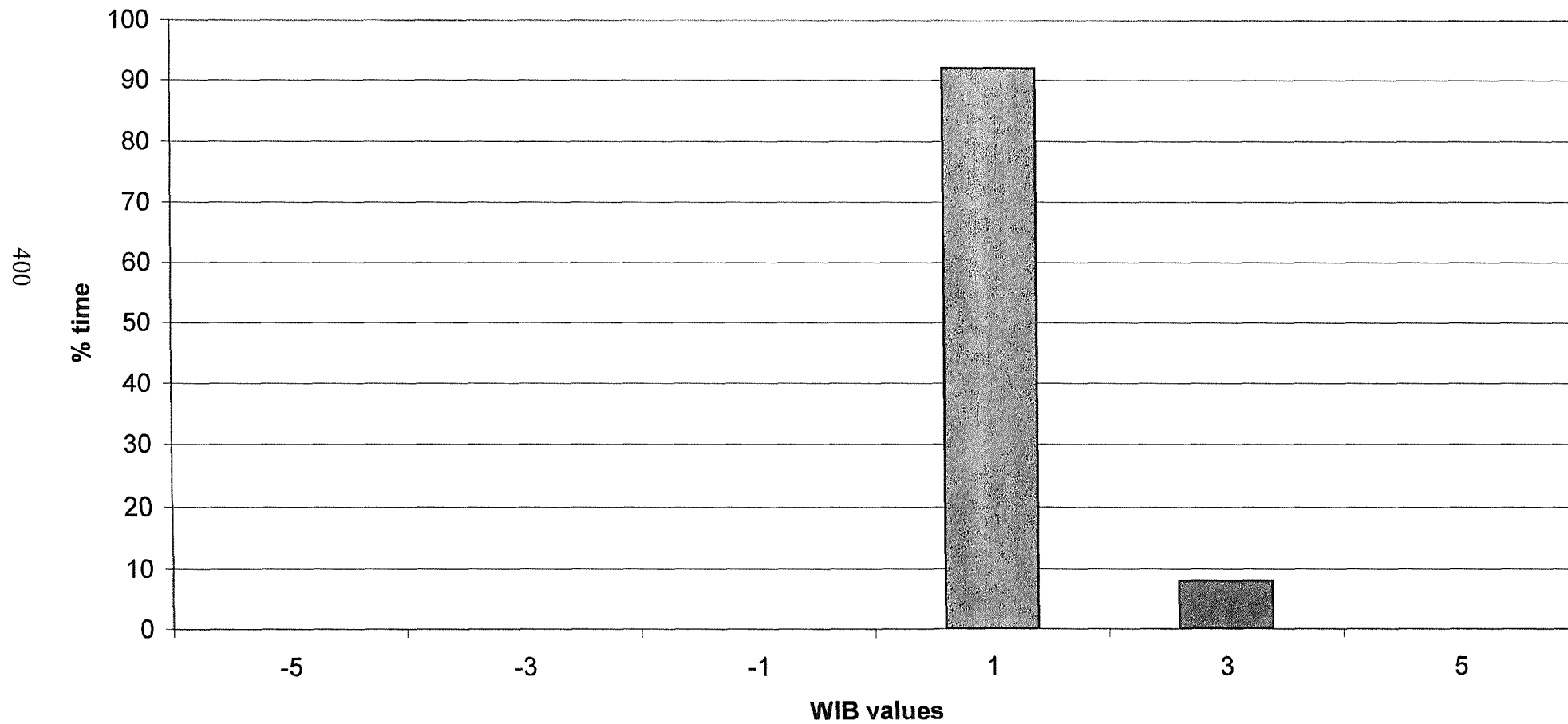
No extra behaviours were noted.

WIB values

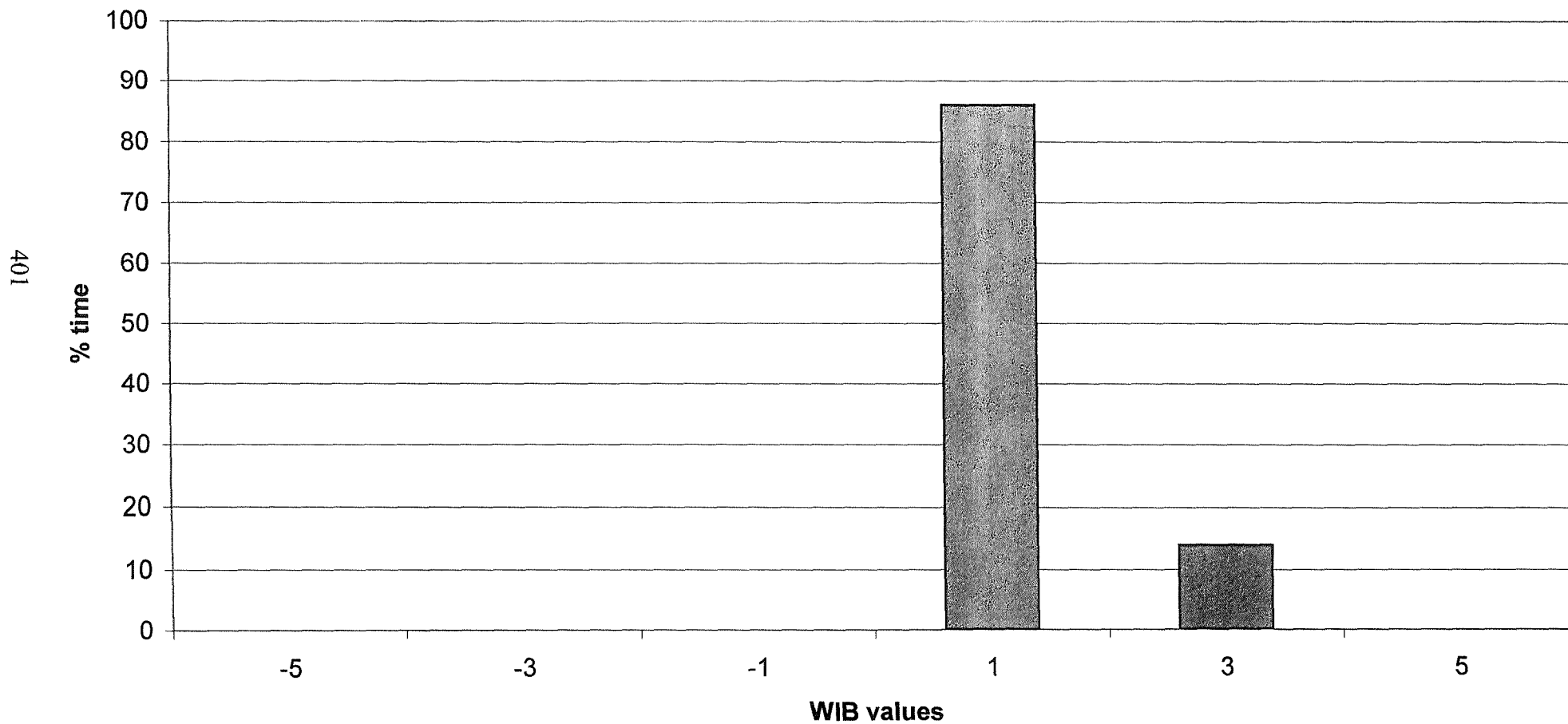
| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|-------|--------|--------|--------|----------|--------|--------|
| Wed | 0 (0) | 0 (0) | 0 (0) | 79 (92) | 7 (8) | 0 (0) |
| Thur | 0 (0) | 0 (0) | 0 (0) | 49 (86) | 8 (14) | 0 (0) |
| Fri | 0 (0) | 0 (0) | 0 (0) | 39 (98) | 1 (2) | 0 (0) |
| Total | 0 (0) | 0 (0) | 0 (0) | 167 (91) | 16 (9) | 0 (0) |

| | Wednesday | Thursday | Friday | 3 days |
|----------------------|-----------|----------|--------|--------|
| Σ WIB scores | + 100 | + 73 | + 42 | + 215 |
| Σ time frames | 86 | 57 | 40 | 183 |
| WIB value | + 1.2 | + 1.3 | + 1.0 | + 1.2 |

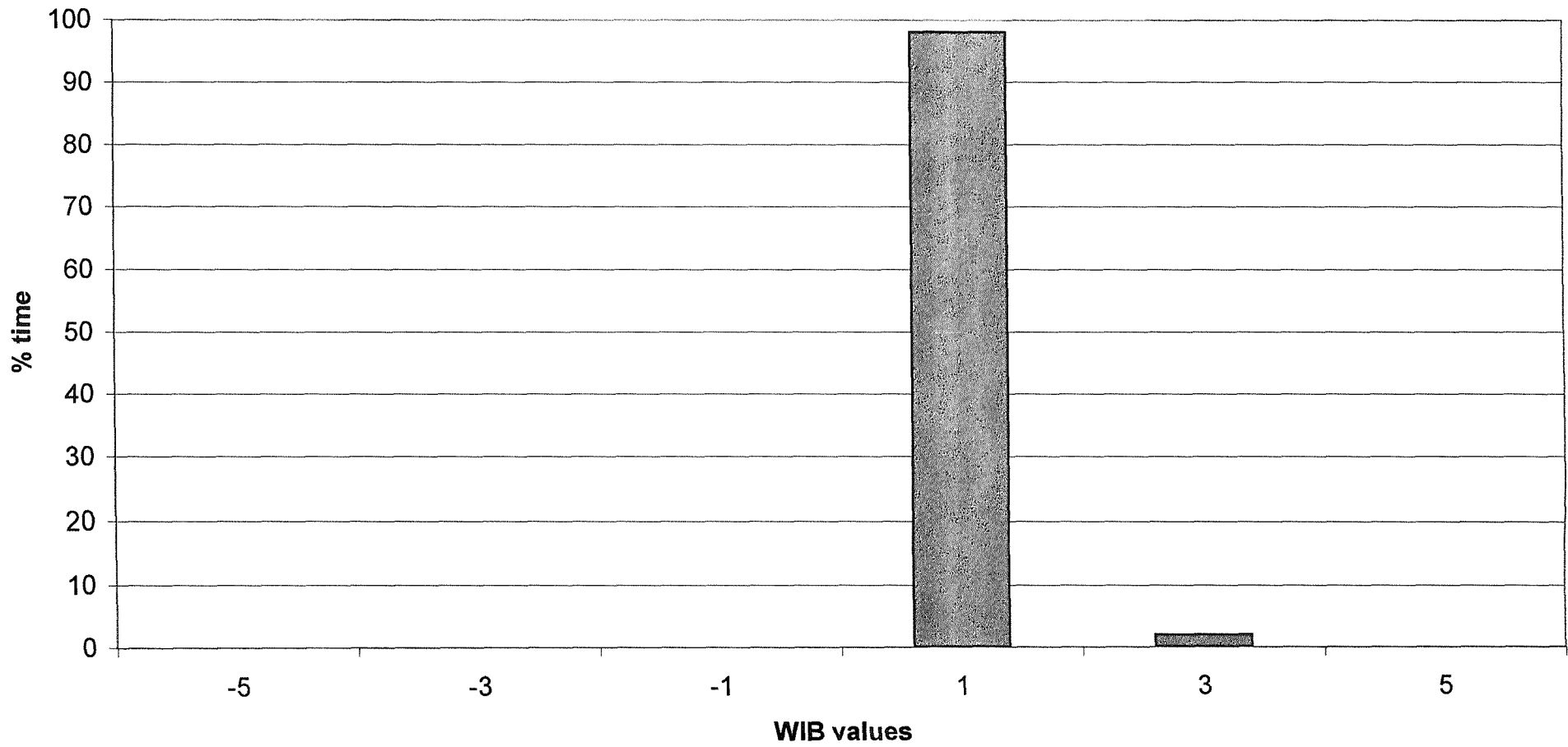
Neil
WIB Profile
Wednesday (Visit 1, Sept 2001)



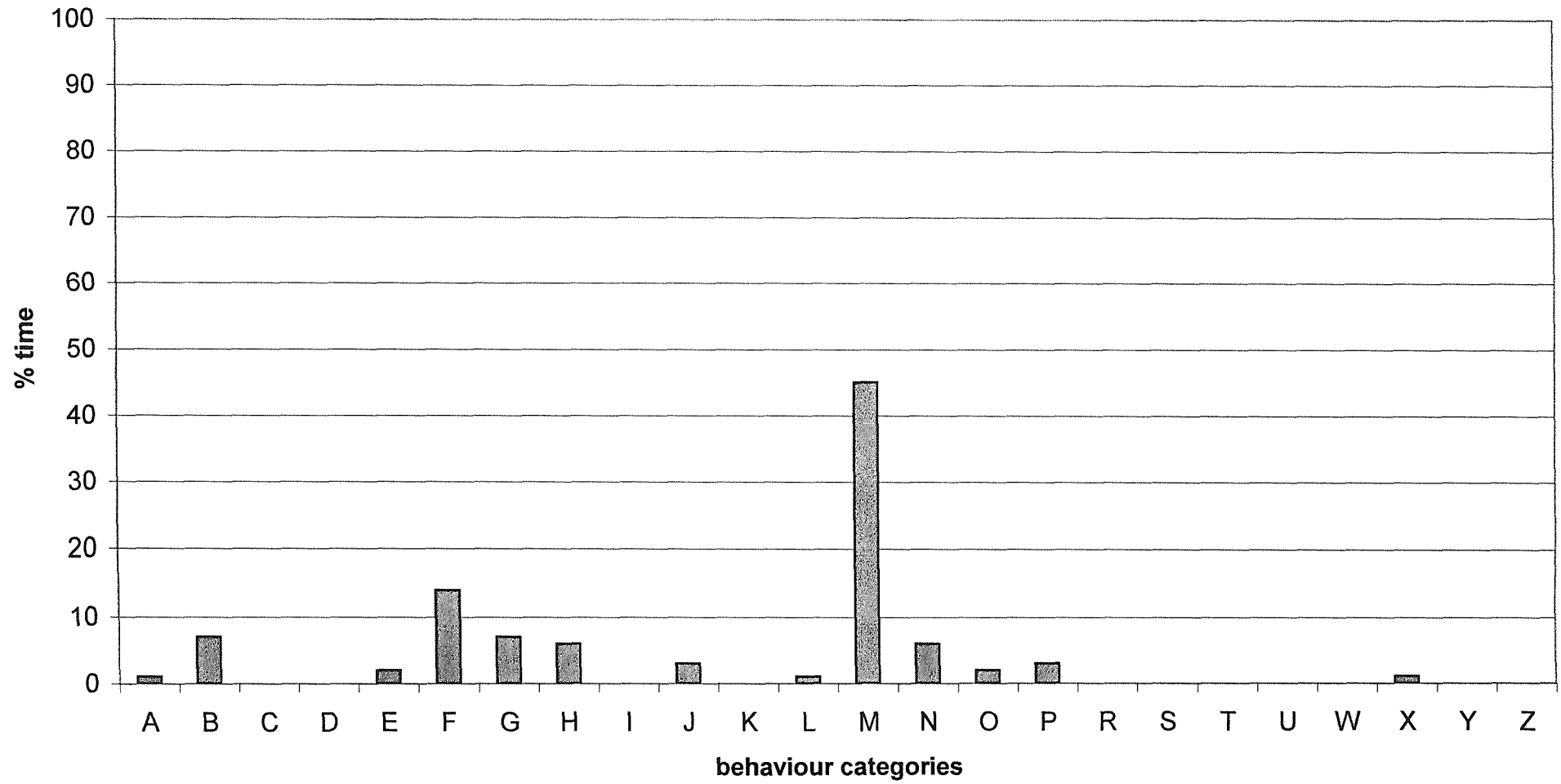
Neil
WIB Profile
Thursday (Visit 1, Sept 2001)



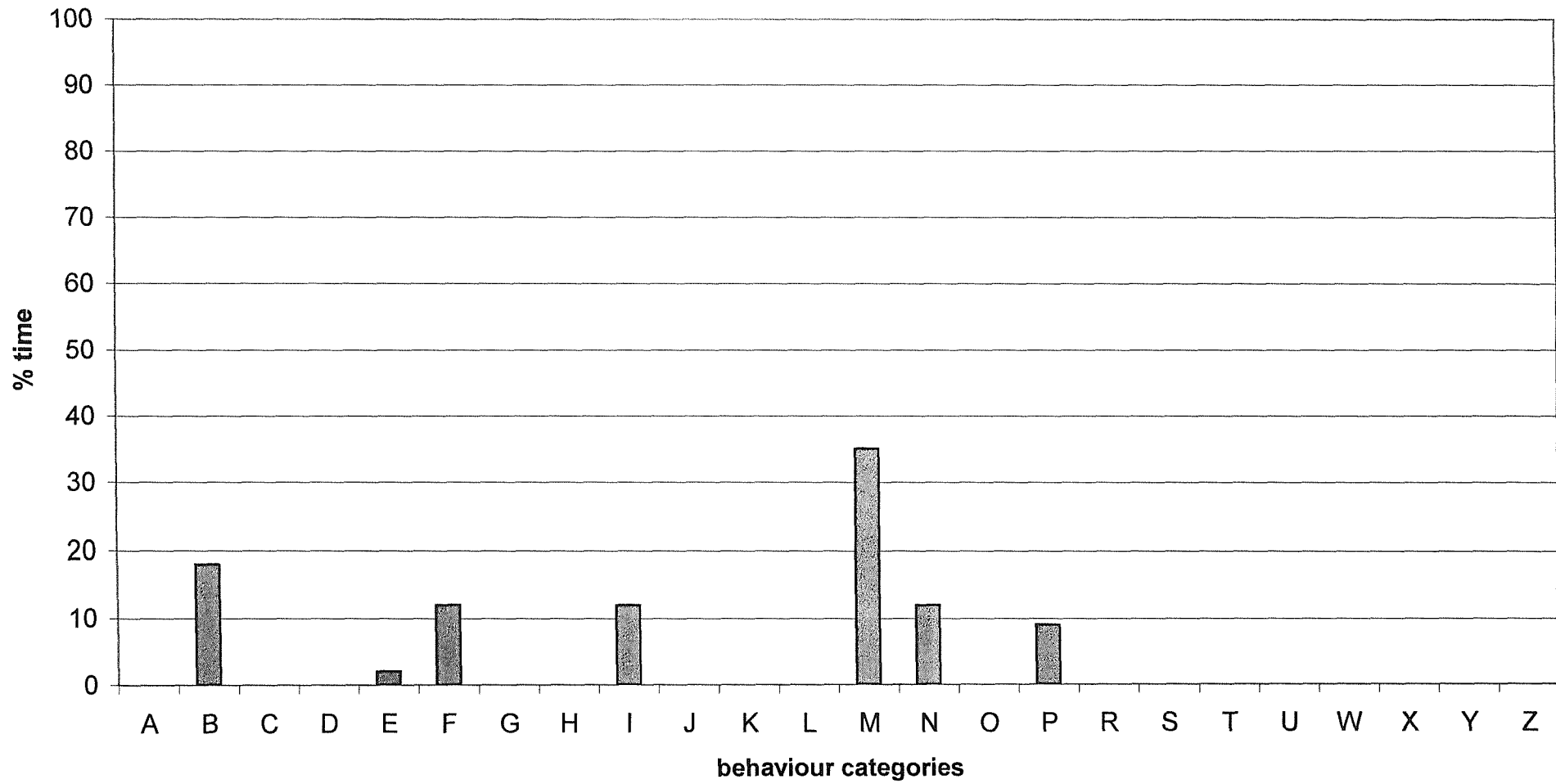
Neil
WIB Profile
Friday (Visit 1, Sept 2001)



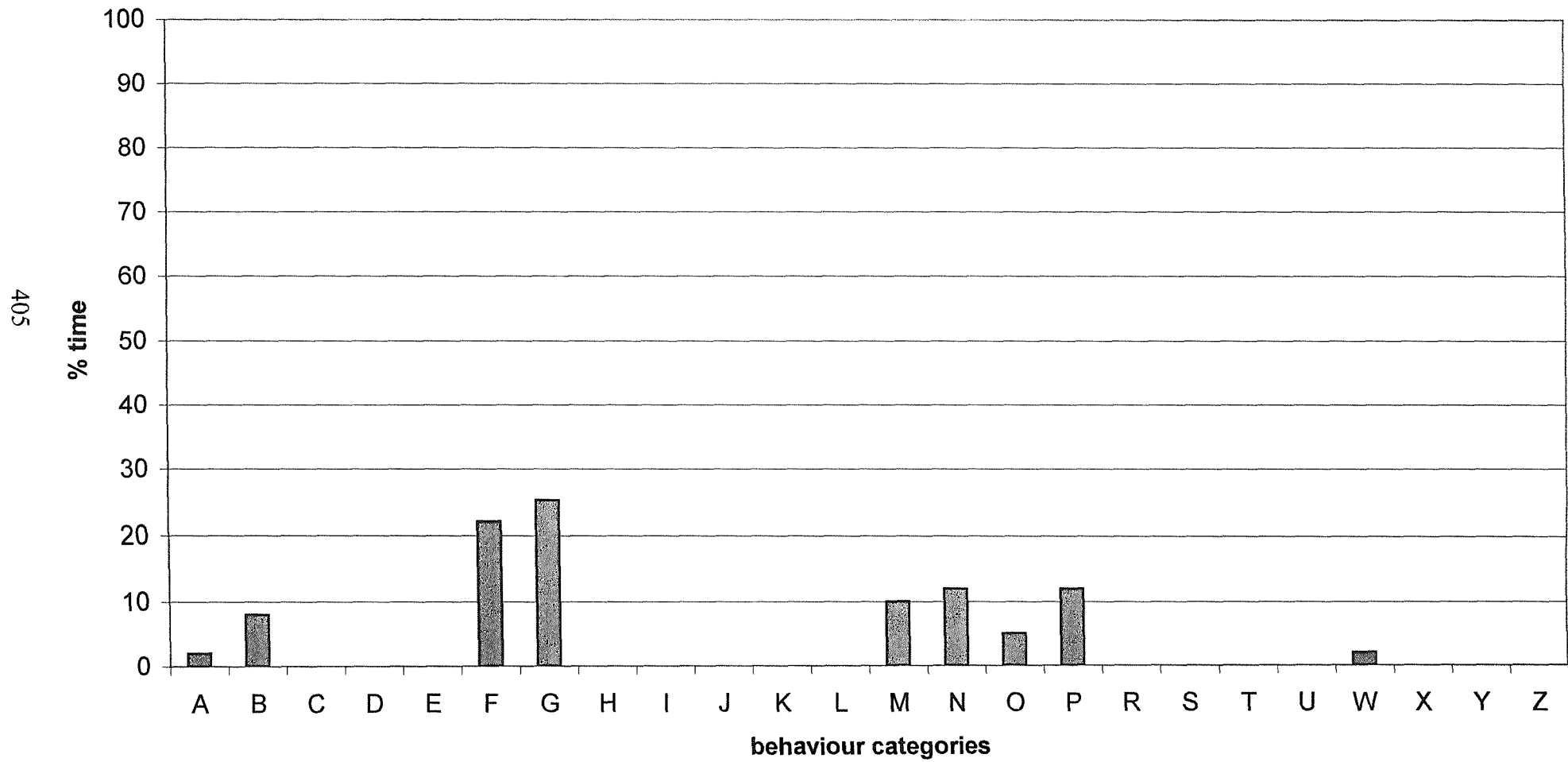
Neil
Behaviour Profile
Wednesday (Visit 1, Sept 2001)



Neil
Behaviour Profile
Thursday (Visit 1, Sept 2001)



Neil
Behaviour Profile
Friday (Visit 1, Sept 2001)



Behaviour Category Grid

Neil, Visit 1, Sept 01

406

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |
|---------|---|----|---|---|---|----|----|---|----|---|---|---|----|----|---|----|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Wed | 1 | 6 | 0 | 0 | 2 | 12 | 6 | 5 | 0 | 3 | 0 | 1 | 39 | 5 | 2 | 3 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 |
| Wed, % | 1 | 7 | 0 | 0 | 2 | 14 | 7 | 6 | 0 | 3 | 0 | 1 | 45 | 6 | 2 | 3 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Thur | 0 | 10 | 0 | 0 | 1 | 7 | 0 | 0 | 7 | 0 | 0 | 0 | 20 | 7 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Thur, % | 0 | 18 | 0 | 0 | 2 | 12 | 0 | 0 | 12 | 0 | 0 | 0 | 35 | 12 | 0 | 9 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Fri | 1 | 3 | 0 | 0 | 0 | 9 | 10 | 0 | 0 | 0 | 0 | 0 | 4 | 5 | 2 | 5 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 |
| Fri, % | 2 | 8 | 0 | 0 | 0 | 22 | 25 | 0 | 0 | 0 | 0 | 0 | 10 | 12 | 5 | 12 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| TOTAL | 2 | 19 | 0 | 0 | 3 | 28 | 16 | 5 | 7 | 3 | 0 | 1 | 63 | 17 | 4 | 13 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 |
| % | 1 | 10 | 0 | 0 | 2 | 15 | 9 | 3 | 4 | 2 | 0 | 1 | 34 | 9 | 2 | 7 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Totals: | | | | | | | | | | | | | | | | | | | | | | | | |
| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |

Elements of Malignant Social Psychology

It is difficult to think of any episodes of MSP during this visit. Two very mild ones may be noted:

Infantilisation (mild)

The owner of the residential home greeted Neil in a very overpowering and jolly way *'Oh well hello Neil!'* This could be seen as a little patronising but Neil seemed to enjoy the experience and smiled broadly.

Banishment (mild)

During the quiz at the day centre no-one asked Neil for an answer, probably due to his lack of speech. This may have been seen as banishment. However he was included at all other times and activities.

Positive Person Work

Claire's calm yet encouraging manner during care of Neil provided excellent examples of good care and positive person work.

Facilitation

This was seen on all occasions when Claire helped Neil with care. For example in shaving she would prompt him to shave himself and then say what a good job he had done before just going over one or two bits again. In dressing she would say *'Can you do your shirt up for me? That would be a great help'*. This teamwork had been a life-long affair.

Play

There were some examples of play at the day centre and residential home where Neil took part in singing or craft activities and was clearly enjoying the experience.

Carer support for intact abilities

This very much links with the ideas mentioned above under facilitation. The teamwork that Claire initiated was clearly a very good way of encouraging Neil to use the abilities he still had, for example in dressing himself, shaving, brushing his teeth and eating. These abilities were still present but required the help by gentle prompting of another. At the day centre and residential home they recognised Neil's ability to feeding himself with prompting and worked with him in this way.

Validation of emotion by carer

Since Neil rarely showed any emotion, either positive or negative, it is difficult to think of any examples here. I asked Claire if she felt Neil must be frustrated and she replied that she thought he would be, but he didn't show it and hence it was difficult to know what he was feeling.

Politeness strategies

I noted only one example of a politeness strategy during this visit. I had been given a glass of wine by Claire and Neil had pre-dinner glass of whiskey. I raised my glass and said '*cheers*' to Neil and he replied '*cheers*' to me. This was a notable event as he has very limited speech and tends to reply '*yes*'.

Aspects of selfhood

In terms of retaining some of his aspects of selfhood, here Claire plays a key role again. For example she always asks if he would like to read the newspaper and passes it to him, remembering that his previous level of intellect was very high. He seems to repeat the headlines again and again.

As a man who has come from a very highly specialised and intellectual job I felt he might feel to some extent 'out of place' when playing games at the day centre or residential home, just as Dr B did in Sabat's case study (Sabat 2001). However, he appeared to be willing to take part where possible.

His lack of speech had reduced his ability to talk about his work and this was noted by one of the carers at the residential home. However Claire helped to keep these memories alive by showing me some of his awards and talking about his work in his presence, trying to include him again and make him feel valued.

Perception and social death

Claire had spoken of the difficulty in knowing what Neil was feeling during his illness. She felt he must be frustrated at times, but that he didn't show it. Although she was uncertain just how much Neil knew or was feeling she still treated him 'as if' he knew what was happening. She still treated him with great respect and as a human being.

Visit 2, February 2002

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Having very limited speech, Neil has to rely on other forms of communication to express his wishes. He also mainly replies 'yes' when asked questions.

Initiating social contact

Although Neil did not initiate social contact verbally during this visit he did initiate contact with me, as we were sitting, by smiling.

Warmth and affection

Neil shows signs of affection when people greet him, in particular towards Claire.

Self Respect

I did not observe any instances which would fit under this category during my stay. Neil produces copious amounts of saliva which can drip onto his clothing. He does not seem to notice this or wipe it away by himself, which you *may* expect as a sign of self respect.

Being helpful

As with the previous visit Neil showed great signs of being helpful when prompted to carry out tasks by Claire. However he appeared to not be able to brush his own teeth this time and Claire used a battery operated toothbrush for him.

Humour

There were no signs of humour.

Bodily relaxation

As with the previous visit Neil showed signs of relaxation during sitting in his chair at both home and in the day centre.

Creative self-expression

Neil sung along to theme tunes from Countdown and Eastenders during this visit. These tended to be moments of increased well-being.

Showing pleasure or enjoyment

As well as during singing Neil also shows some signs of enjoyment when being greeted by others.

Responding appropriately to others

On arriving at the Dudley's on the second day of my visit Neil was not yet up and Claire told me to put my head round his bedroom door and say 'hello'. He smiled and replied 'hello' to me, showing an appropriate response to my greeting. It could be argued that he was merely repeating what I had said to him, but he did not do this on other occasions.

Expressing appropriate emotions

Neil showed very little emotion but did smile when greeted by others.

Holding his own socially

As before, Neil took part in games and activities at the day centre, but needed prompting.

Alertness

During activities Neil remained alert.

Being active

Neil could be described as active but required the initiation and prompting of others for this to happen.

Being purposeful

Neil did not show any signs for this category during my visit.

Indicators of ill-being

Depression or despair

Neil did not show any signs for this category during my stay.

Intense anger

Neil did not show any signs for this category during my stay.

Grief

Neil did not show any signs for this category during my stay.

Anxiety

Neil did not show any signs for this category during my stay.

Fear

Neil did not show any signs for this category during my stay.

Boredom

Neil did not show any signs for this category during my stay.

Physical discomfort / pain

Neil did not show any signs for this category during my stay.

Bodily tension

Neil did not show any signs for this category during my stay.

Agitation

Neil did not show any signs for this category during my stay.

Apathy and withdrawal

Neil did not show any signs for this category during my stay.

Distress

Neil did not show any signs for this category during my stay.

Cultural isolation

Again as with the previous visit I felt that Neil's age and highly intellectual career made him slightly isolated. His isolation could also be seen as a result of his lack of speech too.

Difficulty withstanding powerful others

Neil did not show any signs for this category during my stay.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 2 |
|------------------------------------|---------|
| Making wishes known | 0 |
| Initiating social contact | 1 |
| Warmth and affection | 1 |
| Self-respect | 0 |
| Being helpful | 2 |
| Humour | 0 |
| Bodily relaxation | 1 |
| Creative self-expression | 1 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 0 |
| Alertness, responsiveness | 1 |
| Being active | 1 |
| Being purposeful | 0 |
| Total | 11 |

TOTAL = 11/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 2 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 0 |
| Fear | 0 |
| Boredom | 0 |
| Physical discomfort / pain | 0 |
| Bodily tension | 0 |
| Agitation | 0 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Total | 1 |

TOTAL = 1/26

Dementia Care Mapping (DCM)

During this two day visit I only managed to carry out mapping on the first day, when we were in the Dudley's own home. Unfortunately the day centre were short of staff and so I helped out much more than I would usually. This meant that I was not able to sit and map.

Four hours of continual mapping were carried out on the first day of my visit. Behaviour profiles showing the proportion of time spent in each category are shown graphically for this day. Similarly, a graph showing the well-being / ill-being values is provided.

Tuesday

Mapping periods: 13.45-17.45

**A interacting verbally or otherwise
 (with no other obvious activity)**

One period of category A was noted during mapping.

B being socially involved, but passively

No periods of category B were observed during mapping. Although Neil was sat in his chair he was either asleep or involved in a different category, such as watching the television. When awake something active was taking place.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D.

E engaging in an expressive or creative activity

Neil sung along to some of the theme tunes on television today, and these episodes lifted his well-being to +3.

F eating, drinking

Two episode of eating or drinking were recorded during mapping today.

G participating in a game

H participating in a craft activity

Neil did not engage in category G or H today.

I activity prioritising the use of intellectual abilities

No category I activities were noted during mapping, however, Neil spent some time looking at the newspaper in the morning.

J participating in exercise or physical sports

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

Neil did not engage in categories J K or L today.

M engaging with media

About 55% of the mapping time was spent watching television.

N sleeping, dozing

Neil had a nap after lunch today for about 40 minutes.

O independently engaging in self-care

No periods of own care were noted during mapping.

P receiving practical, physical or personal care

Two time slots were recorded during mapping with Neil receiving personal care.

R participating in a religious activity

S activity related to explicit sexual expression

None of the above categories were noted today.

T direct engagement of the senses

Just under 10% of the total mapping time was spent with the cat 'cleaning' Neil's hair and showing him affection. This did not lift Neil's WIB score.

U communicating without receiving a response

There was no category U noted today.

W repetitive self-stimulation

Before going to sleep after lunch Neil engaged in some repetitive actions in brushing away crumbs.

X episodes related to excretion

Y talking to oneself, or an imagined person; hallucination

None of the above categories were noted during mapping.

Z behaviours that fit no existing category

No extra behaviours were noted during today.

WIB values

| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|------|--------|--------|--------|---------|--------|--------|
| Tues | 0 (0) | 0 (0) | 0 (0) | 53 (95) | 3 (5) | 0 (0) |

| | Tuesday |
|----------------------|---------|
| Σ WIB scores | + 62 |
| Σ time frames | 56 |
| WIB value | + 1.1 |

Neil, Visit 2, Feb 02

[illegible]

Elements of Malignant Social Psychology

No elements of MSP were observed during this visit.

Positive Person Work

Facilitation

As with the previous visit Claire and Neil worked together in many situations. This facilitation was made possible by Claire. For example in helping Neil to move to the table and sit down she would talk him through the steps very patiently; *'let's move over to the table', 'push down on the table here'*.

At the day centre this facilitation was also shown. Here they helped Neil move to the table without his frame.

Carer support for intact abilities

The week before my visit Neil had been on respite and Claire noticed that he had become a little *'lazy'* with his eating, due to care staff feeding him she felt. Here she prompted him so as to encourage him to feed himself, as she knew he could.

Although Claire helped Neil move to the table with the aid of his frame at home, the care staff at the day centre allowed him to walk (assisted) without his frame.

Validation of emotion by carer

I did not observe any examples of validation of emotion during this visit. As mentioned previously, it is difficult to know what emotion Neil is feeling

apart from the infrequent occasions when he smiles. His lack of speech is something that Claire finds difficult and she spoke of missing '*chat*'.

Politeness strategies

I did not observe any instances which could be categorised as politeness strategies during this visit.

Aspects of selfhood

In terms of selfhood I felt the only difference between this visit and the previous one was that there was no mention of his previous work. Whether this was a change in how people related to Neil now or whether it was my being a 'newcomer' last time, who didn't know Neil's history, that made for this change it is difficult to ascertain.

Perception and social death

Throughout this visit, as for the previous visit, Claire treated Neil with respect and as a fellow human. I feel this must be quite hard as she spoke of her missing his chat. However this could be seen as a sign that Claire is not writing Neil off as a person because of his lack of verbal ability.

Appendix seven

Mr and Mrs Archer

Visit 1, November 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Monty makes his wishes quite clear. For example he constantly asked Frances when meals will be ready and at the day centre he often asked Pat to repeat quiz questions he had not heard.

Initiating social contact

I observed Monty initiating social contact on several occasions, for example to the new taxi driver taking him to the day centre.

Warmth and affection

I would not describe Monty as a loving man but he did on occasion talk about how lucky he was to have Frances.

Self Respect

As a dominating man with a loud, overpowering voice I feel Monty shows he has self respect. He makes his wishes known and talks about himself at great length. I feel this may be a legacy of his past, being brought up on a farm where his father was manager of a large number of workers. Monty's manner with nurses and carers could be likened to that of a master ordering his servants around. Monty seems unaware of the effect of this on some.

Being helpful

I did not observe Monty being helpful during this visit.

Humour

I did not observe any signs of humour at this visit.

Bodily relaxation

Often spending time in his chair and despite his severe leg ulcers, Monty showed clear signs of relaxation at times.

Creative self-expression

Monty briefly took part in a pastry making activity but no actual signs of creative self expression were noted.

Showing pleasure or enjoyment

Monty showed some signs of pleasure whilst recounting tales from his past, and also at getting answers correct in the day centre quiz.

Responding appropriately to others

Monty seems oblivious to the feelings of others. However I do not think this is part of his illness but a life-long characteristic. For example when he married Frances he made it clear that he did not approve of her work despite her love of her chosen career and clear ability.

Expressing appropriate emotions

Monty seemed pleased to see visitors and greeted them with pleasure. He also seemed anxious at times, for example when he became confused about how he would be getting home from the day centre.

Holding his own socially

Monty was able to hold his own socially with anybody. His manner was forceful and dominant and he would often take centre stage in social exchange, initiating it frequently.

Alertness

Monty seemed alert when there were either visitors or activities. He appeared much more alert at the day centre and would sometimes drop of to sleep in his chair at home.

Being active

Monty could be described as active as he would rarely be content to sit in his chair, preferring either talking to others or reading.

Being purposeful

Monty's forceful manner ensures that he comes across as purposeful, initiating contact and in his active search for discussion.

Indicators of ill-being

Depression or despair

Monty did not show signs of depression during this visit.

Intense anger

Monty did not show intense anger at this visit. However he seemed quite an aggressive man in his manner.

Grief

I did not observe any signs of grief at this visit.

Anxiety

Monty showed some signs of anxiety. For example on the first evening he became quite concerned that I hadn't told my father where I was despite my reassurance.

Fear

I did not observe any signs of grief at this visit.

Boredom

Monty showed occasional signs of boredom, for example at the day centre when he kept asking if there was going to be a lecture.

Physical discomfort / pain

Monty has leg ulcers, is quite overweight and appears to have discomfort from his legs from time to time. However he does not grumble openly about this.

Bodily tension

Monty did not show signs of bodily tension during this visit.

Agitation

When Monty became anxious he also showed signs of agitation.

Apathy and withdrawal

I did not observe signs of apathy and withdrawal at this visit.

Distress

There were no signs of great distress at this visit.

Cultural isolation

I would suggest that Monty shows some signs of cultural isolation in that his early years were spent in an upper class home where he was used to seeing his father order servants around. Monty tends to have a very dominant way of talking to others, which is sometimes construed as rude. Whilst I didn't feel that Monty noticed this it still leaves him out on a limb to some extent. In addition his problems with hearing mean that he can miss out on pieces of conversation, again making him insist that people repeat what they were saying.

Difficulty withstanding powerful others

Monty did not show any signs of this category, in fact quite the reverse is true!

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 1 |
|------------------------------------|---------|
| Making wishes known | 2 |
| Initiating social contact | 2 |
| Warmth and affection | 1 |
| Self-respect | 1 |
| Being helpful | 0 |
| Humour | 0 |
| Bodily relaxation | 1 |
| Creative self-expression | 0 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 0 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 2 |
| Alertness, responsiveness | 2 |
| Being active | 2 |
| Being purposeful | 2 |
| Total | 17 |

TOTAL = 17 / 30

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

| | Visit 1 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 1 |
| Bodily tension | 0 |
| Agitation | 1 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Total | 6 |

TOTAL = 6 / 26

Elements of Malignant Social Psychology

Banishment (mild)

When Monty came out of hospital he was allowed back home on the condition that he did not go upstairs due to his mobility problems. A gate has been fixed at the bottom of the stairs preventing him from going up. This could be seen as an example of banishment.

Treachery (moderate)

Frances tells Monty that his visit to the day centre is a '*social morning*' and that he may get a lecture. This means that Monty is disappointed when there is no lecture and he often comments that he doesn't think much of the course as they don't learn anything.

Accusation (severe)

Monty appeared to enjoy taking part in the quizzes in that he answered many of the questions. Because of his hearing difficulties he had to ask for the questions to be repeated. Pat became very frustrated with this and in front of all the other clients thrust the book into his hand saying '*you read it!*' Whilst this did not appear to upset Monty it can nevertheless be seen as an example of MSP.

Positive Person Work

I did not notice many examples of positive person work during my stay. I felt that this in part could be due to Monty's forceful nature which often was interpreted as rude by carers. Whilst Frances was clearly used to his manner she appeared to spend quite a bit of time out of the room he was in during my visit.

Facilitation

Monty finds watching the television a little confusing if he can't concentrate on the plot. Frances realises this and often explains things to him whilst they watch together. This enables him to watch the programme for longer before he becomes frustrated.

Carer support for intact abilities

Monty is still able to do a number of things for himself, and Frances does not try to take over these tasks. For example, he can still dress himself and put his shoes on but can sometimes struggle with this due to his great height and weight. Frances would check if he wanted assistance and then allow him to complete the task himself.

Also due to his great stature he had difficulty in getting in and out of his chair and had acquired an electric lifting chair. Although he would sometimes get muddled about how to work the chair Frances would remind him and then allow him to operate it himself. In addition he also had mobility problems but used a frame to get about without aid from others.

Validation of emotion by carer

Due to his memory difficulties Monty repeats the same questions again and again. Frances is very patient in her answers and repeats them so as to try and reassure him.

As he is not allowed to go upstairs anymore (on doctors orders, or he wouldn't have been allowed home) he has a bed in the dining room. So that he doesn't wake up alone and feel anxious Frances also sleeps downstairs in the dining room.

Whilst watching television Monty can become confused as he finds concentrating on the plot difficult. To help with this Frances tells him what is happening so that he can watch for longer, although this must disturb her own viewing somewhat.

Politeness strategies

Despite his dominant manner Monty also shows signs of politeness. For example in letting me through a door first, despite his mobility difficulties. Also when sneezing he would exclaim '*excuse me!*'

Aspects of selfhood

Monty seems very proud of his past and often talks of his father and his extensive farm. The dominance of men in the society he was raised in very much shows through into his manner today, which can cause offence to some. However there are also aspects of his past which cause him some insecurity in his current situation. He spoke to me of his first wife and her infidelity. He seems often to be anxious if Frances goes across the road to visit a friend. On one occasion when she popped out to give a friend the newspaper he said to me, '*well this isn't marriage is it?*' This possessiveness seems to have been a theme in their marriage over the years with her having to leave her job. In his current situation he can become quite anxious if he doesn't remember where Frances is, for example at the day centre.

Perception and social death

Frances clearly realises that Monty can feel very confused and frustrated at times, and she tries to alleviate this where possible, for example in answering his repeated questions calmly and patiently. She is also aware

of his insecurity and possessiveness towards her, which becomes heightened at times. This is a trait which has been present throughout their marriage and the anxiety of his dementia seems to increase the feeling at times.

Visit 2, July 2002

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Monty often made his wishes known. However his wishes are not always met, for example he wanted to sit outside in the morning with his relatives but Frances said it was too difficult to move him and helped him out later. He also can make his wishes known in an aggressive way, for example when becoming angry with the carer.

Initiating social contact

As before, Monty would often initiate social contact. For example he introduced himself to another client at the day centre and they spoke about their similar ages.

Warmth and affection

Monty showed some signs of affection towards his relatives at this visit.

Self Respect

It could be argued that Monty's anger with the carer helping him to wash is a sign of self respect as he said he didn't need help. I also noticed that when Frances asked if he needed help at lunchtime he answered crossly '*no I don't need help!*'.

Being helpful

Monty didn't show any signs of helping others during this visit.

Humour

Monty joked with the district nurse about women wearing trousers a lot nowadays. However she didn't find this amusing.

Bodily relaxation

Monty showed some signs of bodily relaxation, for example in dozing on and off in his chair outside in the warm sun.

Creative self-expression

There were no signs of creative self-expression during this visit.

Showing pleasure or enjoyment

Monty showed pleasure when greeting relatives and also on discovering that he was the same age as another client at the day centre.

Responding appropriately to others

As before I found Monty not particularly sensitive to the feelings of others. For example he didn't appear to notice that the district nurse was not amused at his slightly sexist jokes about women and trousers.

Expressing appropriate emotions

Monty showed pleasure on greeting relatives and also anxiety when confused about how he would get home from the day centre.

Holding his own socially

Monty is very able to hold his own socially and often initiates social contact with others.

Alertness

Monty is generally very alert, in particular during this visit, which Frances said was because there was a lot of stimulation as so many relatives had been visiting.

Being active

Monty showed clear signs of being active during this visit.

Being purposeful

Monty's manner shows he is purposeful in his behaviour and he is often seeking activity or conversation.

Indicators of ill-being

Depression or despair

Monty didn't show any signs of depression or despair at this visit.

Intense anger

Monty became very angry with the carer who came some mornings to help him wash. Frances said that this had happened before.

Grief

There were no signs of grief during this visit.

Anxiety

Monty showed some signs of anxiety, for example in the afternoon at the day centre he asked how he would be getting home repeatedly.

Fear

Monty didn't show any signs of fear during this visit.

Boredom

Monty showed some signs of boredom on occasion at the day centre, asking '*are we having a lecture this afternoon?*'

Physical discomfort / pain

Monty shows some signs of discomfort when trying to get around and now needed assistance more often to move.

Bodily tension

Monty didn't show signs of bodily tension during the visit.

Agitation

Monty shows signs of agitation when he becomes anxious.

Apathy and withdrawal

Monty showed some signs of withdrawal when with his relatives in the garden as he couldn't hear what they were saying.

Distress

No signs of distress were noted.

Cultural isolation

As before his hearing difficulties can lead him to become left out at times during conversation. His background also makes him different from others in his interactions and responses.

Difficulty withstanding powerful others

Monty showed no difficulty in this respect and as able to stand up for himself.

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 2 |
|------------------------------------|---------|
| Making wishes known | 2 |
| Initiating social contact | 2 |
| Warmth and affection | 1 |
| Self-respect | 1 |
| Being helpful | 0 |
| Humour | 1 |
| Bodily relaxation | 1 |
| Creative self-expression | 0 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 0 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 2 |
| Alertness, responsiveness | 2 |
| Being active | 2 |
| Being purposeful | 2 |
| Total | 18 |

TOTAL = 18 / 30

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

| | Visit 2 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 1 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 1 |
| Bodily tension | 0 |
| Agitation | 1 |
| Apathy and withdrawal | 1 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Total | 7 |

TOTAL = 7 /26

Elements of Malignant Social Psychology

Banishment (severe)

Monty wanted to go outside with his relatives to sit in the sun but Frances said it was too difficult to move him and left him in on his own until nearly lunchtime.

Withholding (moderate)

Monty cannot get up the stairs now and Frances only sleeps downstairs with him if he is ill. This shows the strength of a longitudinal study such as this because she was sleeping downstairs with him during the last visit as he was still able to wander upstairs at night. I had recorded this as validation previously, although it could still be seen as validation when she stays with him if he's ill.

Ignoring / outpacing (mild)

The relatives were chatting together over lunch and Monty was not always able to hear what was being said. Sometimes they would repeat things for him but not always as the pace of conversation was sometimes fast.

Treachery (moderate)

As before Frances tells Monty that his visit to the day centre is a '*social morning*' and that he may get a lecture. This means that Monty is disappointed when there is no lecture and he often asks if there will be one.

Invalidation (severe)

When Monty shouted at the carer '*get out of here!*' as she came into the bathroom to try and help with washing she replied '*you'll talk to me with respect!*' before leaving.

Positive Person Work

There were no examples of positive person work during this visit.

Carer support for intact abilities

When Frances asked if Monty needed any help during lunchtime he was quick to answer '*no I don't need help!*' in a rather angry manner. However one example of support for intact abilities is that Frances makes sure Monty has the paper to read as he is still able to read the headlines, even though he may read the same ones again and again.

Validation of emotion by carer

The episodes of malignant social psychology noted during this visit leave me finding it difficult to highlight areas where there was validation, since the very opposite was observed.

Politeness strategies

I did not observe any politeness strategies during this visit.

Aspects of selfhood

At this visit I saw a slightly different side to Monty. Here was a man who was used to being in charge of his home, his family and his life and now he was feeling this slip away. I observed his angry outburst at the carer coming into the bathroom to help him. He did not feel that he needed help, and if he did need help then he had a wife who would be helping. His family had gathered together to see his eldest daughter, visiting from Switzerland, and he wasn't always able to talk with them – either because he had been left inside by Frances, or because he couldn't hear what they were saying and they were too caught up in the conversation to actually hear it.

All of the above examples can be seen in the light of his previous experiences: of being able to 'order' servants to help when *he* wanted; to be head of his family and in control of what happened. This can be contrasted with Gilbert Woody, who despite his failing abilities is still very much treated as head of the household within his family. He still commands the respect that Monty seems unable to. The respect that Monty's carer now asks of him.

Perception and social death

There were a few clues at this visit to Frances's perception of dementia. After his angry outburst at the carer she went in and said '*morning Monty*', as if nothing had happened. This could be seen as her view that Monty will forget things as soon as they've happened. In reality he may forget what he has said but still felt angry and confused. This feeling has not been validated.

Visit 3, November 2002

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

As before, Monty clearly makes his wishes known.

Initiating social contact

Again Monty still shows clear signs of initiating social contact, for example with Eddie, one of the residents at Homestead, over lunch.

Warmth and affection

Monty shows some signs of affection when talking about Frances to me. He spoke during this visit of her good cooking.

Self Respect

As with previous visits I felt that Monty's manner in dealing with people shows his self respect still intact. However, this visit he often described himself as 'useless'. A side I had not observed before.

Being helpful

Monty did not show any signs of being helpful during this visit.

Humour

Again the district nurse became the focus for Monty's sexist humour. This was not appreciated! (But Monty did not seem to notice).

Bodily relaxation

At times Monty showed signs of bodily relaxation.

Creative self-expression

There were no examples of creative expression observed.

Showing pleasure or enjoyment

Monty showed pleasure on occasion, for example whilst chatting to Eddie over lunch at Homestead.

Responding appropriately to others

As before, Monty does not seem to take notice of other people's feelings, for example when making sexist comments to the nurse. Similarly when trying to interrupt Frances telling me about her work.

Expressing appropriate emotions

Monty shows signs of enjoyment at times and also signs of anxiety when worried about how he would get home from the day centre.

Holding his own socially

As before Monty is very able to hold his own socially, often dominating the conversation.

Alertness

Monty remains alert throughout the day, except during his routine afternoon nap.

Being active

Monty showed clear signs of being active at this visit.

Being purposeful

As before, Monty's manner indicates he is purposeful.

Indicators of ill-being

Depression or despair

There were no signs of depression or despair.

Intense anger

Monty showed some signs of anger when Frances was trying to tell me about her work as a journalist.

Grief

For the first time since meeting Monty I observed some signs of grief in that he referred to himself on a couple of occasions as '*useless*'.

Anxiety

As before, Monty showed some signs of anxiety when at the day centre, wondering how he would get home and if Frances knew where he was.

Fear

There were no signs of fear during this visit.

Boredom

I did not observe any signs of boredom during this visit

Physical discomfort / pain

Monty showed some signs of physical discomfort.

Bodily tension

I did not observe any signs of bodily tension.

Agitation

During his episodes of anxiety Monty also showed signs of agitation.

Apathy and withdrawal

I did not observe any signs of this during the visit.

Distress

There were no signs of distress during this visit.

Cultural isolation

As before his hearing problems can lead to difficulties, but this time the carer was very patient with him during the bingo calling. Again his background makes his manner different from the others at the day centre.

Difficulty withstanding powerful others

Monty showed no difficulty in this respect.

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 3 |
|------------------------------------|---------|
| Making wishes known | 2 |
| Initiating social contact | 2 |
| Warmth and affection | 1 |
| Self-respect | 1 |
| Being helpful | 0 |
| Humour | 1 |
| Bodily relaxation | 1 |
| Creative self-expression | 0 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 0 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 2 |
| Alertness, responsiveness | 2 |
| Being active | 2 |
| Being purposeful | 2 |
| Total | 18 |

TOTAL = 18 / 30

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

| | Visit 3 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 1 |
| Grief | 1 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 0 |
| Physical discomfort / pain | 1 |
| Bodily tension | 0 |
| Agitation | 1 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Total | 6 |

TOTAL = 6 /26

Elements of Malignant Social Psychology

Invalidation (mild)

During this visit I only observed one event which could be seen as an example of MSP. The district nurse was dressing Monty's leg and he was making sexist jokes (as him often did). Rather than perhaps laughing with him in a rare moment when he showed enjoyment she chose to ignore his comments and pulled a knowing face at me. These were jokes that he often made in her presence but could have been seen as a sign of him trying to even the power balance. However it could also be argued that the nurse had every right to find the sexist remarks offensive.

Positive Person Work

Validation

A new member of staff had arrived at Homemead. She was very good with the clients, who warmed to her. During the bingo calling Monty would

often ask her to repeat a number as he hadn't heard it the first time. This she did with great patience and skill, so that he could still take part in the game. This was not the usual reaction from staff when he couldn't hear properly.

Carer support for intact abilities

At this visit Monty's mobility was slightly improved and he was again able to walk with the aid of a frame and get himself in and out of his chair. Frances saw this as a good sign and encouraged him to walk by suggesting that he should '*do two circuits of the house*' when he suggested having a walk around.

Validation of emotion by carer

The main example from this visit is that illustrated above under positive person work.

Frances's response to Monty's annoyance, for example, is to ignore the emotion he is showing rather than to validate it. However I suspect this is how she dealt with his possessiveness during their marriage.

Politeness strategies

At Homemead Monty became quite anxious and kept asking me if Frances knew where he was, and showed concern about how he would get home. Each time I reassured him he looked very relieved and said '*thank you very much*'.

Aspects of selfhood

Old patterns of behaviour, for example his possessiveness towards Frances, were still present at this visit. His annoyance at her attention diverted from him was plain to see as was his dislike of her discussing her work. Whilst this is not exactly a positive aspect of his character it is nevertheless a continuation of one aspect of his self, something that is still remaining.

At this visit I also saw the vulnerable side of Monty. The side that feels he is now *'useless'*. Some of the roots of this vulnerable side may have also been from his upbringing. He spoke for the first time of his jealousy towards his older brother who had been given his father's name for his middle name. His confusion and anxiety resulting from his dementia were perhaps accentuating these vulnerable aspects of his self.

Perception and social death

For the first time at this visit Frances spoke of wondering what it must be like for Monty. She was recounting a recent event where he had become annoyed with a relative who was, according to Frances, *'feeding her dog like a lap dog'*. She said *'I wonder what it must be like to be him?'* This indicates that she doesn't think that he would have no insight or feelings but that his illness may cause his angry outbursts *because* of what he is feeling.

Appendix eight

Mr and Mrs Reed

Visit 1, July 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Anne clearly made her wishes known, often asking to go to bed or saying that she wanted to lie down.

Initiating social contact

Anne often initiated social contact. She hugged her son on seeing him and threw her arms around the bus driver when he arrived at the day centre. Anne had been a very gregarious woman in her earlier years.

Warmth and affection

Anne showed a lot of warmth and affection towards people. For example she would often hold my hand and tell me I was '*pretty*' or '*lovely*'.

Self Respect

Anne showed some signs of self respect. For example she like Thomas to apply make-up each morning as she had always taken pride in her appearance.

Being helpful

Anne showed no signs of being helpful during my visit.

Humour

Anne showed no signs of humour during my visit.

Bodily relaxation

Anne was often tense and anxious and this showed in her posture. She showed no signs of bodily relaxation, even sitting forward on her seat when travelling.

Creative self-expression

I noted one example of creative self expression when Anne did some weaving at Homemead. Although only briefly, Anne was engaged in this activity.

Showing pleasure or enjoyment

Anne showed some pleasure when meeting people, for example on the coach trip.

Responding appropriately to others

Anne said that she had enjoyed her day at Homemead when asked by Thomas in front of the others. However on getting in doors she told him she had not liked it. This shows that she has an awareness of appropriate responses in front of others.

Expressing appropriate emotions

Anne was happy when greeting people, and showed an aggressive side when Thomas annoyed her. Her emotions were appropriate.

Holding his own socially

Anne was able to hold her own at the day centre when she was keen to reserve the seat next to her for me. She would not allow others to sit there saying it was for her friend.

Alertness

Anne was often alert but anxious.

Being active

Anne was active in that she cut up her own food, moved around unaided and used the speech she had to communicate effectively.

Being purposeful

Anne showed some signs of being purposeful in her actions, for example when wanting to leave the day centre she knew she had to find Geoff.

Indicators of ill-being

Depression or despair

I felt that Anne's wish to go to bed or to lie down appeared to be a need to get away from the pain (physical and psychological) that she felt. The organiser from the Alzheimer's society, Agnes, told me she felt it was an attempt to escape.

Intense anger

Anne became angry with Thomas on the coach and dug her nails into his hand. He said that she would often do this.

Grief

I did not note any particular examples of grief during this visit.

Anxiety

Anne showed anxiety most of the time. She was very anxious when travelling or when at the day centre. At home she would be anxious to go to bed.

Fear

Anne showed fear as well as anxiety on occasions.

Boredom

Anne did not show any signs of boredom.

Physical discomfort / pain

Anne had severe arthritis and often showed signs of pain.

Bodily tension

Anne was often anxious and this showed in her body posture which was tense. For example when travelling she would sit on the edge of her seat and grip my hand.

Agitation

Anne showed signs of agitation when travelling, often asking if we were nearly there. At the day centre she would try and leave when someone opened the door.

Apathy and withdrawal

Anne was not sleepy but would often try and go to bed. I felt this was a sign of her wanting to withdraw.

Distress

Anne was often in a state of distress.

Cultural isolation

I felt that Anne may have been isolated to some extent because of her language. Although she mainly spoke in English she would occasionally use her native tongue.

Difficulty withstanding powerful others

Anne had difficulty in withstanding Thomas. She would often show distress at what he would tell her to do but would still do it. For example when she wanted to sit in a different place on the coach he would not allow her to. Similarly he would often prevent her from going to bed during the day.

Indicators of well-being

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 1 |
|------------------------------------|---------|
| Making wishes known | 2 |
| Initiating social contact | 2 |
| Warmth and affection | 2 |
| Self-respect | 1 |
| Being helpful | 0 |
| Humour | 0 |
| Bodily relaxation | 0 |
| Creative self-expression | 1 |
| Showing pleasure or enjoyment | 1 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 2 |
| Holding their own socially | 1 |
| Alertness, responsiveness | 2 |
| Being active | 2 |
| Being purposeful | 1 |
| Total | 18 |

TOTAL = 18 / 30

Indicators of ill-being

0 = never , 1 = sometimes, 2 = often

| | Visit 1 |
|---|---------|
| Depression or despair | 2 |
| Intense anger | 1 |
| Grief | 0 |
| Anxiety | 2 |
| Fear | 1 |
| Boredom | 0 |
| Physical discomfort / pain | 2 |
| Bodily tension | 2 |
| Agitation | 2 |
| Apathy and withdrawal | 1 |
| Distress | 2 |
| Cultural isolation | 2 |
| Difficulty withstanding powerful others | 2 |
| Total | 19 |

TOTAL = 19 / 26

Dementia care mapping

On arriving I spent an hour mapping and the results are presented below. However, I took the decision that I could not map Anne effectively because, as with Mr Archer, there was too much high negative expressed emotion and I would find my attention divided as Anne often sought comfort in me. Ethically I felt I could not withhold comfort just to seek data. As an 'observer as participant' I would have to take this decision.

| Sunday | BCC | WIB |
|--------|-----|-----|
| 14.00 | | |
| 14.05 | | |
| 14.10 | | |
| 14.15 | | |
| 14.20 | M | +1 |
| 14.25 | M | +1 |
| 14.30 | M | +1 |
| 14.35 | M | +1 |
| 14.40 | M | +1 |
| 14.45 | M | +1 |
| 14.50 | A | -3 |
| 14.55 | A | -3 |
| 15.00 | A | -1 |
| 15.05 | D | -3 |
| 15.10 | A | -1 |
| 15.15 | A | -1 |
| 15.20 | D | -3 |
| 15.25 | A | +3 |
| 15.30 | | |

The initial 30 minutes of M +1 were when Anne sat after lunch looking at a magazine before we drove to her son's. However in the car she became anxious and agitated. She was very distressed at times and Thomas ignored this distress. I decided not to continue mapping and held Anne's hand to try and reassure her.

Elements of Malignant Social Psychology

Intimidation (moderate)

When I first arrived at Thomas and Anne's we had lunch. During lunch Anne kept asking Thomas if she could go to bed. After a few times Thomas replied, *'If you ask me that again I'll punch you on the nose'*. This was not said in an aggressive way, rather a matter of fact manner.

Invalidation (moderate)

The journey to her son's was difficult for Anne as she seemed frightened. Thomas made no attempt to calm her and she clung onto my hand tightly.

Ignoring (very severe)

I have categorised this event as very severe because of the content of the conversation during the presence of Anne. Thomas often talked about her as if she was not there. However, on the way to her son's he took this element of malignant social psychology to its extreme. He had asked if I was married and then told me he had a 'partner', Tanya, who was a friend of Anne's. Thomas and Tanya had become more than friends after Anne's illness when the three of them met in Spain. He told me that his children knew and accepted the situation, understood why. Anne was in the back of the car during this conversation.

Mockery (mild)

I often found Thomas's tone when talking to Anne to be sarcastic. An example of this occurred on the way to her son's when we had nearly arrived. He turned to her and said sarcastically, *'Are you happy Anne? We're nearly there.'*

Mockery (very severe)

We arrived at Thomas and Anne's son's home and greeted the family. Anne wanted to lie down but wasn't allowed and became agitated. As she tried to get up from the sofa Thomas exclaimed, *'Sit! Sit! Stay! Stay! Good dog! Good dog!'*

Imposition (moderate)

When we got onto the coach to take us to the manor house Anne wanted to sit on one of the aisle seats (she later told me that she'd wanted to see more). Thomas insisted that she sat between myself and him.

Mockery (severe)

On the coach trip back from the manor house Thomas announced, in earshot of others, *'Well it's been a real pleasure taking you out Anne, you're such a joy to take out'*.

Infantilisation (moderate)

Over tea at the manor house Thomas said to the Alzheimer's society organiser, Agnes, in front of Anne, *'I've got a built in babysitter tonight'* referring to myself.

Banishment (severe)

In the evening Thomas went out to meet his friends after first dropping me next door to spend the evening with Nora. We left Anne alone in the house, in bed.

Positive Person Work

Validation

The first example of positive person work was observed during the doctor's consultation. Anne, Thomas and myself were present. Thomas had been talking about Anne as if she wasn't there and the doctor, sensing Anne's distress, touched her hand in a reassuring way from time to time.

Another example of validation was seen on the bus home from the day centre. Anne had realised that the driver was taking a different route and was concerned. The driver was very reassuring and told her he was just dropping a parcel off.

Carer support for intact abilities

It is difficult to think of support in this section. Thomas helps Anne to get ready for the day centre by applying her makeup, but does this for her.

Anne can still feed herself by cutting up the pieces of food into smaller amounts and using a spoon. Thomas does not try to cut them up for her. She also is able to go to the toilet herself but forgets to flush at times. Thomas reminds her when he goes to flush it afterwards.

Validation of emotion by carer

The large number of examples of malignant social psychology illustrate how little validation Anne received. The only examples are seen under the positive person work section and are by people Anne sees occasionally.

Politeness strategies

When we arrived at the doctor's reception Anne pointed to the pile of magazines saying to me, *'you can have a look'*.

Aspects of selfhood

Despite the manner in which Thomas behaves towards Anne he still helps to keep a very important (for her) aspect of her selfhood intact. Recognising that she has always taken pride in her appearance he helps to keep this going by applying her make-up every day. He also paints her nails and dyes her hair from time to time.

Anne used to be a gregarious person who loved to be amongst people. She now wants to go to bed, even when she is visiting her son.

Perception and social death

Soon after I had arrived Thomas said to me, in front of Anne, that she had no idea what we were talking about. This view became clear as the visit progressed, with Thomas talking about his affair in front of her. Clearly he believes that Anne is socially dead and is no longer treating her as a human. His malignant social psychology is evidence for this. However he did say to me during the visit that he wanted to know what *'they'* think of, wondering, *'whether anything goes through their mind or is it just blank?'*

Nora, the next door neighbour also shares the view that Anne is socially dead, telling me that she feels Anne *'isn't there any more'*.

However there was evidence to suggest that this is not the case, for example when we went onto the coach Anne showed concern saying, *'it wont be like yesterday will it?'* showing that she may have memories of the difficult journey

to her son's the day before. Similarly she remembered that Thomas had not allowed her to sit in a aisle seat on the journey to the manor house. She told me, *'I wanted to sit there before but Thomas told me off. I wanted to be able to see more'*. In the day centre she knew who could help to get her home – the bus driver. She told me, *'when he comes you must stand up straight away, you must do what I tell you, and then we can go'*. She also recognised that I would be able to tell him where to go to get home, saying to me *'you can communicate better'*. This final quote indicates that she realises her own limitations in communication and hence has awareness.

Appendix nine

Mr and Mrs Jackson

Visit 1, April 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

A few years back someone from social services took Jim and Eileen to look at a home where Eileen could be looked after for respite care. After they returned to their home Jim found Eileen *'sobbing her heart out'* and she begged him *'please don't send me away'*.

The ability to make her wishes known currently was indicated on several occasions during my stay; Jim wears a hearing aid and has a loop attachment to use in conjunction with the television. He said that this means he cannot always judge a suitable level of volume for others who may be watching. During 'Songs of Praise' on Sunday Eileen turned to me and said *'it's not loud enough is it?'* and Jim turned the sound up.

While we were walking round the outside of the cathedral Eileen turned to Jim saying, *'come on Jimmy, I'm getting cold!'*

Initiating social contact

During the first morning of my visit Jim went out to the kitchen to make some coffee. Eileen and I were watching the London Marathon on television, and a reporter was interviewing the winner. This participant didn't speak English and so had an interpreter present. During one of the non-English passages Eileen turned to me and said, *'sounds like double Dutch to me!'* and laughed.

She would often make comments during television programmes, thus initiating contact. During the Lennox Lewis fight which was featured on the news she exclaimed *'they seem to be having a good go! – punched his eye!'*

She would also initiate social contact in other situations, for example, when we went into C&H Fabrics for a coffee she spotted some material and turned to me saying *'oh look!'*

Warmth and affection

Obviously still very much in love as a couple, Eileen and Jim shared many affectionate moments. Eileen would often look fondly into his eyes, hug him or clasp his hands after they had shared a joking moment together. She also showed affection towards others when they greeted her, for example her neighbour who popped in kissed her and she responded in kind. Two other neighbours met us in Chichester and both greeted her. She stood with one of them and held her hand during the whole conversation, and smiled warmly throughout.

Self Respect

Eileen needed to be dressed by Jim in the morning, but throughout the day would straighten her skirt if it was slightly crooked. During the Alzheimer's Society lunch she also brushed some crumbs from her skirt, and some that had fallen into the crease of her handbag. However, during the Alzheimer's Society lunch I remarked to her that I thought everybody looked smart, and she replied, *'except me'*.

Being helpful

Eileen often showed signs of wanting to help, or perhaps feeling that she should help in some way. Whilst Jim prepared meals, or when myself and Jim were washing up, she would come out and say *'what have I got to do Jimmy?'* He would, more often than not, reply, *'nothing duck, you go and sit down'*. She would often go away and then come back in again, repeating the cycle. Sometimes she would straighten the flowers in a

vase in the lounge or straighten a plate in the kitchen in an attempt to help in some way. However on being told she had nothing to do she didn't appear in any way disappointed, in fact there was a good banter between them about not doing chores. When she came into the kitchen whilst we were washing up on one occasion he asked her jokingly, *'have you come to do the washing up? "No!"* she replied and they both laughed together. Another time when we were washing up he called out to her, *'have you finished the hovering and dusting then?'* She came into the kitchen smiling and replied, *'as much as I'm going to do!'* and they laughed.

During one afternoon of my stay, Eileen came over and collected my tea cup saying, *'have you finished?'*

Humour

Humour was one of the great things they shared together in their relationship. Humour about the chores is discussed under the section 'being helpful' above.

Jim had asked Eileen and myself if we wanted a cup of tea. She replied that she didn't, but when he came in with tea for him and myself she asked jokingly, *'where's mine?'* He replied, *'you said you didn't want one'* and she said, *'I'm only pulling your leg!'*

Bodily relaxation

Although Eileen did spend some of her time repetitively walking between the kitchen and the lounge, straightening the flowers in the vase in the lounge and a board on the side in the kitchen, there were nevertheless times when she relaxed. Whilst watching television with Jim, or whilst sitting next to Jim on the sofa she would often relax as he stroked her leg or held her foot.

Creative self-expression

Jim had mentioned Eileen's continuing ability and love of singing which has remained throughout her illness. As a member of a singing group during her earlier life, she knows a range of songs and has a strong voice. She likes to sing at church occasions and also to her great-grandson. I witnessed her love of singing and her beautiful voice during Songs of Praise when she joined in with all of the hymns and was in a very high state of well-being.

Showing pleasure or enjoyment

Eileen often showed great pleasure in every day activities as well as during her singing. While we were at the Alzheimer's Society lunch some of the staff came round and offered food. Each time Eileen's face lit up as she enjoyed different items.

When neighbours greeted Eileen she looked very pleased to see them and showed great warmth towards them.

Responding appropriately to others

During my stay I helped Jim by drying the dishes while he washed up. On one occasion Eileen came out and on seeing me washing up said, '*you're doing a good job*'.

Expressing appropriate emotions

Jim described Eileen as a good natured person, and there were always signs of this side of her personality. She was happy to greet visitors and grateful when offered food or drink. Eileen presented as a very happy and contented person during my stay, and the only other emotion I saw was slight anxiety at times when she would appear confused and ask, '*what have I got to do Jimmy?*' She would often repeat this, but eventually would become calm and contented again.

Holding her own socially

Their playful banter gave Eileen many opportunities to hold her own with Jim. She would often 'give as good as she got'. For example, when asked jokingly if she had finished the hovering and dusting, to reply '*as much as I'm going to do!*'

She was also aware of Jim's own failing memory for certain words, and in finishing sentences at times. After tea one evening Jim had begun to share a story with me, '*many years ago...*' when he became distracted. Eileen asked him, '*many years ago what?!*' Similarly while he was talking about their previous holidays and was trying to remember a place name she said, '*where is it?!*' again joking with him.

Alertness

Eileen did doze off in her chair at times during the day. However whilst awake she was rarely just staring vacantly, but would take an active interest in what was on the television. During the live showing of the London Marathon she exclaimed, '*look at all those people!*' However on occasions when other people were present, for example, the next door neighbour, or friends at the Alzheimer's Society lunch, and they were in conversation which excluded Eileen, her eyes would sometimes glaze over. However on these occasions when I, or someone else spoke to her, she became engaged instantly.

Being active

Eileen shows signs of making use of her remaining abilities. She still walks reasonably moderate distances. They live on a steep hill and she is still able to walk back up the hill from getting a paper with Jim in the morning, albeit more slowly than she used to.

Her speech is much reduced but she still uses it to communicate with others. Although the jobs she can do around the house are now limited she still helps with the washing up, and if there are no chores to be done

she may straighten items in the kitchen, or flowers in the lounge, as she may always have done.

Being purposeful

By expressing her needs about for example, being cold, to Jim, Eileen is showing signs of feeling able to make things happen. At one point when Eileen told Jim, '*come on Jimmy, I'm getting cold!*' we went back to the car. At home he found her a blanket.

If there were cups on the table Eileen would take them out to the kitchen. If there were no chores which needed doing she may straighten items in the kitchen, or flowers in the lounge, as she may always have done.

Indicators of ill-being

Depression or despair

Eileen showed only one very small sign of depression during my stay: Eileen wore smart, good quality clothes which suited her well. Jim now selects items for her to wear. During my stay he asked my opinion on the match between a skirt and jacket he had found in her wardrobe – they were an excellent match that my own mother would have been proud of! Eileen wore this combination to the Alzheimer's Society lunch where everyone had dressed up. I remarked to Eileen that I thought everyone there looked smart and she replied, '*except me*'.

Intense anger

Eileen showed no signs of anger, however small, during my stay.

Grief

Agitation may be viewed as a sign of grief. Perhaps in Eileen's case her wandering to and from the kitchen and the lounge, straightening certain items, could be seen as grief for the loss of status as homemaker.

However Jim told me that Eileen was always a very tidy person, so this straightening may still be serving a purpose to her as a form of tidying.

The remark by Eileen at the Alzheimer's Society lunch about her not being smart (in the section above on depression) may indicate that she feels some loss in terms of her perception of her appearance.

Anxiety

Eileen showed some signs of anxiety when, at times, she asked Jim repetitively, '*what have I got to do Jimmy?*' Her wandering to and from the kitchen and lounge straightening certain items could also be viewed as an indication of underlying anxiety, although this was not visible facially. In addition, Jim told me that Eileen was always a very tidy person, so this straightening may still be serving a purpose to her as a form of tidying.

Fear

Eileen showed no signs of this intense form of anxiety during my visit.

Boredom

Eileen's repetitive questioning '*what have I got to do now Jimmy?*' and restless wandering could be viewed as signs of boredom. However the wandering may be, for Eileen, engaging in work around the home as she straightened certain items during her pacing and Jim confirmed that she had always been a tidy person.

Physical discomfort / pain

Eileen showed no signs of physical discomfort during my stay.

Bodily tension

Eileen often showed signs of bodily relaxation, for example, when sitting with Jim on the sofa, or when enjoying a coffee at C & H Fabrics in Chichester. She showed no signs of bodily tension during my visit.

Agitation

Eileen's repetitive questioning '*what have I got to do now Jimmy?*' and restless wandering are signs of agitation, but it must be noted that during these occasions she showed no signs of ill-being, and may be an expression of work around the home.

Apathy and withdrawal

The only time Eileen showed slight signs of apathy or withdrawal was when there were more than three people present and she wasn't being engaged by any of them in conversation, for example during one evening when her next door neighbour visited, and at the Alzheimer's Society lunch. However, it must be noted that in these instances she was always responsive to stimulation and became engaged when spoken to.

Jim told me that he tries to stop Eileen from sleeping too long during the day and stimulates her, giving her something to do by, for example, throwing a rolled up piece of paper on the floor. He says that as a tidy woman, Eileen can't bear a piece of rubbish on the floor for long and will get up and tidy it.

Distress

Eileen did not show any signs of distress during my stay.

Cultural isolation

Eileen and Jim have a very good network of neighbours and friends surrounding them, who they have known for many years. These neighbours are also elderly and some have their own health problems too. This was a strong community where people helped one another. During my stay Jim did a small plumbing job for their next door neighbour.

They have friends with whom they go out for a meal at the local pub each Friday. This has been such a long standing tradition that the landlord has affectionately named them 'The Friday Club'.

Eileen is still very much included in activities with these friends and neighbours. However unless they actually direct their conversation to her she can, at times, lack engagement. Her cultural isolation, although very minimal, would be based on her having dementia and being much slower and more verbally limited in her communication.

Difficulty withstanding powerful others

I did not witness Eileen in any environment which included a powerful other. Her banter with Jim may lead to the conclusion that she would be able to give as good as she gets.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 1 |
|---|---------|
| Making wishes known (non-destructively) | 2 |
| Initiating social contact | 1 |
| Warmth and affection | 2 |
| Self-respect | 1 |
| Being helpful | 2 |
| Humour | 2 |
| Bodily relaxation | 2 |
| Creative self-expression | 2 |
| Showing pleasure or enjoyment | 2 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 1 |
| Alertness, responsiveness | 1 |
| Being active | 2 |
| Being purposeful | 1 |
| Score | 23 |

TOTAL = 23/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 1 |
|---|---------|
| Depression or despair | 1 |
| Intense anger | 0 |
| Grief | 1 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 0 |
| Bodily tension | 0 |
| Agitation | 1 |
| Apathy and withdrawal | 1 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Score | 7 |

TOTAL = 7/26

Dementia Care Mapping (DCM)

Approximately 12 hours of DCM were carried out over the three days (7 hours, 4 hours and 1 hour respectively). Behaviour profiles showing the proportion of time spent in each category are shown graphically for each day. Similarly, graphs showing the well-being / ill-being values are given.

Sunday

Mapping periods: 11.30-14.35, 15.30-16.45, 17.45-19.05, 20.00-21.00

This was the longest total mapping period of the stay. As can be seen from the WIB summary tables, Eileen spent all of the mapping period in a state of well-being, with 90% being in a state of +1.

**A interacting verbally or otherwise
(with no other obvious activity)**

Eileen spent some of the mapping time talking – sometimes having a joke with Jim. When joking her WIB score increased to +3.

B being socially involved, but passively

Eileen spent about a quarter of the mapping time in a state of B. This may be due to Jim spending quite a bit of time talking to me. However she did join in on occasion.

C being socially uninvolved, withdrawn

During the entire mapping period over three days, Eileen did not show any signs of ill-being. However some of her time spent in category B, could be coded as 'ambiguous B/C', even though no distress was evident. In this case the B would be subject to the 30 minute deterioration rule and would 'downgrade' to a C after 30 minutes continuous ambiguous B. This did not happen during any of the mapping periods.

Jim was keen to avoid Eileen '*sleeping too much*' or entering C type behaviour. The only time Eileen was in danger of entering an ambiguous B/C type behaviour was when Jim was otherwise engaged with other people for example, during Sunday evening when their next door neighbour visited.

D unattended distress

There were no signs of category D during Sunday.

E engaging in an expressive or creative activity

The activities recoded as E during Sunday related to Eileen watching Songs of Praise and singing along in a high state of well-being to the hymns.

F eating, drinking

Approx 10% of mapping time was spent in this category.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Eileen did not participate in any activities of this nature during Sunday.

J participating in exercise or physical sports

Eileen and Jim had already been out for a walk to buy a paper before I arrived on Sunday. Their paper shop was approximately half a mile away and involved walking back up a very steep hill.

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

There was a lot of overlap between these two codes in Eileen's case. From where I was sitting in the lounge I did not immediately notice that Eileen's walking from the lounge to the kitchen and back again included her straightening some flowers in a vase, and also some items in the kitchen.

M engaging with media

Eileen watched the television on and off during the day. She took a particular interest in some programmes, initiating a chat with me about both the London Marathon and a boxing match.

N sleeping, dozing

Eileen spent just over 10% of the total mapping time for Sunday sleeping.

O independently engaging in self-care

Time engaged in this code today referred to Eileen straightening her skirt on occasions.

P receiving practical, physical or personal care

This was not witnessed during the mapping periods but was an integral part of their day, for example in getting dressed and undressed.

R participating in a religious activity

Although no behaviour was code as R during the mapping period it could be argued that the time Eileen spent singing to 'Songs of Praise' (coded E) could have been coded as R.

S activity related to explicit sexual expression

There was no behaviour observed during Sunday of a sexual nature.

T direct engagement of the senses

Although coded E, singing along to the hymns on Songs of Praise could have been coded T in parts, since many senses were being engaged and Eileen was in a high state of well-being (+5) for some of the time. Additionally, when sitting with Eileen, Jim would often stroke her leg or hold her foot as she rested.

U communicating without receiving a response

Behaviour of type U was not observed during Sunday.

W repetitive self-stimulation

Eileen did not engage in any behaviours of this type during Sunday. However it could be argued that some of the repetitive walking from kitchen to lounge could be coded as W.

X episodes related to excretion

These episodes were not recoded during mapping periods.

Y talking to oneself, or an imagined person; hallucination

No behaviour of this code was observed during any time on Sunday.

Z behaviours that fit no existing category

No extra behaviours were noted during Sunday.

Monday

Mapping periods: 12.00-13.50, 14.00-16.00

Before the mapping periods started we had spent the morning in Chichester, having a coffee, walking around the shops and round the outside of the cathedral. The mapping started when we returned. I only mapped during the afternoon as I became very tired in the evening and Jim spent quite a bit of the evening chatting to me. As well as requiring quite a lot of concentration and attention to map whilst trying to engage in a conversation, it is also time when the carer is not in their usual 'mode' with the person with dementia.

Again Eileen remained in a state of well-being throughout the mapping period (90% of her time in a state of +1). This was typical of her mood throughout the rest of the day.

A interacting verbally or otherwise (with no other obvious activity)

Eileen spent a little over 10% of the mapping time talking.

B being socially involved, but passively

As for yesterday, Eileen spent some time in a state of B, just over 15 % of the mapping time.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Monday.

E engaging in an expressive or creative activity

Eileen did not engage in any category E on Monday.

F eating, drinking

A quarter of the total mapping time was spent in category F.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

Eileen did not engage in any activities of these types during Monday, except when we walked around C & H Fabrics to get a coffee she showed some interest in the materials laid out on the shelves, but Jim was keen to get a coffee so we didn't linger.

J participating in exercise or physical sports

Although no time periods were recorded as J during the mapping we did walk quite a long way during the morning around Chichester.

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

As for yesterday, there was a lot of overlap between these two codes. Eileen goes to and from the kitchen and lounge straightening things or sometimes looking for something to tidy. She spent about a quarter of the mapping time doing this.

M engaging with media

Eileen watched the television a little during the day.

N sleeping, dozing

Eileen spent just over 10 % of the total mapping period for Monday sleeping, as she did on Sunday.

O independently engaging in self-care

As for yesterday, Eileen would occasionally straighten her skirt

P receiving practical, physical or personal care

I observed one episode of care during the mapping period.

R participating in a religious activity

Eileen did not engage in any religious activity during Monday.

S activity related to explicit sexual expression

There was no behaviour observed during Monday of a sexual nature.

T direct engagement of the senses

Although not noted during mapping, when sitting with Eileen Jim often stroked her leg or held her foot as she rested.

U communicating without receiving a response

Behaviour of type U was not observed during Monday.

W repetitive self-stimulation

Eileen did not engage in any behaviours of this type during Monday. However it could be argued that some of the repetitive walking from kitchen to lounge could be coded as W.

X episodes related to excretion

These episodes were not recoded during mapping periods.

Y talking to oneself, or an imagined person; hallucination

No behaviour of this code was observed during any time on Monday.

Z behaviours that fit no existing category

No extra behaviours were noted during Monday.

Tuesday

Mapping periods: 09.55-11.10

A very short mapping period on this, the final day of my stay. I was very tired and could only manage just over an hour of mapping. The mapping ended when we drove to the Alzheimer's society lunch.

During the short mapping period Eileen spent approximately 90% of her time in a well-being state of +1. This was typical of Tuesday and, indeed, of the whole stay. The only slight sign of ill-being during Tuesday was

while I was chatting to Eileen at the Alzheimer's lunch and remarked to her that everyone looked smart & she replied '*except me*'. Also during the lunch were periods of 'ambiguous B/C', but not for periods of longer than 30 minutes.

**A interacting verbally or otherwise
 (with no other obvious activity)**

Again Eileen spent a little over 10% of the mapping time talking.

B being socially involved, but passively

Eileen spent about 20% of the mapping time in a state of B. This was in the morning before getting ready for the lunch.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of category C or D during Tuesday.

E engaging in an expressive or creative activity

Eileen did not engage in any E today.

F eating, drinking

No mapping was carried out during meal or tea times.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

J participating in exercise or physical sports

Eileen did not engage in any activities of these types during Tuesday.

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

Although neither of these categories were noted during mapping, as for yesterday Eileen went to and from the kitchen and lounge straightening

things or sometimes looking for something to tidy, and there is some overlap between these codes.

M engaging with media

Eileen did not engage with any media, such as watching the television, whilst I was there on Tuesday.

N sleeping, dozing

Eileen spent 60 % of the total mapping period for Tuesday sleeping. However it must be noted that only 1 hour 15 minutes were spent mapping on Tuesday, during these quiet periods.

O independently engaging in self-care

As for yesterday, Eileen would occasionally straighten her skirt, but this was not noted during mapping.

P receiving practical, physical or personal care

I observed one episode of care during the mapping period.

R participating in a religious activity

Eileen did not engage in any religious activity during Tuesday

S activity related to explicit sexual expression

There was no behaviour observed during Tuesday of a sexual nature.

T direct engagement of the senses

Although not noted during mapping, when sitting with Eileen, Jim would often stroke her leg or hold her foot as she rested.

U communicating without receiving a response

Behaviour of type U was not observed during Tuesday

W repetitive self-stimulation

Eileen did not engage in any behaviours of this type during Tuesday's mapping. However it could be argued that some of the repetitive walking from kitchen to lounge could be coded as W.

X episodes related to excretion

These episodes were not recoded during mapping periods.

Y talking to oneself, or an imagined person; hallucination

No behaviour of this code was observed during any time on Tuesday.

Z behaviours that fit no existing category

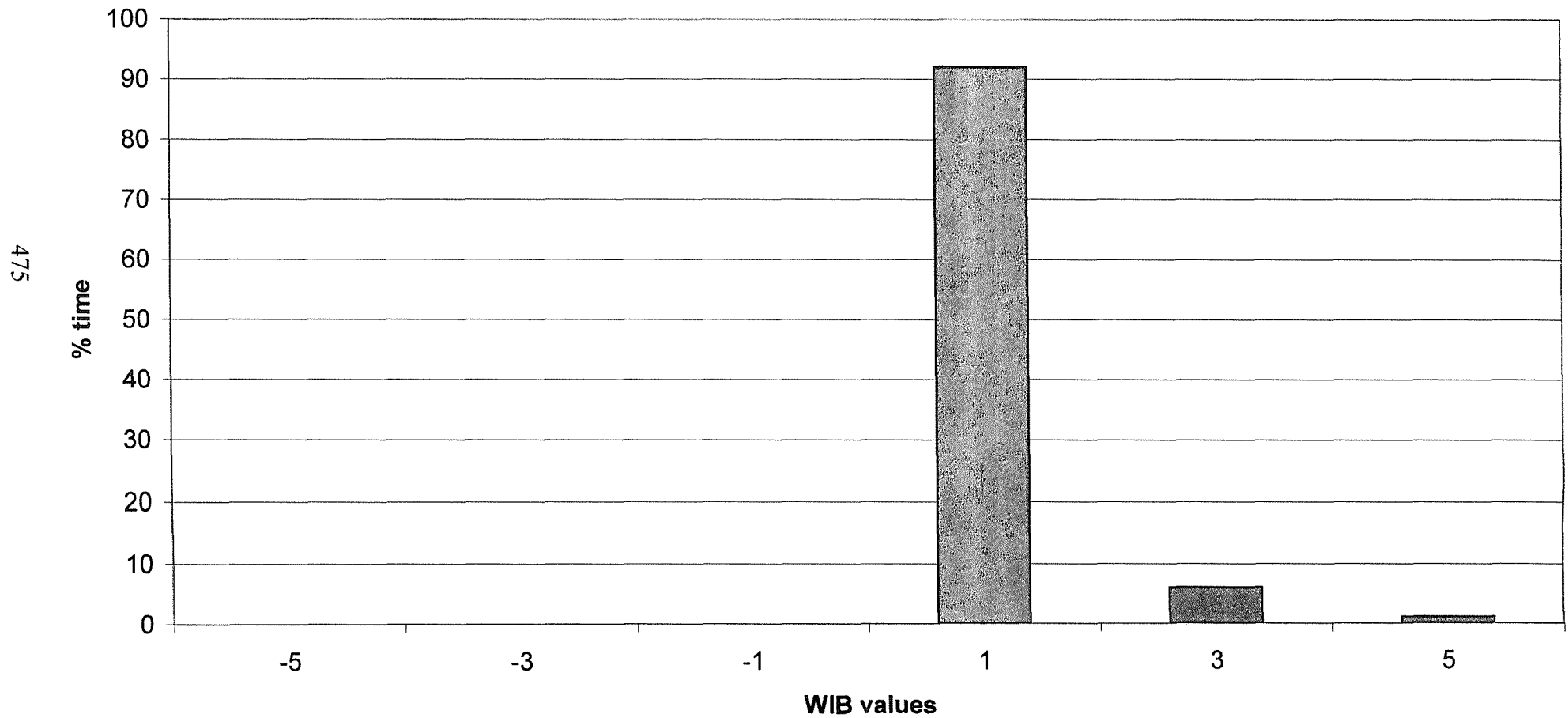
No extra behaviours were noted during Tuesday.

WIB values

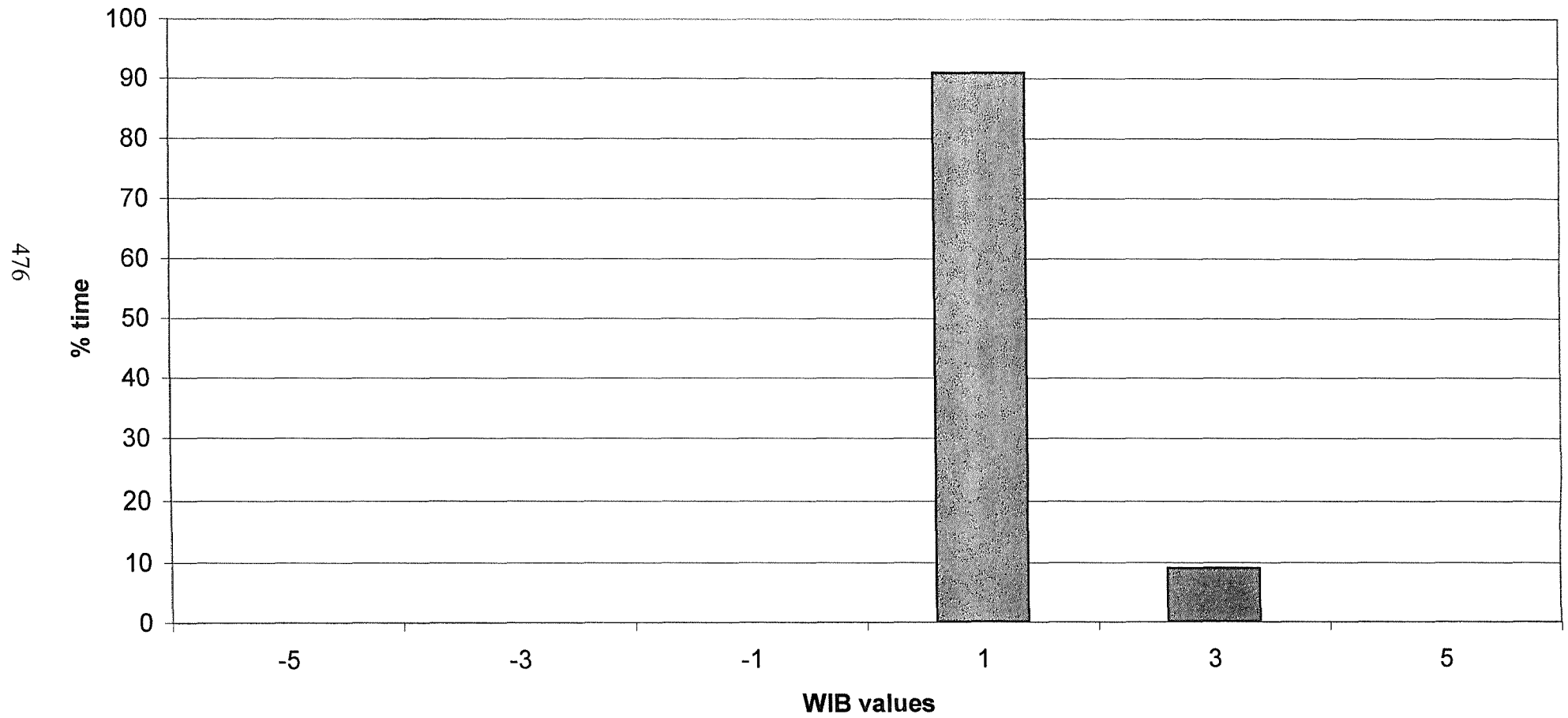
| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|-------|--------|--------|--------|----------|--------|--------|
| Sun | 0 (0) | 0 (0) | 0 (0) | 74 (92) | 5 (6) | 1 (1) |
| Mon | 0 (0) | 0 (0) | 0 (0) | 42 (91) | 4 (9) | 0 (0) |
| Tues | 0 (0) | 0 (0) | 0 (0) | 14 (93) | 1 (7) | 0 (0) |
| Total | 0 (0) | 0 (0) | 0 (0) | 130 (92) | 10 (7) | 1 (1) |

| | Sunday | Monday | Tuesday | 3 days |
|---------------|--------|--------|---------|--------|
| Σ WIB scores | + 94 | + 54 | + 17 | + 165 |
| Σ time frames | 80 | 46 | 15 | 141 |
| WIB value | + 1.2 | + 1.2 | + 1.1 | + 1.2 |

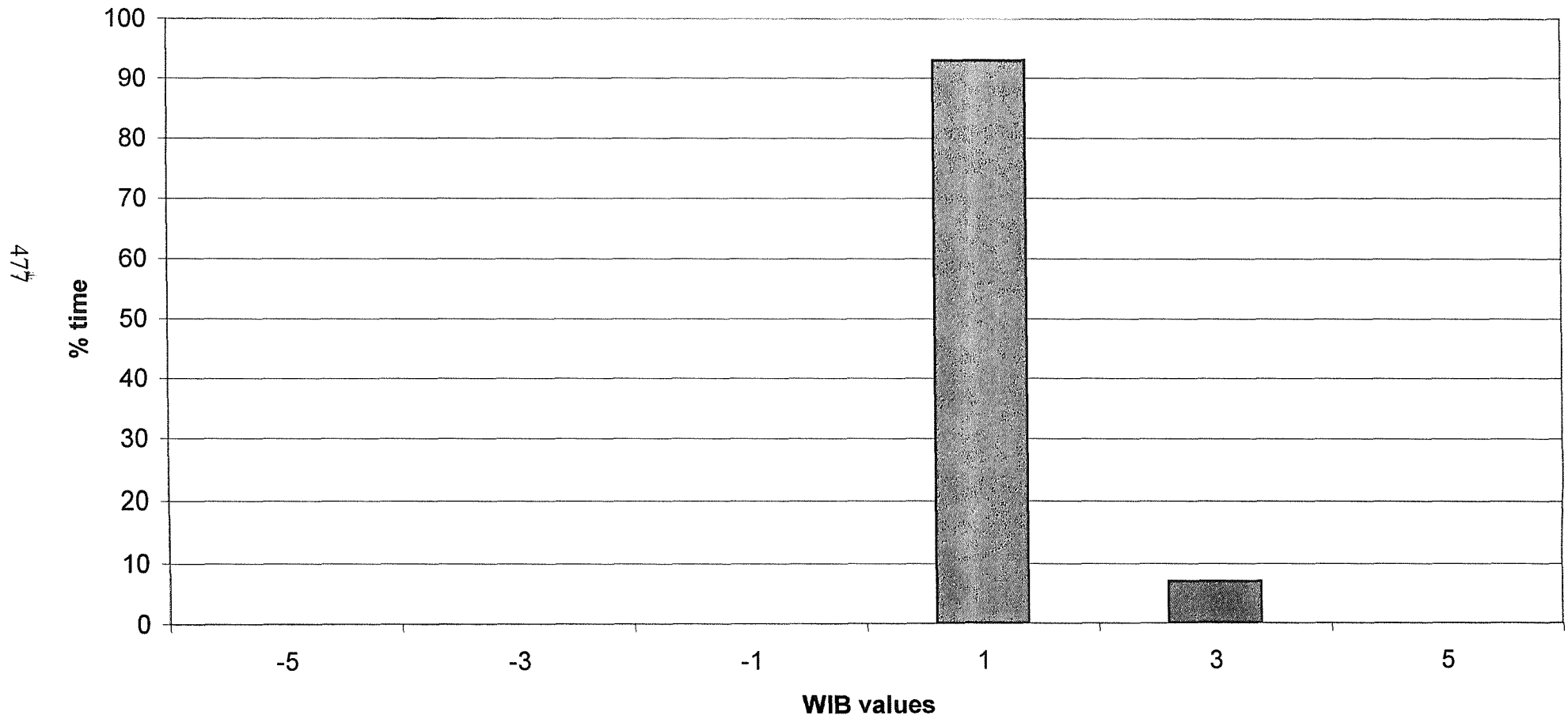
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WIB Profile
Sunday (Visit 1, April 2001)**



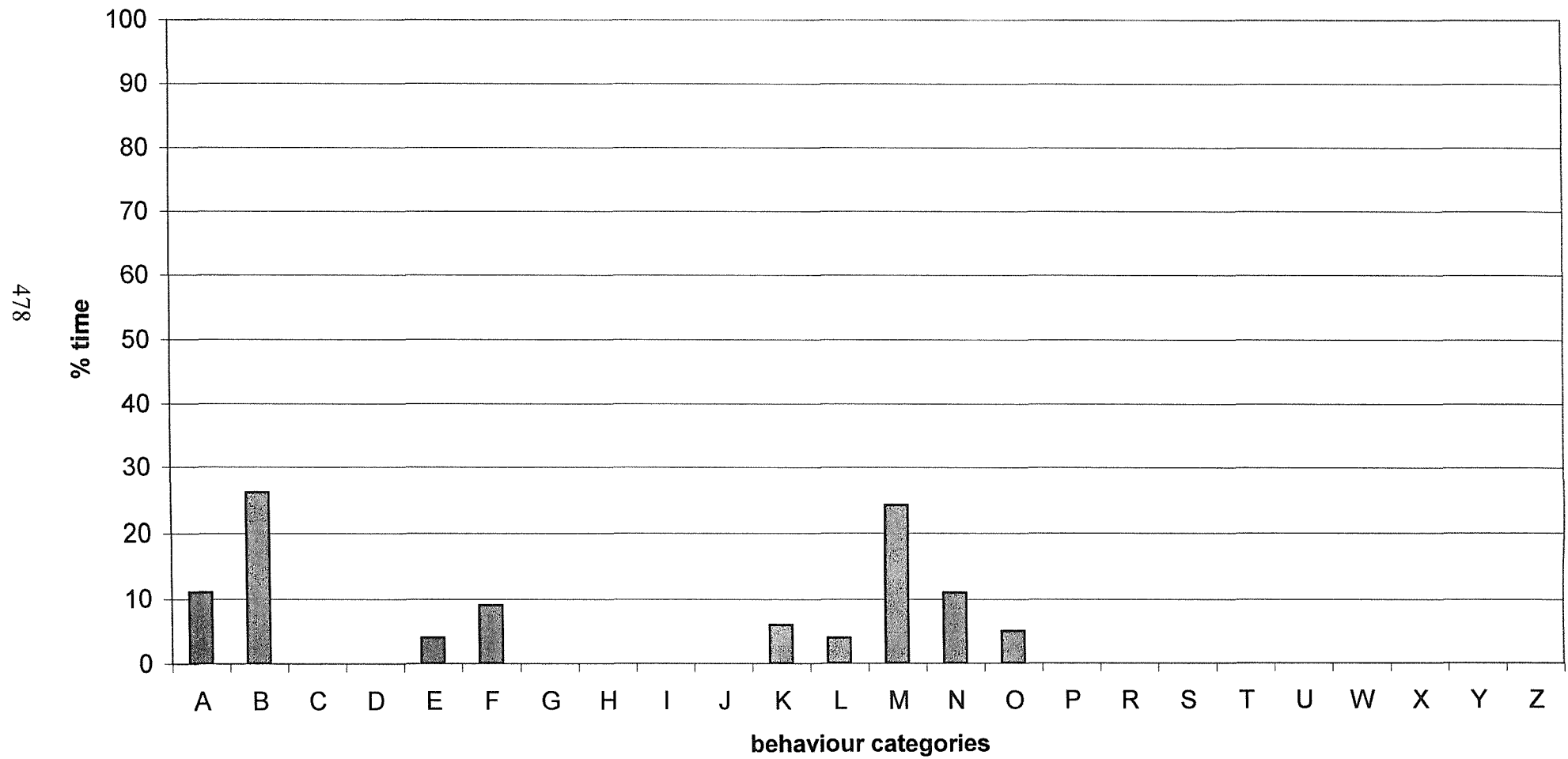
**Eileen
WIB Profile
Monday (Visit 1, April 2001)**



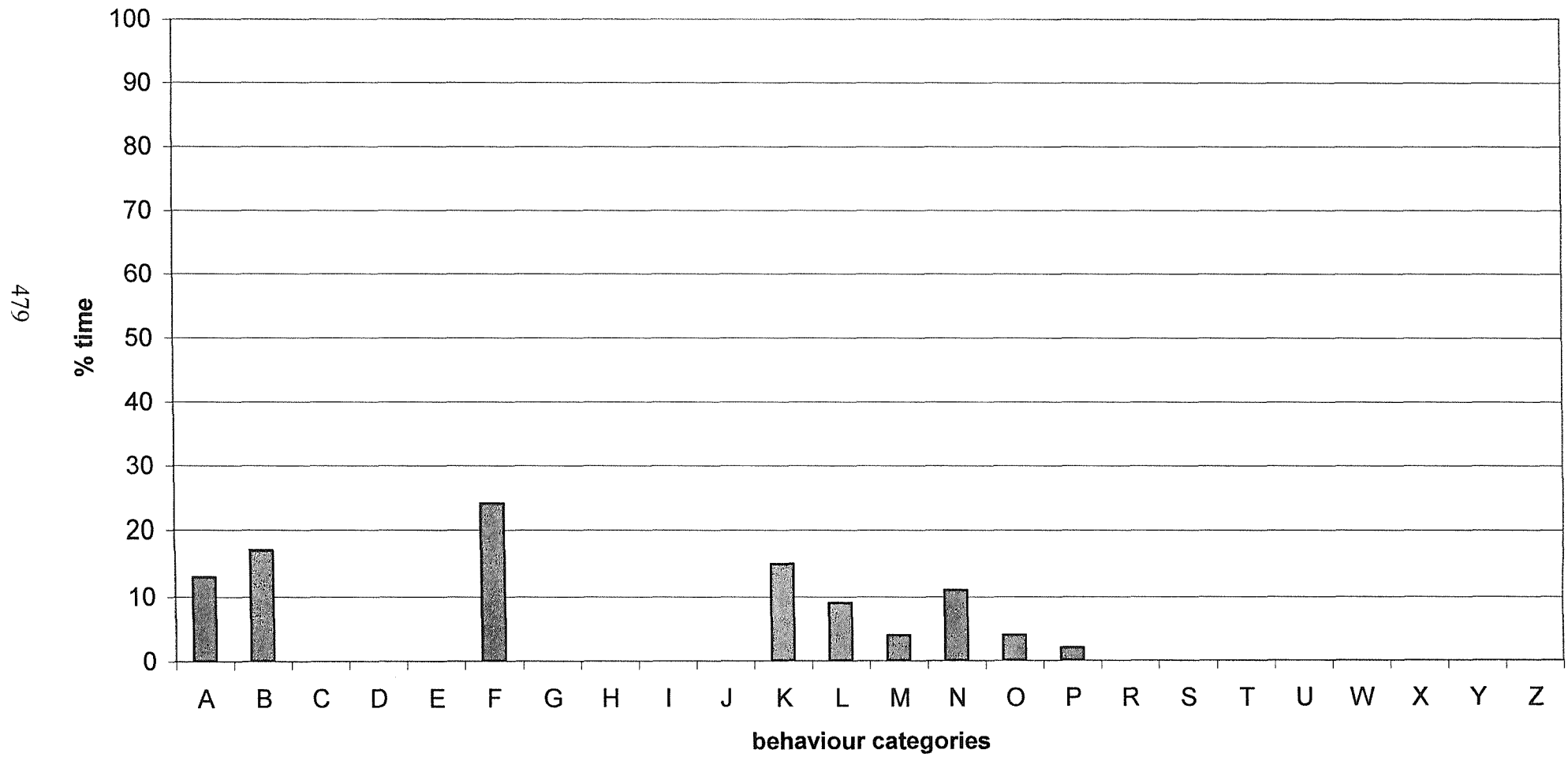
Eileen
WIB Profile
Tuesday (Visit 1, April 2001)



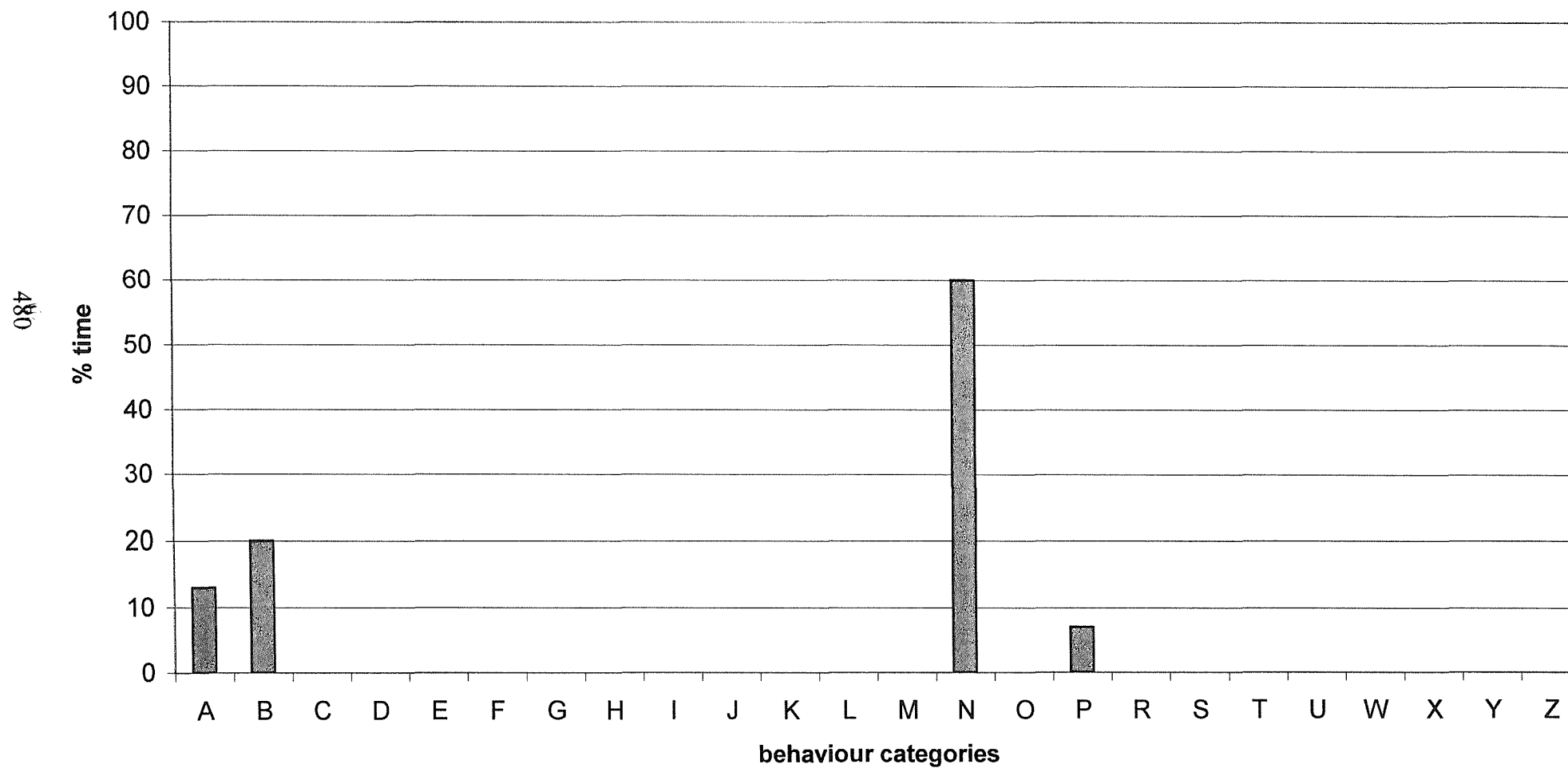
Eileen
Behaviour Profile
Sunday (Visit 1, April 2001)



Eileen
Behaviour Profile
Monday (Visit 1, April 2001)



Eileen
Behaviour Profile
Tuesday (Visit 1, April 2001)



Behaviour Category Grid

Eileen, Visit 1, April 2001

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |
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| Sun | 9 | 21 | 0 | 0 | 3 | 7 | 0 | 0 | 0 | 0 | 5 | 3 | 19 | 9 | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Sun,% | 11 | 26 | 0 | 0 | 4 | 9 | 0 | 0 | 0 | 0 | 6 | 4 | 24 | 11 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
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| Mon | 6 | 8 | 0 | 0 | 0 | 11 | 0 | 0 | 0 | 0 | 7 | 4 | 2 | 5 | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Mon,% | 13 | 17 | 0 | 0 | 0 | 24 | 0 | 0 | 0 | 0 | 15 | 9 | 4 | 11 | 4 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
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| Tue | 2 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 9 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Tue,% | 13 | 20 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 60 | 0 | 7 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
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| TOTAL | 17 | 32 | 0 | 0 | 3 | 18 | 0 | 0 | 0 | 0 | 12 | 7 | 21 | 23 | 6 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| % | 12 | 23 | 0 | 0 | 2 | 13 | 0 | 0 | 0 | 0 | 8 | 5 | 15 | 16 | 4 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
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| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |

Elements of Malignant Social Psychology

Ignoring (moderate)

On Sunday evening the next door neighbour came round for a chat. She greeted Eileen, but then spent her time talking exclusively to Jim and I. Eileen's face glazed over, and in terms of DCM she would be in a state of ambiguous B/C.

At the Alzheimer's Society lunch Eileen, Jim and myself sat on a table some of their friends from the group. Nobody actually talked directly to Eileen from the group.

Mockery (severe)

During her visit the next door neighbour was trying to remember a word and said *'oh I'm getting like Eileen!'* in Eileen's presence.

Positive Person Work

Timalation

While Eileen and Jim sat together on the sofa he would often stroke her leg or hold her foot.

While Jim and the male neighbour talked together, Eileen and his wife stood with them, holding each other's hand. Eileen smiled throughout.

Recognition

After their joking and banter together Eileen and Jim would laugh, clasp hands and gaze into each other's eyes.

On meeting some of their neighbours in Chichester one of them came up and faced Eileen directly saying *'oh hello Eileen, you take good care'*.

Play

Eileen and Jim's joking banter, as detailed in earlier sections of this report, was a strong feature of their communication together.

Caregiver support for intact abilities

Generally Eileen managed to eat her food un-aided, but Jim did assist in cutting up some of the less manageable items, such as slices of ham. Jim lets Eileen wash up, he says she is a tidy person, and will clear up dishes if she finishes eating first. She did take my tea cup out on one occasion while I was staying. Although she has some difficulty finding where to put the dishes (apparently she sometimes puts them in the oven), he does let her do this chore. However while I was staying, Jim and I tended to do the washing up. She did not seem to mind this at all and beamed when he said she could go and sit down in the lounge while we did the dishes.

Jim is also content to let Eileen wander between the kitchen and lounge making small tidying attempts. This may help to maintain some of Eileen's sense of self as 'homemaker'.

Validation of emotion by caregiver

On the few occasions when Eileen asked Jim *'what have I got to do Jimmy?'* or *'what am I doing Jimmy?'* sometimes repeating the same question many times, Jim would answer very patiently, reassuring her, for example *'nothing duck, come and sit down we'll be going to bed shortly'*. This suggested that Jim understood that Eileen felt slightly anxious and he took steps to reassure her.

When they sat together on the sofa he often held her foot or stroked her leg, helping her to settle.

On the whole Eileen showed positive emotions during my visit. When she was joking with Jim he would often cuddle her or look affectionately at her, helping to prolong the moment.

As Eileen did not show any outward signs of ill-being during my stay it was not possible to see Jim's reaction to negative emotions. However he did speak of a time a few years back when someone from social services took Jim and Eileen to look at a home where Eileen could be looked after for respite care. After they returned to their home Jim found Eileen *'sobbing her heart out'* and she begged him *'please don't send me away'*. He said he would not. Similarly Eileen had not enjoyed going to a day centre a few years ago and so he did not send her again.

Politeness strategies

I noted a couple of minor possible indications during my stay.

When I met Eileen again on the first morning of my stay Jim introduced me and Eileen shook my hand, smiling.

When we came back into the house from our visit to Chichester I said *'after you'* to her, allowing her to go indoors first. *'Thank you!'* she replied.

Jim had asked Eileen and myself if we wanted a cup of tea. She replied that she didn't, but when he came in with tea for him and myself she asked jokingly, *'where's mine?'* He replied, *'you said you didn't want one'* and she said, *'I'm only pulling your leg!'*. This reply of Eileen suggests that she does understand what he would have felt like if she hadn't told him that she was only having a joke with him.

Aspects of selfhood

There were many aspects of Eileen's 'selves' that were kept intact by the help of others:

'Self as wife' was still very much present. A couple who still showed each other a lot of affection after so many years together, Eileen and Jim presented to the world as a pair.

'Self as valued friend' was kept intact by the neighbours who met us in Chichester and stood holding Eileen's hand, making her feel included. Similarly, Eileen still being one of the 'Friday Club' at her local pub helps to keep this self intact.

'Self as homemaker'. Jim allowed Eileen to potter and tidy, even if she put the dishes away in the wrong place. This may serve to keep this aspect of her self intact.

Perception and social death

Jim's view of caring for someone with dementia is that *'you don't know what is going inside their head so you have to keep an open mind'*. He cited a couple of episodes of lucidity which had made him question what Eileen was still able to think and feel. The trip to the local home with someone from social services who had thought Jim might want some respite had resulted in Eileen breaking down and sobbing when back at home, begging him not to send her away. This had particularly struck Jim. On another occasion they had gone out for the day to a new museum in Basingstoke on a coach with the Alzheimer's society. The very next day as they were walking to the paper shop they had spotted a similar coach parked nearby and Eileen wanted to get on it, remembering (in Jim's view) the trip the day before and how much she had enjoyed it.

Her ability to sing and remember the words from songs fascinates him and again reinforces his view that there is more *'going on'* than we sometimes give credit for.

The Bristol Activities of Daily Living (BADLS)

Scores:

Completed by Jim Jackson 38

Completed by Alison Carr 29

I had awarded slightly lower scores for items dealing with intimate care, as I had not observed this. I did, however, observe Jim helping Eileen to put on a jacket and she moved her arms to help, so scored dressing as 'unable to dress self but moves limbs to assist', whereas Jim scored dressing as 'unable to assist and requires total dressing'.

My scores were generally indicating a slightly higher level of ability than Jim did.

The Behaviour Rating Scale for Psychological and Social Problems (BPS)

| | cognition/ | | mood | | social contact | | total |
|---------|------------|-------------|------|-------|----------------|----------|--------|
| Jackson | 41/44 | very severe | 4/28 | light | 13/20 | severe | 70/140 |
| Carr | 35/44 | severe | 0/28 | none | 7/20 | moderate | 49/140 |

Again, my scoring reflected slightly higher abilities and a slightly lower level of care than Jim's scores. This, in part, may be due to my relative unfamiliarity with Eileen, but may also reflect a different view from

observer to carer. With hindsight, and after completing this written report, I would increase my mood score from 0 to be more in line with Jim's.

Visit 2, October 2001

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

Eileen is clearly able to make her wishes known both at home with Jim and at the day centre. At home when asked if she wants a cup of tea she will reply, '*oh yes please!*' Both at home and at the day centre she will ask for help when wanting to go to the toilet.

Initiating social contact

As before, Eileen initiated social contact easily. For example when I arrived she pointed out the garden to me saying how lovely the colours were.

Warmth and affection

Eileen shows a lot of affection towards Jimmy, sitting close together on the sofa they often hold hands and gaze into each others eyes.

Self Respect

As before, I observed Eileen straightening her skirt from time to time. She also pointed out some bristles on her chin to Jim who said he would pluck them out.

Being helpful

Eileen is often found between the kitchen and lounge tidying, or seeming to tidy. She was very helpful towards another client at the day centre, showing her how to roll the dice and encouraging her when she did it right.

Humour

There is still a lot of humour and 'private jokes' between Eileen and Jim, where they laugh together and hold each others hands after teasing each other.

Bodily relaxation

Both at home and in the day centre Eileen was able to relax fully. At home when she slept in the afternoon she was cuddled up to Jim.

Creative self-expression

Eileen's love of singing shined through during this visit, moving her into higher states of well-being.

Showing pleasure or enjoyment

Eileen often showed pleasure, for example after watching a television programme she turned to me and said how lovely it was. She also took great delight in the flowers in the garden, in particular the pink ones.

Responding appropriately to others

Eileen realises that Jim is hard of hearing and repeated what she said whenever he asked. She also gave support to the lady at the day centre who wasn't sure how to roll the dice.

Expressing appropriate emotions

Eileen shows joy when singing or watching other people sing, and is occasionally anxious when she can't find Jim.

Holding her own socially

Eileen is comfortable in the company of others. This was evident at the day centre. At home she jokes with Jim and 'gives as good as she gets' as at my previous visit.

Alertness

Eileen is alert a lot of the time, either taking part in what is going on or watching, for example the bird on the bird table feeding.

Being active

Eileen's 'work' in walking between the lounge and kitchen straightening things shows that she is active. At the day centre she was always willing to take part in activities.

Being purposeful

As above, Eileen finds things to tidy or straighten. However, she sometimes becomes confused saying, '*what have I got to do now Jimmy?*'

Indicators of ill-being

Depression or despair

Eileen showed no signs of depression or despair at this visit.

Intense anger

Eileen showed no anger during this visit.

Grief

Eileen showed no signs of grief at this visit.

Anxiety

I observed some sign of anxiety once during my visit when Eileen was looking for Jim who was upstairs.

Fear

Eileen showed no signs of fear during this visit.

Boredom

Eileen went to sleep for a couple of hours one afternoon at home. However she did not sleep at the day centre and this could be seen as a sign of boredom at home. On the other hand she slept close to Jim who was cuddling her.

Physical discomfort / pain

Eileen did not show any signs of discomfort during this visit.

Bodily tension

Eileen did not show any signs of tension during this visit.

Agitation

Eileen's constant walking between the kitchen and lounge, straightening things as she goes, could be seen as a sign of some agitation as she does this in a very repetitive manner.

Apathy and withdrawal

Eileen showed no signs of this category during my visit.

Distress

Eileen showed no signs of distress.

Cultural isolation

At the day centre Eileen was very much included and took part willingly in activities.

Difficulty withstanding powerful others

Eileen sticks up for herself when joking with Jimmy and shows no signs of difficulty.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 2 |
|---|---------|
| Making wishes known (non-destructively) | 2 |
| Initiating social contact | 2 |
| Warmth and affection | 2 |
| Self-respect | 1 |
| Being helpful | 2 |
| Humour | 2 |
| Bodily relaxation | 2 |
| Creative self-expression | 2 |
| Showing pleasure or enjoyment | 2 |
| Responding appropriately to others | 1 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 1 |
| Alertness, responsiveness | 1 |
| Being active | 2 |
| Being purposeful | 1 |
| Score | 24 |

TOTAL = 24/30

III-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 2 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 0 |
| Bodily tension | 0 |
| Agitation | 1 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 1 |
| Difficulty withstanding powerful others | 0 |
| Score | 4 |

TOTAL = 4/26

Dementia Care Mapping (DCM)

Approximately 12 hours of DCM were carried out over the three days (4 hours, 6 hours and 1 hour 40minutes respectively). Behaviour profiles showing the proportion of time spent in each category are shown graphically for each day. Similarly, graphs showing the well-being / ill-being values are given.

Sunday

Mapping periods: 11.55-13.45, 14.05-14.50, 17.35-19.00

A interacting verbally or otherwise (with no other obvious activity)

Eileen spent a little time talking during mapping.

B being socially involved, but passively

Eileen spent about a quarter of the total mapping time in a state of B, often when Jim was talking to me. However, at times she would join in with the conversation, and should signs that she had been following it.

C being socially uninvolved, withdrawn

D unattended distress

There were no signs of C or D during Sunday.

E engaging in an expressive or creative activity

Eileen's higher levels of well-being were often during periods of singing – either on her own or along to singing on the television.

F eating, drinking

About 10% of the mapping time was spent eating or drinking tea.

- G** participating in a game
- H** participating in a craft activity
- I** activity prioritising the use of intellectual abilities
- J** participating in exercise or physical sports

Eileen did not engage in any of the above activities during Sunday. The weather was bad so Jim decided not to go out for a walk.

- K** independent walking, standing or wheelchair-moving
- L** performing work or work-like activity

Some of Eileen's time is spent walking to and from the kitchen and lounge. Sometimes this could be coded at K and sometimes L when she appeared to be tidying, with a total of 10% of the mapping time spent in either K or L. When the activity seemed to be totally repetitive I have coded it as W.

- M** engaging with media

Eileen watched some television today but this is mainly coded as R or E as it was a religious programme and she was joining in singing the hymns.

- N** sleeping, dozing

Eileen spent 15% of the mapping time sleeping after lunch.

- O** independently engaging in self-care

Eileen would sometimes straighten her skirt, but this was not observed during mapping.

- P** receiving practical, physical or personal care

No aspects of physical care were carried out during mapping.

- R** participating in a religious activity

25% of the mapping time was spent watching Songs of Praise. Eileen very much enjoyed singing along to the hymns and listening to the readings.

S activity related to explicit sexual expression

T direct engagement of the senses

U communicating without receiving a response

None of the above categories were noted during mapping, although Jim would sometimes stroke her hand or foot when sitting together – and this happened outside mapping.

W repetitive self-stimulation

Although no periods of W were noted during mapping, again Eileen would spend some time walking between the kitchen and lounge as noted under L and K.

X episodes related to excretion

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

None of the above categories were noted during Sunday.

Monday

Mapping periods: 08.35-09.05, 10.05-11.15, 12.35-13.10, 13.45-16.10, 18.30-19.05, 20.35-21.00.

A interacting verbally or otherwise
(with no other obvious activity)

No episodes of talking were noted during mapping, but Eileen did join in the conversation between Jim and myself during other times of the day.

B being socially involved, but passively

A few times during mapping Eileen sat quietly. This was in between walking to and from the kitchen.

- C** being socially uninvolved, withdrawn
- D** unattended distress
- E** engaging in an expressive or creative activity

None of the above were noted during today.

- F** eating, drinking

10% of the total mapping time was spent eating or drinking.

- G** participating in a game
- H** participating in a craft activity
- I** activity prioritising the use of intellectual abilities
- J** participating in exercise or physical sports

None of the above were noted today. Jim would usually take Eileen for a walk to get the paper in the morning but the weather was terrible so we went in the car.

- K** independent walking, standing or wheelchair-moving
- L** performing work or work-like activity

No periods of K were noted during mapping. However just over 20% of the mapping time was spent in L and, as before, this was during walking to and from the kitchen straightening and tidying small items.

- M** engaging with media

Eileen watched some television today and very much enjoyed the programme, telling me it was lovely afterwards.

- N** sleeping, dozing

Just over 40% of the total mapping time was spent sleeping in the afternoon. Whereas this would usually be subject to degeneration in WIB values as Eileen was in close bodily contact with Jim throughout her WIB value was not degraded.

- O** independently engaging in self-care
- P** receiving practical, physical or personal care
- R** participating in a religious activity
- S** activity related to explicit sexual expression
- T** direct engagement of the senses
- U** communicating without receiving a response

None of the above categories were noted during mapping. However Jim occasionally stroked Eileen's foot or hand whilst she was asleep.

W repetitive self-stimulation

Just over 15% of the total mapping time was recorded as W. This was because Eileen's walking to and from the kitchen to undertake work had become very repetitive and each 'cycle' from one room to the other, touching certain objects (perhaps to straighten them) was in the same order. However she did not show signs of ill-being during this time except for one occasion when she was looking for Jim when she was slightly anxious. If the walking to and from the kitchen became more 'purposeful' it was coded as L.

- X** episodes related to excretion
- Y** talking to oneself, or an imagined person; hallucination
- Z** behaviours that fit no existing category

None of the above were noted today.

Tuesday

Mapping periods: 09.05-10.40.

- A** interacting verbally or otherwise
(with no other obvious activity)

No episode of talking were noted during mapping but Eileen did chat to staff and others at Homestead later in the day.

B being socially involved, but passively

One episode of sitting passively was noted as we drove to Homemead.

C being socially uninvolved, withdrawn

D unattended distress

None of the above categories were noted today.

E engaging in an expressive or creative activity

No episode of category E were noted during mapping, but Eileen did sing and dance at Homemead outside of the mapping period.

F eating, drinking

10% of the total mapping time was spent drinking tea at home and later on arrival at Homemead.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

None of the above categories were noted during mapping but Eileen did some handicrafts and played games at Homemead outside of the mapping time.

J participating in exercise or physical sports

At Homemead Eileen took part in the exercising.

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

As before, during mapping Eileen spent some time between the kitchen and lounge (also see W). 5% of the mapping time was coded as L.

- M** **engaging with media**
- N** **sleeping, dozing**
- O** **independently engaging in self-care**
- P** **receiving practical, physical or personal care**
- R** **participating in a religious activity**
- S** **activity related to explicit sexual expression**
- T** **direct engagement of the senses**
- U** **communicating without receiving a response**

None of the above were noted during mapping.

W repetitive self-stimulation

Before we went to the day centre Eileen became 'stuck' in a repetitive cycle of walking between the kitchen and lounge, straightening the fruit bowl etc. This was coded as W and represented 65% of the mapping time, just over an hour.

X episodes related to excretion

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

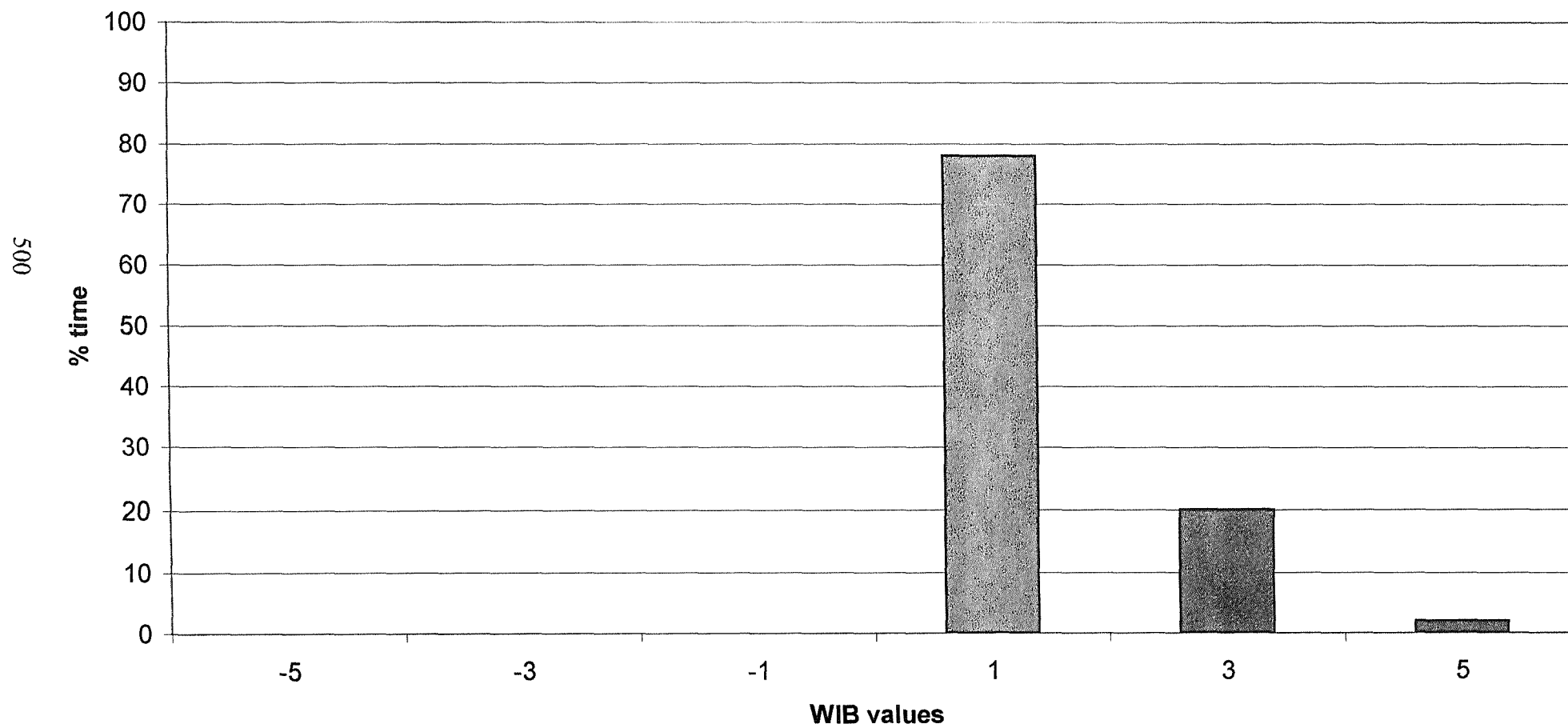
None of the above were observed today.

WIB values

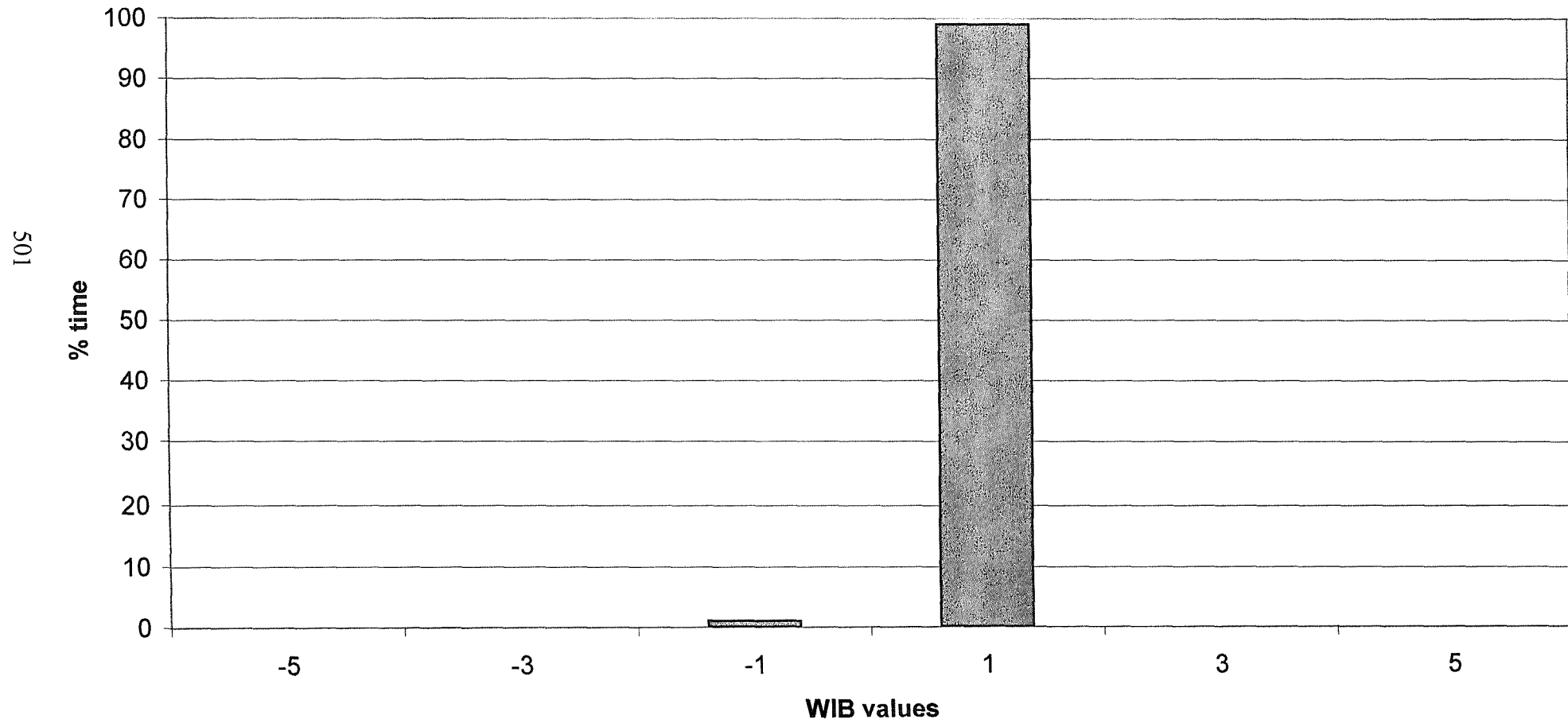
| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|-------|--------|--------|--------|----------|--------|--------|
| Sun | 0 (0) | 0 (0) | 0 (0) | 36 (78) | 9 (20) | 1 (2) |
| Mon | 0 (0) | 0 (0) | 1 (1) | 72 (99) | 0 (0) | 0 (0) |
| Tues | 0 (0) | 0 (0) | 0 (0) | 18 (90) | 2 (10) | 0 (0) |
| Total | 0 (0) | 0 (0) | 1 (1) | 126 (91) | 11 (8) | 1 (1) |

| | Sunday | Monday | Tuesday | 3 days |
|---------------|--------|--------|---------|--------|
| Σ WIB scores | + 68 | + 71 | + 24 | + 163 |
| Σ time frames | 46 | 73 | 20 | 139 |
| WIB value | + 1.5 | + 1.0 | + 1.2 | + 1.2 |

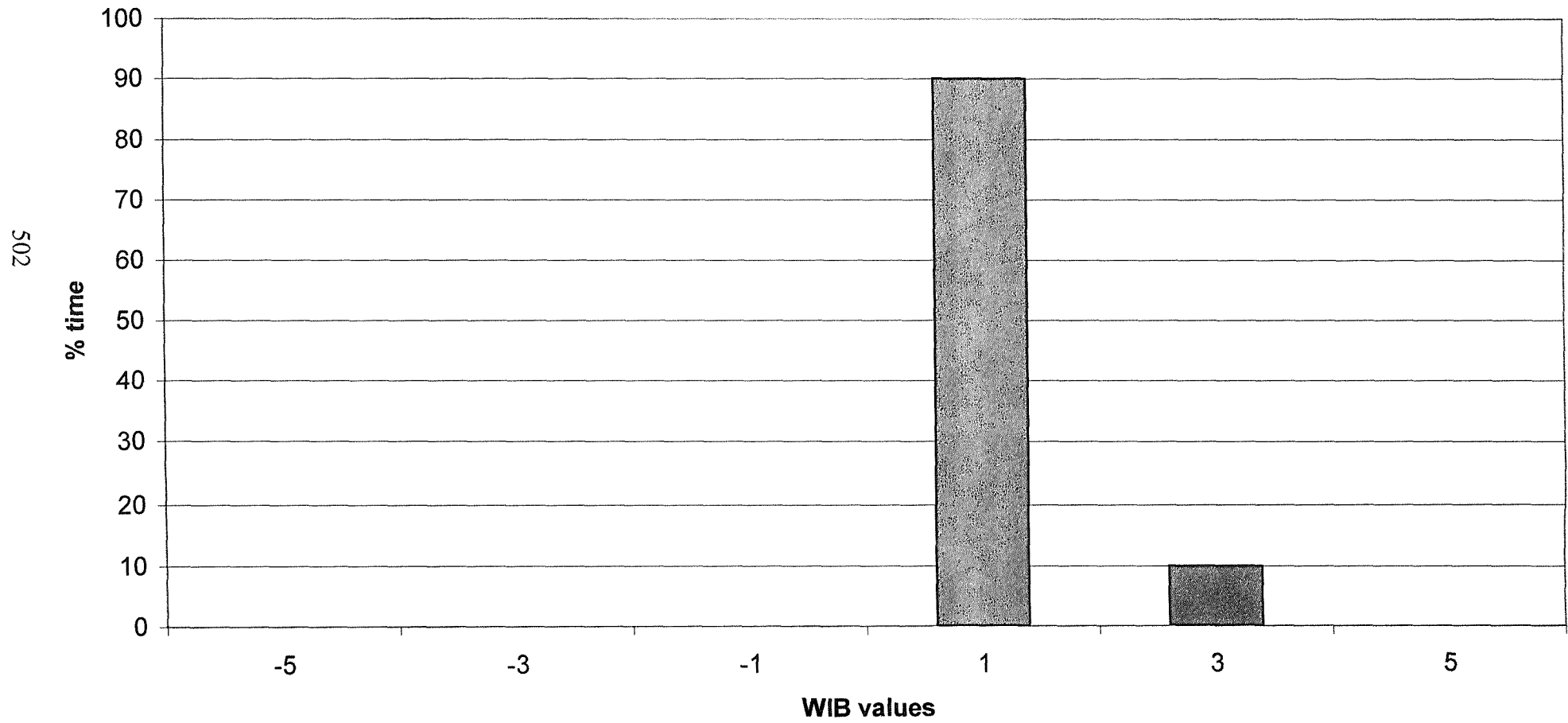
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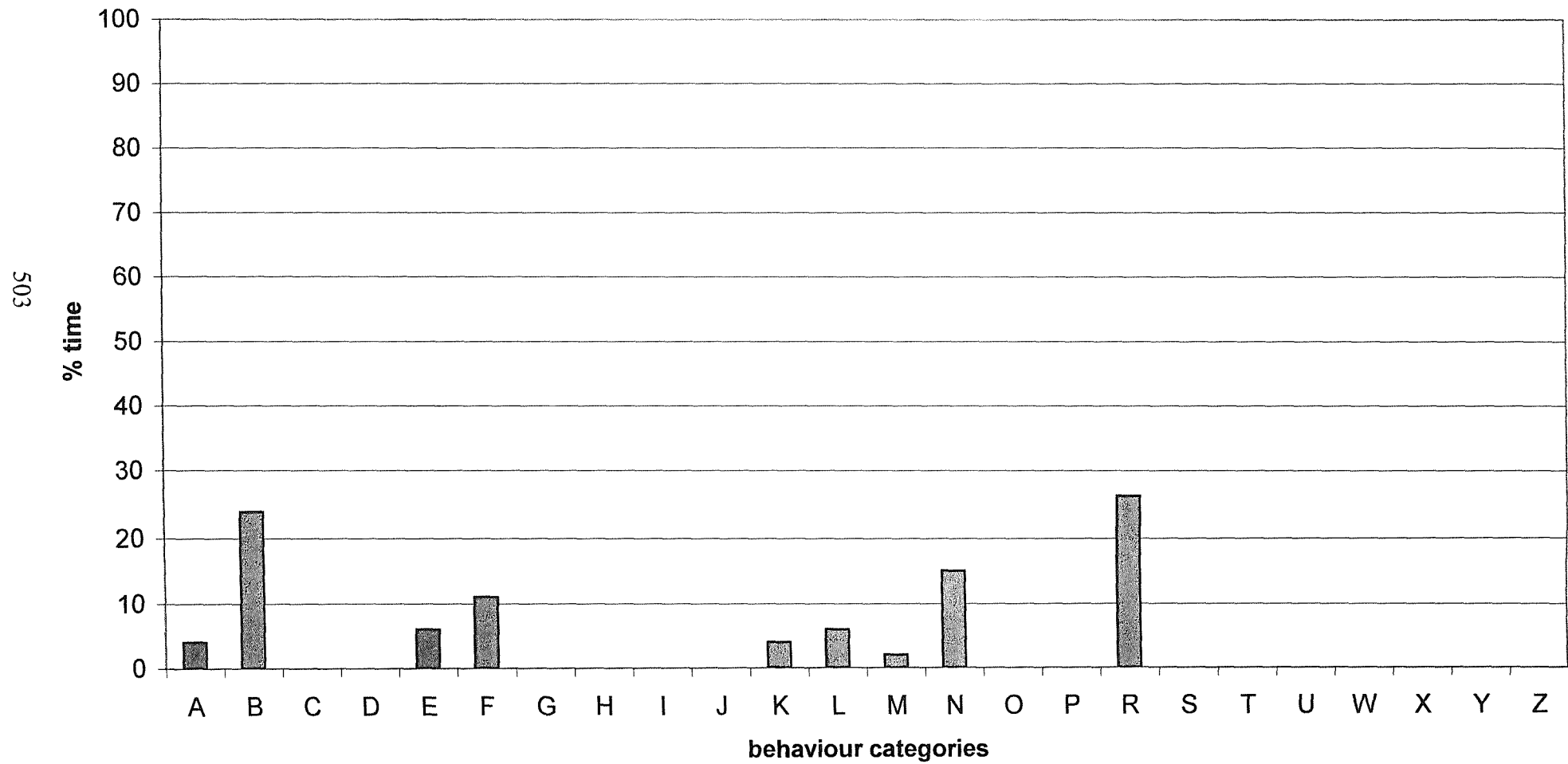
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WIB Profile
Monday (Visit 2, Oct 2001)**



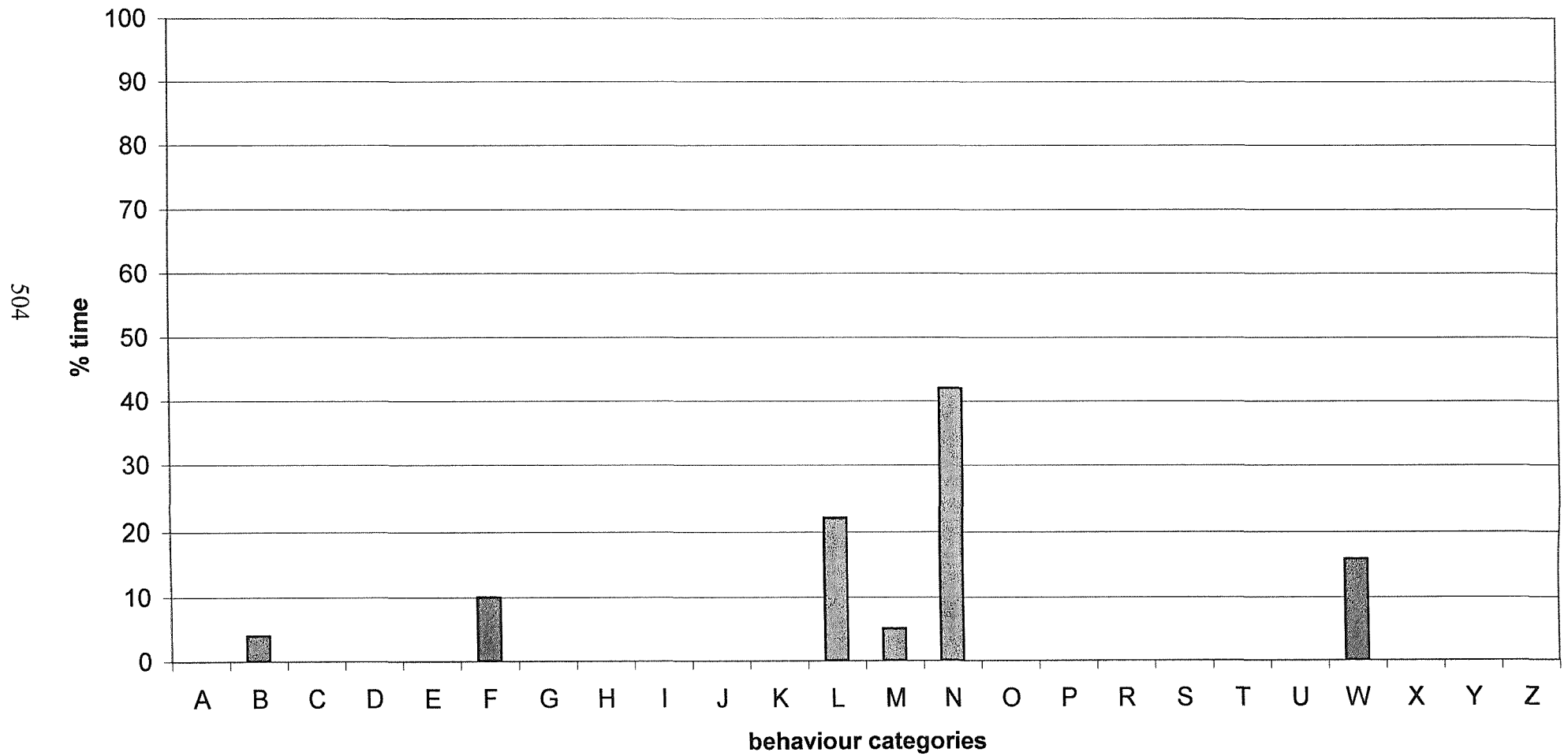
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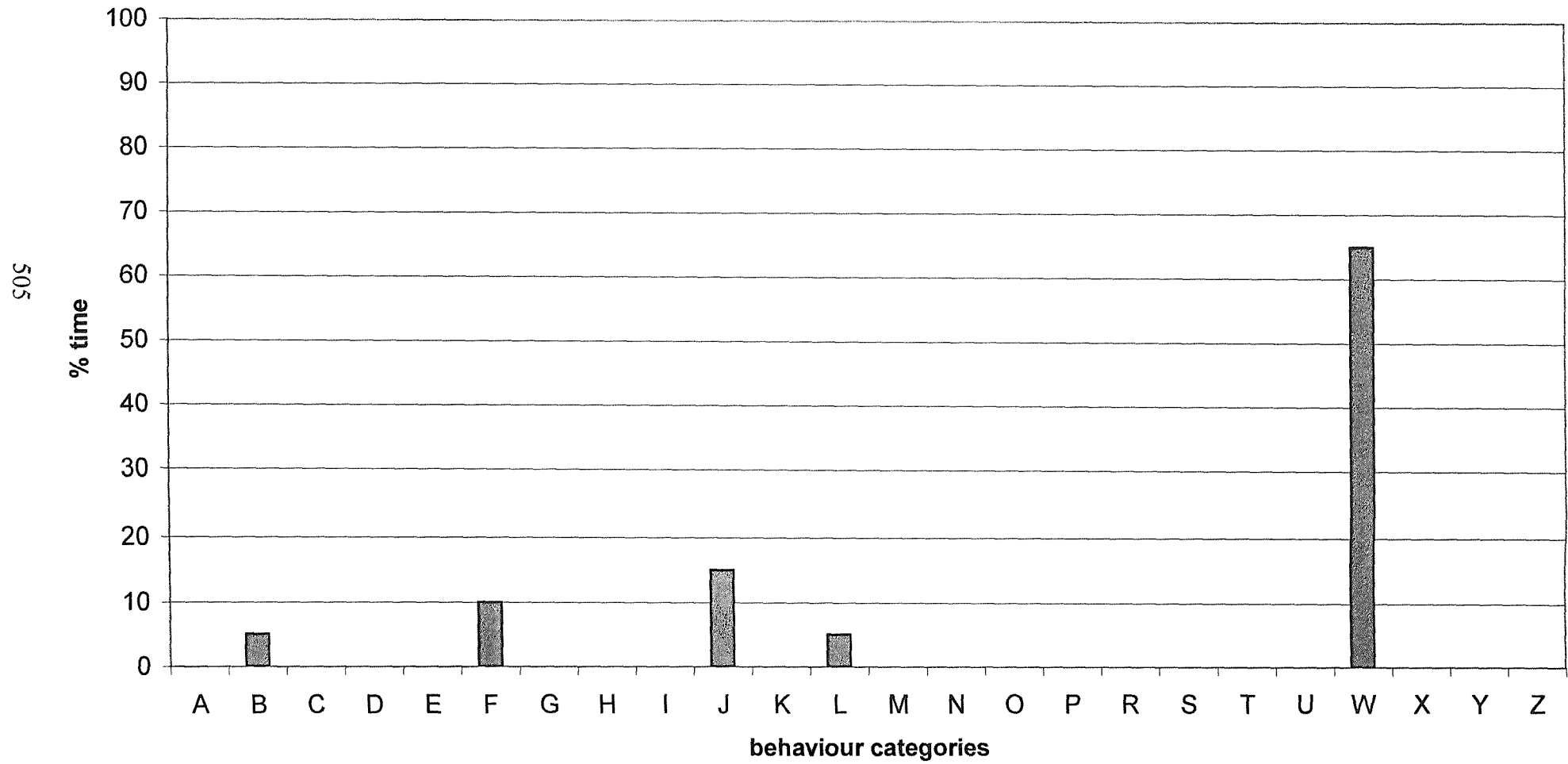
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Behaviour Category Grid

Eileen, Visit 2, Oct 2001

906

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |
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| Sun | 2 | 11 | 0 | 0 | 3 | 5 | 0 | 0 | 0 | 0 | 2 | 3 | 1 | 7 | 0 | 0 | 12 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Sun,% | 4 | 24 | 0 | 0 | 6 | 11 | 0 | 0 | 0 | 0 | 4 | 6 | 2 | 15 | 0 | 0 | 26 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Mon | 0 | 3 | 0 | 0 | 0 | 7 | 0 | 0 | 0 | 0 | 0 | 16 | 4 | 31 | 0 | 0 | 0 | 0 | 0 | 0 | 12 | 0 | 0 | 0 |
| Mon,% | 0 | 4 | 0 | 0 | 0 | 10 | 0 | 0 | 0 | 0 | 0 | 22 | 5 | 42 | 0 | 0 | 0 | 0 | 0 | 0 | 16 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Tue | 0 | 1 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 3 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 13 | 0 | 0 | 0 |
| Tue,% | 0 | 5 | 0 | 0 | 0 | 10 | 0 | 0 | 0 | 15 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 65 | 0 | 0 | 0 |
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| TOTAL | 2 | 15 | 0 | 0 | 3 | 14 | 0 | 0 | 0 | 3 | 2 | 20 | 5 | 38 | 0 | 0 | 12 | 0 | 0 | 0 | 25 | 0 | 0 | 0 |
| % | 1 | 11 | 0 | 0 | 2 | 10 | 0 | 0 | 0 | 2 | 1 | 14 | 4 | 27 | 0 | 0 | 9 | 0 | 0 | 0 | 18 | 0 | 0 | 0 |
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| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |

Elements of Malignant Social Psychology

Only one episode of MSP was noted during this stay. This was at Homemead, and applied to all the clients present.

Disparagement (moderate)

Whilst playing a board game called 'treasured memories' staff would read out the 'action' cards which were then to be carried out by clients. For example, Eileen demonstrated the hop-scotch. However, on looking at some cards the staff members decided '*they wont be able to do that*' and turned to another card. This meant that the spontaneity of the game was lost as staff searched for something '*they*' would be able to do. It would have been better to have selected cards to remove before the game.

Positive Person Work

Timalation

When sitting together Jim would often stroke Eileen's her foot or hand, causing her to smile and relax.

Collaboration

When engaged in personal care of Eileen, Jim would help her to get dressed, but it would be very much a joint effort, often with jokes and laughter.

Facilitation

When Jim gave Eileen her dinner he would give her a spoon and fork as he knew that she could manage with these. He would also always check if she needed any help and only cut up some food if she said she did want help.

Facilitation

One of the examples of positive person work is carried out by Eileen herself and helps to illustrate her high level of well-being. During a game in the afternoon the lady sitting next to Eileen couldn't manage to roll the dice. Eileen showed her how to and when she started to do so on her own gave encouragement saying, *'that's right, that's the way'*.

Caregiver support for intact abilities

Eileen still had many abilities intact, such as being able to eat unaided, but sometimes requiring the food to be cut into smaller pieces. Here Jim would always check before cutting and only help if Eileen asked. Similarly with getting dressed, washing and other personal care Jim would help Eileen but not take over. He would facilitate her ability to dress and they would be working together, often joking as they did.

Validation of emotion by caregiver

When Eileen was happily singing along to hymns Jim would encourage her, saying how lovely her voice was, joining in with her happy mood. When she became 'stuck' in her movement from the kitchen to the lounge straightening things he would try to encourage her to come and sit down, but she would often carry on. If she went to do some washing up he would often say *'don't worry about that I'll do it later'*. And although she looked pleased I wondered if she was searching for something to do. She would often say, *'what have I got to do now Jimmy?'* and he would answer *'nothing duck'*. This would suggest that he may not recognise her need for doing some 'work' in the home as she used to do. However he later spoke of trying to keep her busy by throwing paper on the floor so she would have something to tidy.

Politeness strategies

After lunch one day during my visit I took my tray out to the kitchen. Eileen was already out in the kitchen and on seeing me appear with my tray said, *'oh thank you very much!'* Similarly at the day centre when brought a cup of tea she would be very delighted and say *'oh thank you!'*

Eileen also understood Jim's need to have things repeated at times because of his hearing difficulties and she would repeat things if he looked baffled or said *'what?'*

Aspects of selfhood

Eileen's clear enjoyment of singing, something she used to do a lot of in her younger days, is still present and encouraged by both Jimmy and also the staff at the day centre.

She is much liked by the staff at the day centre as she is always happy and enjoys the activities. She is very appreciative of staff bringing her tea or lunch and sees this as a great treat. She also helps those less able than herself at the centre.

Jim and Eileen still attend the 'Friday Club' lunches with friends at the local pub, ensuring that Eileen is still included in her original social circle of friends.

However one aspect of Eileen's self, self as homemaker, I felt caused some difficulties. Jim is happy to do the washing up and meal preparation, and whilst Eileen seems pleased when he says, *'Don't worry duck, I'll do it'*, her repetitive walking to and from the kitchen and lounge straightening items suggests that this aspect of her selfhood is no longer fulfilled. However on another level Jim realises this and 'creates' work by throwing paper on the floor for her to tidy.

Perception and social death

Jim talked to me about how Eileen is now *'living in a void, a vacuum'*. He said that he has to do his best to fill that vacuum. Whilst initially I felt that meant he saw Eileen as socially dead, on deeper reflection I changed my mind as he added that he thought it must be terrible to be that person living in a vacuum, being able to move around but not to do anything any more. In other words he sees people with dementia as having diminishing abilities but still feeling emotions, and further sees the carers role as helping to fill the *'vacuum'* by initiating activities and helping them to pass the time. He went on to explain that he felt that the carer's interaction with the person with dementia was an important one because sometimes people with dementia can become very upset. He felt that the carer should try to *'take the line of least resistance'* and prevent the person with dementia from becoming upset. I would liken this view as favouring validation over reality orientation.

Visit 3, May 2002

Well-being / ill-being profiles:

Indicators of well-being

Making wishes known

As before, Eileen expresses her wish to know what to do next by continually asking Jim, 'what do I have to do now Jim?' She asks Jim to take her to the toilet rather than her sister, Ivy. The incident whilst on respite, asking Ivy to help her get out of here also shows she is clearly able to make her wishes known.

Initiating social contact

I noticed less examples of Eileen initiating social contact, perhaps as I was not observing her at Homestead this time. However she did point out some yellow flowers in a field whilst we were in the car.

Warmth and affection

As before, Eileen showed a great deal of warmth towards Jim.

Self Respect

Ivy often asked Eileen if she wanted to go to the toilet. However Eileen clearly did not want Ivy to take her and she whispered to Jim to take her later.

Being helpful

Eileen spends much of her day looking for something to tidy or do. I felt she was attempting to be helpful around the house.

Humour

Eileen and Jim frequently share jokes and laughter together. I noticed Jim tickling Eileen at one point and she moved to a WIB state of +5.

Bodily relaxation

Eileen is able to completely relax on the sofa with Jim at times and dozes cuddling up to him.

Creative self-expression

Eileen continually sings as she walks from lounge to kitchen, sometimes in a state of high well-being.

Showing pleasure or enjoyment

When joking with Jim or singing Eileen showed clear enjoyment.

Responding appropriately to others

I didn't note any examples of this category at my final visit.

Expressing appropriate emotions

When Eileen is joking with Jim or looking at flowers she shows great joy. When Jim goes out of the room (at home) she appears lost and anxious.

Holding her own socially

As before Eileen still gave as good as she got when joking with Jim.

Alertness

Eileen shows alertness to her surroundings, spotting the yellow flowers in the field, and pointing out Ivy in the garden.

Being active

Eileen still eats without aid, after Jim has cut her food into smaller pieces. She also works together with him in dressing and washing.

Being purposeful

Eileen shows some signs of being purposeful in trying to straighten items in the kitchen or the fruit bowl in the lounge. However this can become very repetitive.

Indicators of ill-being

Depression or despair

There were no signs during this visit.

Intense anger

I did not observe Eileen being angry during this visit. However Ivy claimed that Eileen had punched her when she tried to make her take her coat off.

Grief

There were no signs during this visit.

Anxiety

Eileen showed some signs of anxiety when she couldn't find Jim and would call upstairs after him. Also her continual wandering to and from the kitchen could be seen as anxiety, but she showed no visible signs and hence have been recorded as agitation.

Fear

Eileen showed no signs of fear during this visit.

Boredom

Eileen's wandering could be seen as a sign of boredom as she appears to be looking for jobs to do.

Physical discomfort / pain

This time Eileen had a sore knee, which became stiff at times.

Bodily tension

There were no signs during this visit.

Agitation

Eileen's constant wandering to and from the kitchen may be seen as agitation.

Apathy and withdrawal

There were no signs during this visit.

Distress

There were no signs during this visit.

Cultural isolation

There were no signs during this visit.

Difficulty withstanding powerful others

Eileen is able to 'give as good as she gets'. Her refusal to take her coat off when Ivy tried to make her is a sign of this.

Well-being checklist

0 = no sign, 1 = some signs, 2 = significant signs

| | Visit 3 |
|---|---------|
| Making wishes known (non-destructively) | 2 |
| Initiating social contact | 1 |
| Warmth and affection | 2 |
| Self-respect | 1 |
| Being helpful | 2 |
| Humour | 2 |
| Bodily relaxation | 2 |
| Creative self-expression | 2 |
| Showing pleasure or enjoyment | 2 |
| Responding appropriately to others | 0 |
| Expressing appropriate emotions | 1 |
| Holding their own socially | 1 |
| Alertness, responsiveness | 1 |
| Being active | 2 |
| Being purposeful | 1 |
| Score | 22 |

TOTAL = 22/30

Ill-being checklist

0 = never , 1 = sometimes, 2 = often

| | Visit 3 |
|---|---------|
| Depression or despair | 0 |
| Intense anger | 0 |
| Grief | 0 |
| Anxiety | 1 |
| Fear | 0 |
| Boredom | 1 |
| Physical discomfort / pain | 1 |
| Bodily tension | 0 |
| Agitation | 2 |
| Apathy and withdrawal | 0 |
| Distress | 0 |
| Cultural isolation | 0 |
| Difficulty withstanding powerful others | 0 |
| Score | 5 |

TOTAL = 5/26

Dementia Care Mapping (DCM)

Approximately 5.5 hours of DCM were carried out over the three days (1.5 hours, 4 hours and 0 hours respectively). No mapping was carried out on the final day. Behaviour profiles showing the proportion of time spent in each category are shown graphically for each day. Similarly graphs showing the well-being / ill-being values are given.

Saturday

Mapping periods: 13.25-15.00, 19.00-19.10

A interacting verbally or otherwise (with no other obvious activity)

Just under 5% of the total mapping time was spent in A.

B being socially involved, but passively

Eileen spent just under 10% of the mapping time sitting quietly, in the afternoon.

C being socially uninvolved, withdrawn

D unattended distress

None of the above categories were noted during Saturday.

E engaging in an expressive or creative activity

A total of just under 75% of the mapping time was spent singing. Eileen sung the same song again and again, sometimes moving into a WIB state of +3.

F eating, drinking

No mapping was carried out during meal or tea times today.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

J participating in exercise or physical sports

None of the above activities were noted today.

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

Neither of the above activities were observed during mapping periods but Eileen did walk to and from the kitchen as before.

M engaging with media

We did not watch any television today.

N sleeping, dozing

Eileen did not doze during the day, possibly as Ivy was visiting.

O independently engaging in self-care

Eileen straightened her skirt from time to time.

P receiving practical, physical or personal care

No aspects of physical care were observed during mapping.

R **participating in a religious activity**

S **activity related to explicit sexual expression**

Neither of the above activities were noted on Saturday.

T **direct engagement of the senses**

Jim tickled Eileen whilst they were joking together and she moved into a WIB state of +5.

U **communicating without receiving a response**

This was not observed today.

W **repetitive self-stimulation**

Although this category was not recorded during mapping it must be noted that Eileen's singing was very repetitive and could be seen as self-stimulation, although she was in a positive state of well-being. She also walked from the kitchen to the lounge as before, but not during mapping periods.

X **episodes related to excretion**

Y **talking to oneself, or an imagined person; hallucination**

Z **behaviours that fit no existing category**

None of the above were noted during Saturday.

Sunday

Mapping periods: 10.05-10.55, 13.00-13.45, 15.00-17.00

A **interacting verbally or otherwise**
 (with no other obvious activity)

B **being socially involved, but passively**

Neither of the above were noted during mapping times but Eileen did have some conversation and occasionally sat quietly, after dozing.

C being socially uninvolved, withdrawn

D unattended distress

Neither of the above categories were noted today.

E engaging in an expressive or creative activity

Just under 25% of the total mapping time today was spent singing.

F eating, drinking

Just under a fifth of the mapping time was spent eating and drinking.

G participating in a game

H participating in a craft activity

I activity prioritising the use of intellectual abilities

None of the above were noted today.

J participating in exercise or physical sports

Although there was no J noted during mapping, Jim, Eileen and myself walked to the paper shop in the morning and after lunch Jim took Eileen round the garden to stretch her legs as she was a little restless.

K independent walking, standing or wheelchair-moving

L performing work or work-like activity

Although neither of the above were noted during mapping Eileen spent some time walking between the kitchen and lounge as usual.

M engaging with media

Although no category M has been noted during mapping Eileen did watch some television today.

N sleeping, dozing

Just over half of the total mapping time was spent sleeping. Although this totalled more than one and a half hours it was not degraded in WIB value as she was snuggled up to Jim throughout.

O independently engaging in self-care

P receiving practical, physical or personal care

Neither of the above were noted during mapping but Eileen did straighten her skirt from time to time, and Jim carried out personal care.

R participating in a religious activity

S activity related to explicit sexual expression

T direct engagement of the senses

None of the above were noted today.

U communicating without receiving a response

Not observed today.

W repetitive self-stimulation

One episode of wandering to and from the kitchen was noted today during mapping, but it continued outside mapping from time to time.

X episodes related to excretion

Y talking to oneself, or an imagined person; hallucination

Z behaviours that fit no existing category

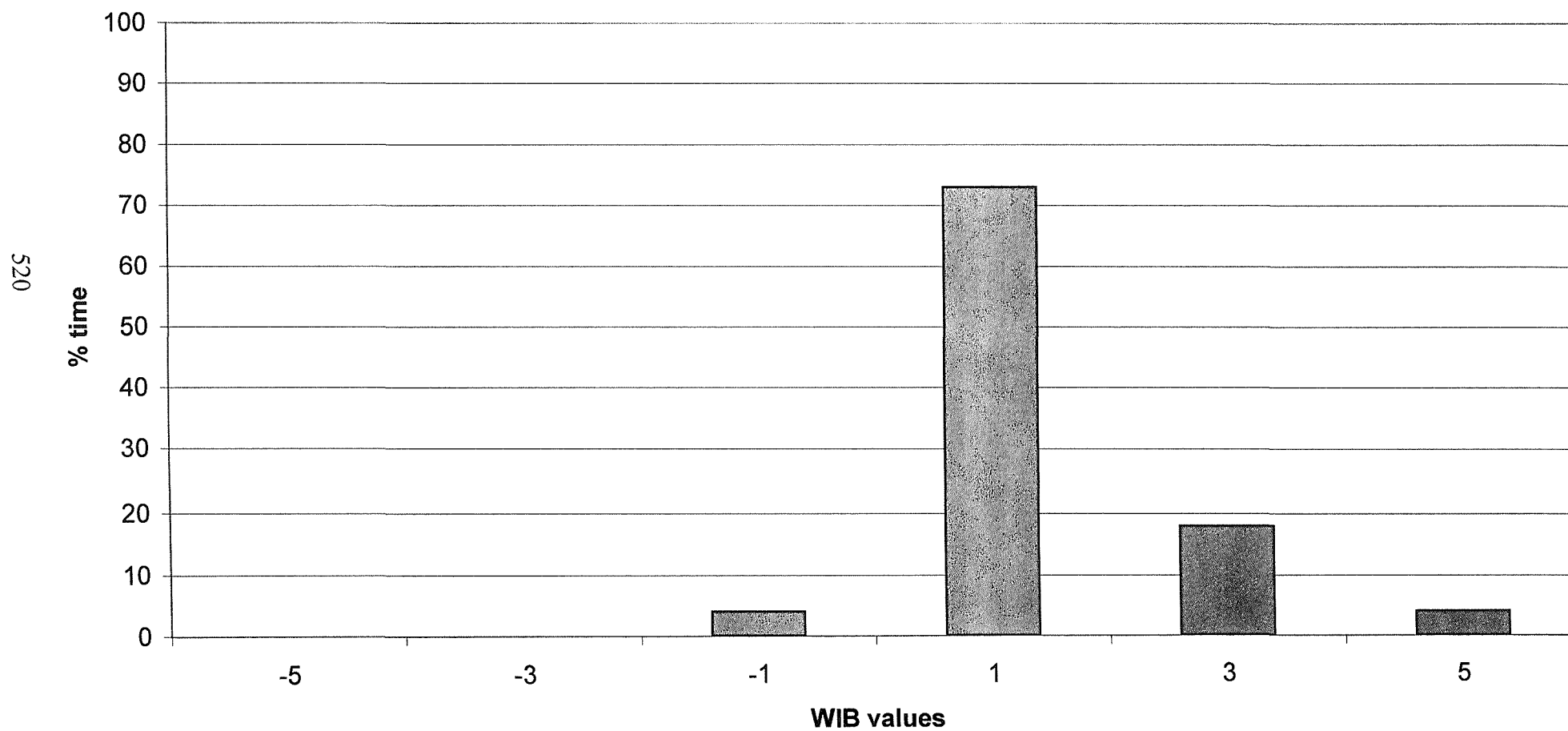
None of the above were noted today.

WIB values

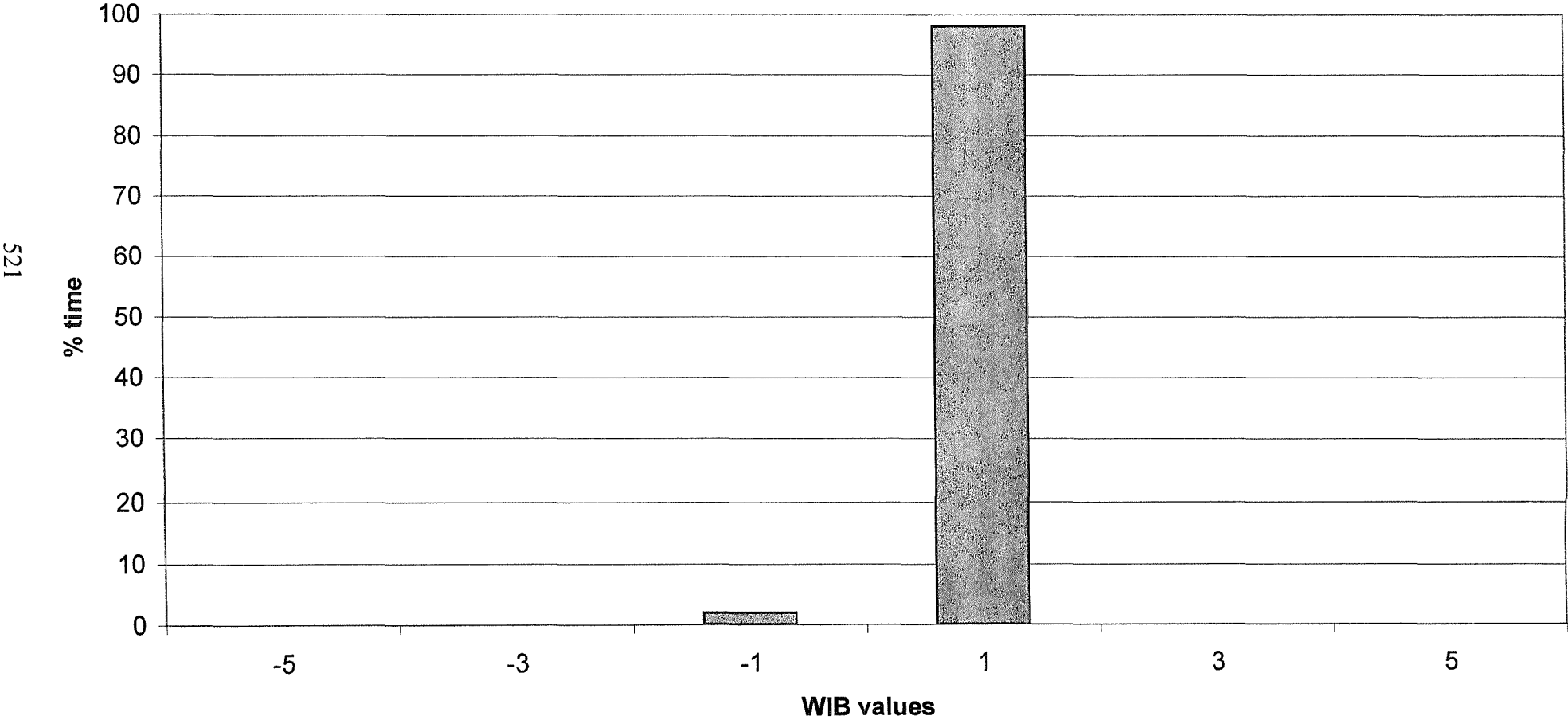
| WIB | -5 (%) | -3 (%) | -1 (%) | +1 (%) | +3 (%) | +5 (%) |
|-------|--------|--------|--------|---------|--------|--------|
| Sat | 0 (0) | 0 (0) | 1 (4) | 16 (73) | 4 (18) | 1 (4) |
| Sun | 0 (0) | 0 (0) | 1 (2) | 45 (98) | 0 (0) | 0 (0) |
| Total | 0 (0) | 0 (0) | 2 (3) | 61 (90) | 4 (6) | 1 (1) |

| | Saturday | Sunday | Total |
|---------------|----------|--------|-------|
| Σ WIB scores | + 32 | + 44 | + 76 |
| Σ time frames | 22 | 46 | 68 |
| WIB value | + 1.4 | + 1.0 | + 1.1 |

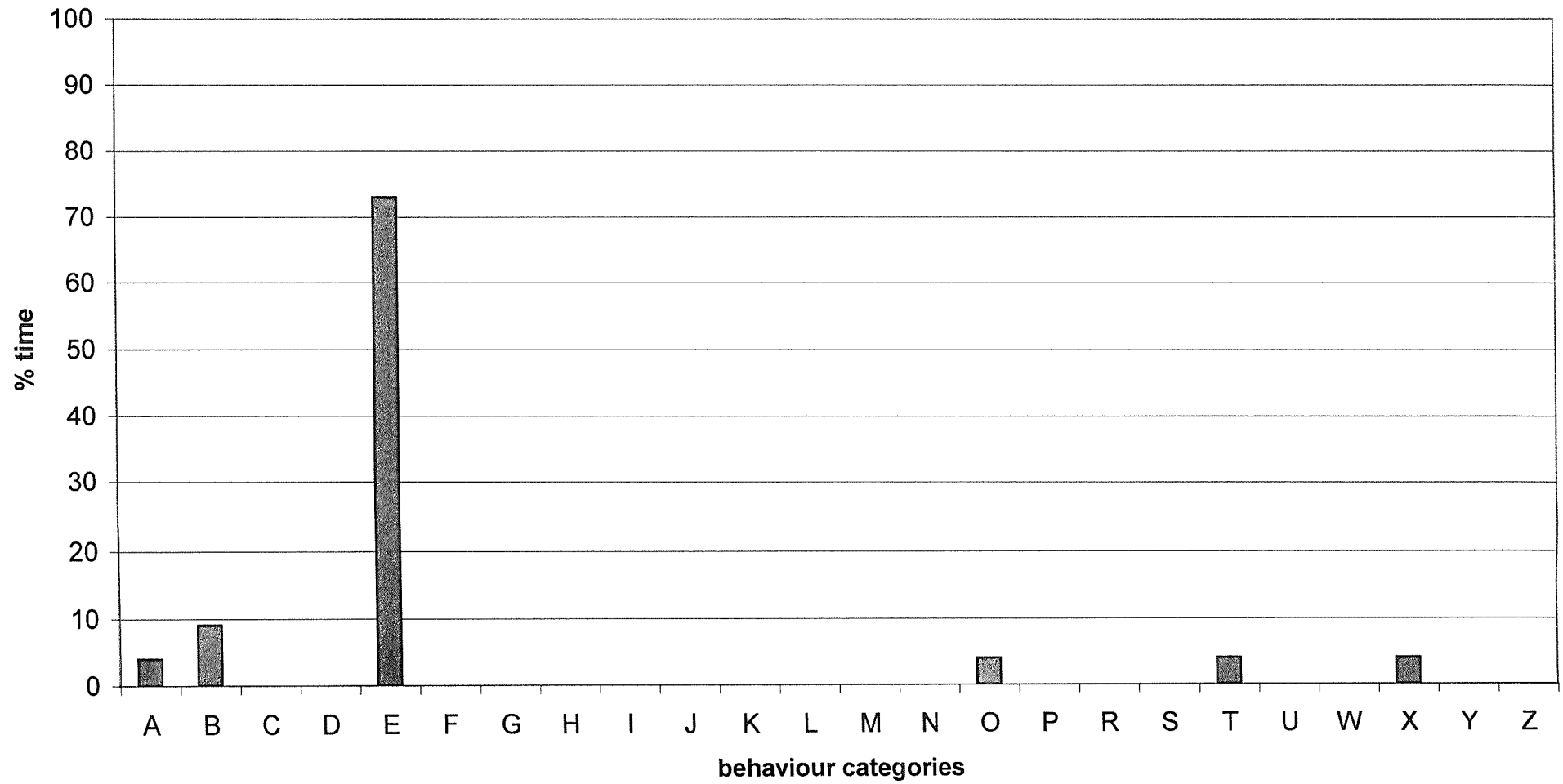
Eileen
WIB Profile
Saturday (Visit 3, May 2002)



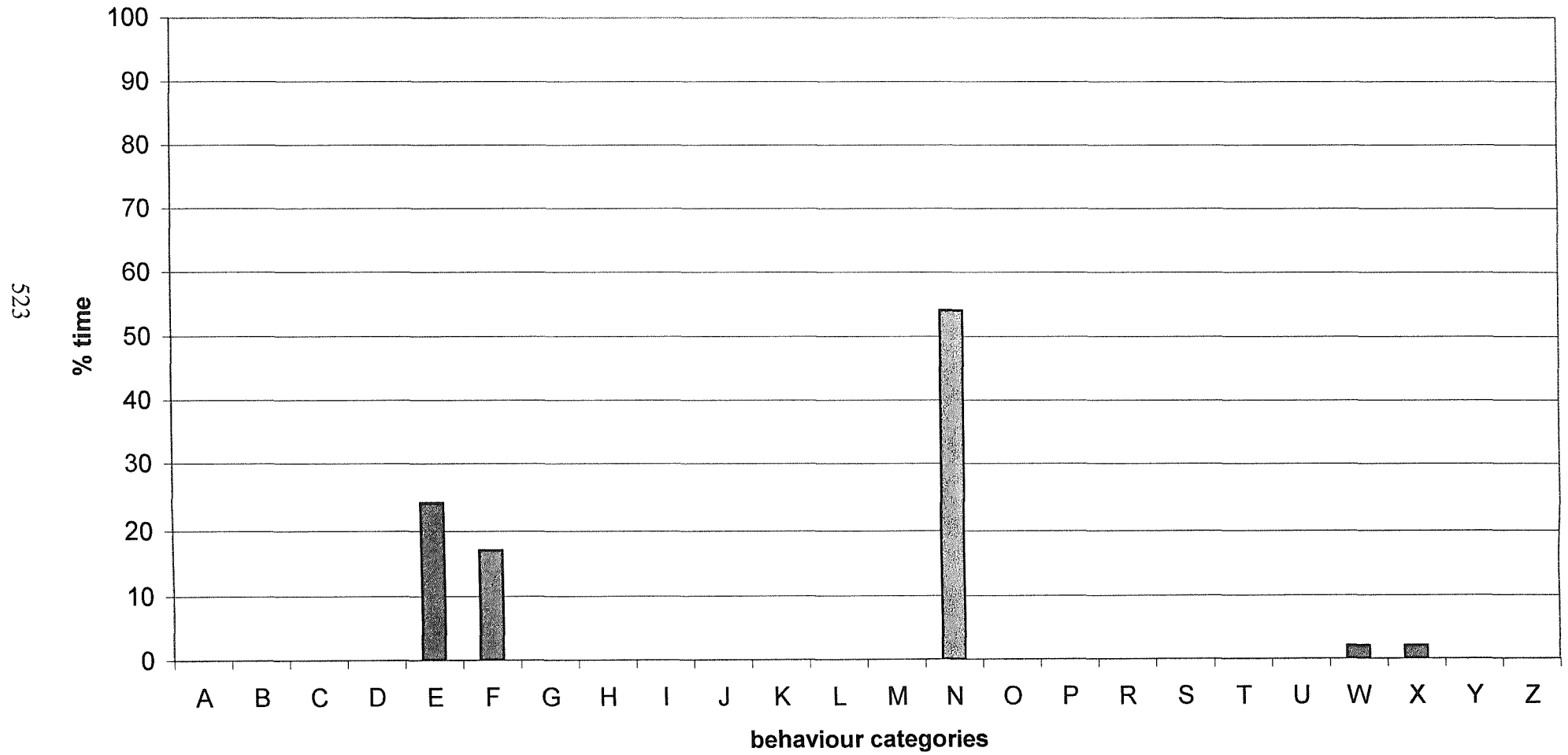
Eileen
WIB Profile
Sunday (Visit 3, May 2002)



Eileen
Behaviour Profile
Saturday (Visit 3, May 2002)



Eileen
Behaviour Profile
Sunday (Visit 3, May 2002)



Behaviour Category Grid

Eileen, Visit 3, May 2002

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |
|-------|---|---|---|---|----|----|---|---|---|---|---|---|---|----|---|---|---|---|---|---|---|---|---|---|
| Sat | 1 | 2 | 0 | 0 | 16 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 |
| Sat,% | 4 | 9 | 0 | 0 | 73 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 0 | 0 | 0 | 4 | 0 | 0 | 4 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| Sun | 0 | 0 | 0 | 0 | 11 | 8 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 25 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 |
| Sun,% | 0 | 0 | 0 | 0 | 24 | 17 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 54 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 2 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
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| | | | | | | | | | | | | | | | | | | | | | | | | |
| TOTAL | 1 | 2 | 0 | 0 | 27 | 8 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 25 | 1 | 0 | 0 | 0 | 1 | 0 | 1 | 2 | 0 | 0 |
| % | 1 | 3 | 0 | 0 | 40 | 12 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 37 | 1 | 0 | 0 | 0 | 1 | 0 | 1 | 3 | 0 | 0 |
| | | | | | | | | | | | | | | | | | | | | | | | | |
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| | | | | | | | | | | | | | | | | | | | | | | | | |
| | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | W | X | Y | Z |

Elements of Malignant Social Psychology

Withholding (moderate)

The only aspect of MSP I noted during this visit is certainly unintentional (as Kitwood says they often are), but during the course of my visits I have come to believe that this is a need of Eileen's which is not being met:

When Eileen walks to and from the kitchen straightening items she asks, *'what have I got to do Jimmy?'* and he replies, *'nothing, there's nothing you've got to do.'* This conversation can be repeated many times. Eileen may be searching for some work to do in the home, as she would be used to doing. However, when she came out to help with the washing up and Jim said that he would do it she seemed very pleased, as if this was a treat. I wondered if there was some small task that Eileen could do so as to make her feel useful in her own home again.

Positive Person Work

Facilitation

Jim recognises that Eileen is still capable of many activities but needs a little help, for example when he dished up her chicken dinner he made sure he had cut the meat from the bone for her.

He often helped her to the toilet, but if she had already gone upstairs he called up *'are you there yet?'* as he realised she was now becoming more disorientated at home. He would also call out directions to help her.

Timalation

Jim and Eileen were joking together and he tickled her making her laugh and moving her to a WIB state of +5. When sitting together he would often stroke her foot or hand.

Caregiver support for intact abilities

As above, Jim realises Eileen's remaining abilities and works with her to help her in personal care or other care tasks.

However I do feel Jim could try to find some small household jobs for Eileen to do as she appears to have a need here which is not being met.

Validation of emotion by caregiver

Eileen rarely shows signs of ill-being, even when wandering. When she became agitated and tried to open the front door Jim took her for a stroll round the garden.

He recognises her great love of singing and even though he says it drives him *'round the bend'*, he suggests songs for her to sing.

When sitting with Eileen he cuddles her and she clearly feels relaxed and secure.

Politeness strategies

I did not observe any politeness strategies during this visit.

Aspects of selfhood

Eileen's self respect is clear to see when she refuses to be taken to the toilet when Ivy asks and instead whispers to Jim to take her.

Whilst her 'self as homemaker' may be compromised now that Jim has taken over the household chores, her 'self as wife and friend' is still very much nurtured by Jim who cuddles up to her and holds her hand.

In joking with her Jim keeps this aspect of her self alive. An aspect which Ivy seemed unable to tap into.

Eileen is still a member of the 'Friday Club' at her local pub, so remains part of this important social circle, and clearly enjoys the outings according to Jim.

Perception and social death

Jim spoke again about feeling that it was important for the carer to help keep the person with dementia in a happy frame of mind, otherwise he felt it was a vicious circle, with the person becoming upset and in turn upsetting the carer.

His view that the person with dementia should be helped to remain happy suggests that he believes that they still have emotions and hence are not socially dead in that sense. The fact that he still takes Eileen to the Friday club also suggests that he does not view her as socially dead, as indeed do most of their interactions together. However he did say that he found caring for Eileen '*boring*'. But considering his excellent positive outlook on life, he made the best of what he had.