Playing Together

Analysing the co-occupation of a person with dementia playing Scrabble with his family

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The project

- SCoRe project - 3rd year OT students as co-researchers
  - 3rd year of project
- Part of PhD research project
  - Nick Pollard & Sally Fowler-Davis (Sheffield Hallam)

Question
How do people with dementia and ‘partners’ actively work together within shared occupations to facilitate meaningful participation?
The stage, the cast

The cast (performers)
• Arthur (late 70s, Alzheimer’s disease)
• Mary (mid 70’s)
• Jane (daughter, 40 something)
  – Pseudonyms (RCOT 2015)

The stage (environment)
• Arthur and Mary’s home living room
  • Jane lives nearby, visits regularly
• Regular engagement in shared occupations
• Dynamics
  • Reciprocal roles (Merrick 2012)
**Practice Context**

‘It can be difficult when working with people who have cognitive difficulties to get the right balance between person-centred facilitation and simply ‘taking over’ in a way that disempowers the person’

Capstick, 2004

**Research Context**

‘Very little research exists on persons with dementia doing things together with others, either with persons without dementia – such as other family members or professional staff – or with other persons with dementia’

Hydén, 2014, p115
Co-occupation

- Co-occupation - occupation is created by and between two or more people
  - ‘Doing for’, ‘doing alongside’ ‘doing with’ (Doidge 2012)
  - Interdependence (Hammel 2009)
- A ‘dance’ between the occupations of one person & another, where each shapes the other’s participation (Pierce 2009)
  - Occupation is social, cultural and ecological in nature
- An original concept developed within occupational science (Pierce & Marshall 2004)
  - Research into mothering occupations
  - Intertwined with attachment processes (Whitcomb 2012)
- A shared, multidimensional, field of interaction (Zemke & Clark 2006; Pickens & Pizur-Barnekow 2009)

As mother and daughter “developed a reciprocal relationship and began attaching, generic activities became co-occupations; the activities provided the vehicles of creating meaning that supported their relationship” (Price & Miner, 2009, p. 77)
Previous research into shared occupations of people with dementia with others

- Van Nes (2012) - co-occupation of walking as couple
- Vikstrom et al (2005) - shared activity of tea making as couple
- Hydén (2014) - shared activity of meal preparation with formal caregivers
- Majlesi & Ekström (2016) - shared activity of baking buns
- Wey et al (2017) - baking scones as a co-occupation
Occupation oriented research methodology

Enactivist epistemology (Di Paolo, Rhohde and De Jaegher, 2014).

Participatory action research

Enacted consent
Study objectives:

To observe and analyse, using grounded theory micro-analysis, video observational data of a person with dementia being included in a family game of Scrabble.

To identify how all participants in this co-occupation collaboratively engage with each other to share tasks, roles and demands and co-construct meaning.

To critically discuss and synthesise theoretical, research and practice implications.
Recruitment criteria

People with >6 month diagnosis of dementia

Over 60

Engage in activities with carer at least twice a week

Those activities should be shared activities:

Meaningful and regularly enjoyed by both parties

PWD plays a significant role and the carer has a facilitatory role

Not activities the carer does for the person or takes over

Interested in what is facilitation and how is it enacted?

Activities it is realistic and appropriate to film (e.g. not intimate care)

Activities should be around 10-30 minutes long
Methods: Data Collection

- Participants recruited from Dementia Café in region
- Home visits made to participants interested in taking part - screen
- Participant information sheet in everyday language and consent forms given at home
- At least 1 week to review the sheet and form
- So far have obtained several sets of video data including baking, gardening, housework and game playing activities
- Previous analysis presented of 1 pair (father and daughter) making cheese scones together (Wey et al, 2017)
- Also obtained a second recording of the father, his wife and daughter playing Scrabble
Methods: Why Video?

‘...video is the only method that is sufficiently sensitive to be capable of capturing micro-communications and that for research participants who are non-verbal and therefore communicate by means of macro and micro non-verbal communications, there is no other method of collecting original information explaining what was happening in their field of interest...’

Griffiths, 2013, p31

Analysis grounded in direct observation of enacted events

Camera could be placed under control of participants
Methods: Grounded theory – stages of analysis
(Strauss and Corbin, 2014; Harker & Kerr, 2015)

- **Data collection**: Observations, video data, field notes, memos, transcripts
- **Immersion in data**: Familiarisation – micro-level - moment by moment observation, line by line reading and re-reading transcripts, field notes and memos
- **Coding**: • Open, Axial and Selective/Theoretical • Constant comparison – 2 groups, back-&-forth, previous analysis & research
- **Grounded Theory**: Emerging grounded theory – explanation of what is going on for participants, ongoing iterative process as more data added – further comparison
Video data originally transcribed by students in previous year, including noting observational data (environment, actions, NVC, temporal information)

- Preliminary analysis (Open, Axial, tentative concepts)
- Not shown to current students until completion of their axial coding

Methods: Coding process

- **Coding**
  - Open
    - Form initial categories by breaking down, comparing, conceptualizing, categorizing data...
  - Axial
    - Identify a central phenomenon
    - Explore causal conditions
    - Identify the context and intervening conditions
    - Specify strategies
    - Delineate the consequences
  - Selective
    - Select the core category
    - Relate it to other categories
    - Validate those relationships
    - Fill in categories that need further development

- Promoting rigor
- Tabletop games
- Mind mapping
Themes and concepts

Analysis identified 4 interdependent themes, each comprising a central hypothesis and several core concepts and sub-concepts.

A contextual theme relating to how participants responded and adapted to the demands of the occupation and of the environment.

3 themes relating to how the family played together to promote meaningful engagement for all participants.
Co-occupational engagement

- Engagement as a family that ‘plays together’
- Enacted through e.g.:
  - forms of reciprocal interaction
    - turn-taking
    - mirroring
  - promotion of agency
  - communication of feelings and needs
    - through dialogue, NVC and action
  - shared responsibilities and roles
    - continual negotiation
Promotion of couplehood
(Mary looks at Arthur's tile holder)
(Arthur moves tile holder towards Mary)
Mary: Mmm (looks up at Arthur and smiles)
(Arthur makes a face by sticking out tongue at Mary and then smiles)
(Mary chuckles and looks at board)

Co-occupational ‘telepathy’

Promotion of choice (agency)
Jane: Do you think you might be able to manage this one or do you want a little bit of help
Arthur: I think we might be able to see how things go
Jane: Okay (moves back away from Arthur)

Mirroring (reciprocity)
Arthur: One for you (in a sing song tone)
Mary: Thank you (also in a sing song tone)

Communication through action
Mary shakes bag and places in front of Arthur and angles it towards him

Note examples can relate to more than one theme, there are several things going on here.
Engagement in the game created an interpersonal field of interaction and experience that existed on multiple levels:
- physical (embodied, enacted, ecological, praxis),
- emotional (enjoyment, love/affection/care/support, playfulness),
- intentional (attention, goals, meanings, purpose, empathy),

Time/effort within the game was not simply about the game per se, but creating and nurturing that shared world:
- such as through interpersonal reminiscing, playfulness and synced physical contact
- and shared family language, humour and ways of doing things (family culture)
Reminiscence to create common backdrop
Jane: It’s a while since we’ve played - isn’t it actually?
Mary: It is
Arthur: That’s right

Shared action
Jane and Arthur – counting the scores together

Playful competition
Jane: No cheating by the way (laughs)
(Arthur makes a face by sticking out tongue at Mary and then smiles)
Mary: That’s alright I know you want to [win] (laughs)

Shared attention
Arthur takes responsibility to turn the board towards each person
Jane repeatedly looks up at board and down towards her tile holder to signify that she is thinking to others (also signposts turn taking)

Shared family language
Arthur: And one for... oh drat (smiles)
‘Drat’ was used a few times by all
A Shared World

• Attunement (Whitcomb 2012; Griffiths & Smith 2016)
  • primarily mediated by co-occupational engagement
• Walmsley and McCormack (2014) ‘in step’ and ‘out of step’ flow of communication
• We propose this goes beyond communication per se,
  • that flow is also co-occupational and exists on an embodied, procedural and ecological level

• Processes and patterns of disruption and re-connection
Support with kindness

- How do carer’s ‘sense’ or ‘know’ when to step in to provide support, and when and how to step further back and facilitate?

- Often in reality there is a fine line or no exact line at all – situational variables
  - Carer knowledge?
**Scaffolding**

Jane: And what else would come after that possibly to make a word? Even if it was just a 3-letter word [that] you've got there

Arthur: [Mmm]

Arthur: Yeah (places tile on board)

Jane: Yep

**Adapting level of support**

Jane (to Arthur) remembering that one counts as anything

Jane (to Arthur) so you need to pick up some more tiles (after a few seconds)

Mary to Arthur - you need 3 more tiles

**Promoting comfort**

Jane: if I put the board like that mum are you okay to then...

Mary: Yes yes

Mary: I was just thinking if it's that way dad could see better

**Maintenance of well-being**

Jane: Do you want to have another go each and then we'll call it quits? (checks watch)

Arthur: Yeah by all means

Mary: Yep

Jane: Well done darling that was a good way of doing it then wasn't it actually

Arthur: Yeah (places tiles on tile holder)

Dynamically and interactively adapting the level of support enabled carers to 'tune-in' in action to what level worked best, to step in when needed and pull back when not
In the game we saw interdependence emerge as a dynamic & negotiated (transactional) process

- A continuum not a binary construct

- Engagement in the co-occupation provided the lived experiential space (shared world) through which carer’s judged ‘in the moment’ when to step in or step back

Support with kindness
A space where partners are attuned to each other physically, emotionally, practically and meaningfully

Support and facilitation levels are continually modulated dynamically, based on feedback and mutual monitoring of responses to demands

Creates the medium through which partners recognise and respond to each others needs and goals by providing an occupational and ecological connection

Creates the medium through which partners, interdependently, perform the co-occupation

Attunement cycle

Co-Flow cycle

Shared World

Support with Kindness

Co-occupational Engagement
Conclusions

• Move away from binary ‘independence vs dependence’ support construct
  • Continuum of interdependence and capability levels

• Central importance of kindness and compassion within the partner relationship
  • In-tune and out-of-tune patterns of co-occupational engagement and performance
  • Disruptions and oscillations in cycles of co-occupational flow and attunement may impact on that engagement and performance

• Occupational performance as distributed process within co-occupations
  • e.g. shared problem solving, shared lexicon, shared sequencing and use of signposting, shared performance
  • New language

• A focus on the occupational and co-occupational ecosystem as a functional & meaningful whole and unit of analysis within occupational science
  • Enabling access and distribution of potential resources within ecosystem
    • Carer skills and skills of the person with dementia
  • Maintenance/creation of meaning
References


References


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