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Playing Together

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

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- Kaitlin Gallighan, Amy Crisford, Emily Rivers, Lauren Hill, Laura Edwards – YSJ Students

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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

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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)

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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 inter-action (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)

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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 & Ekstrőm (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

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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*

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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

Methods: Coding process

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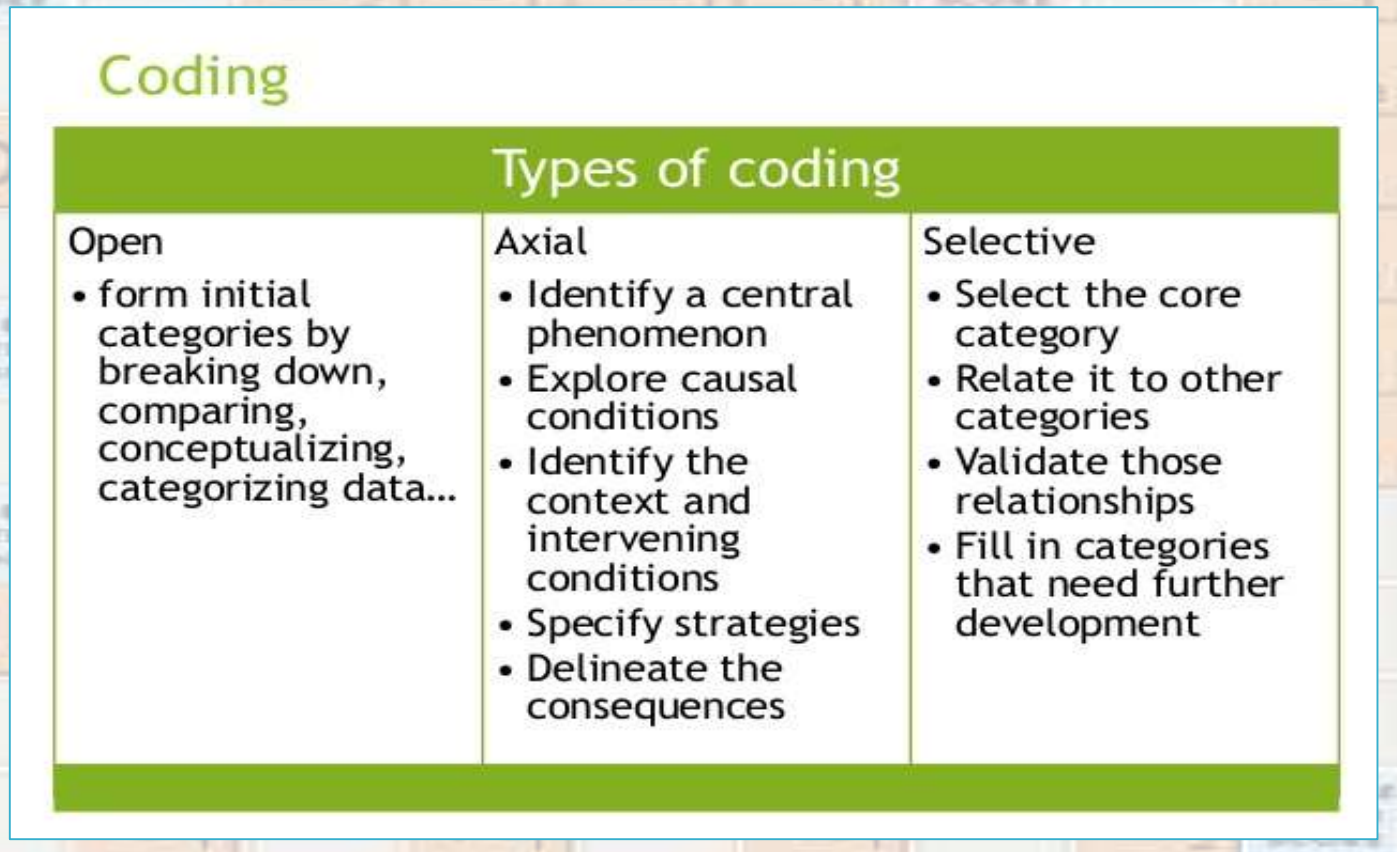
- **Video data originally transcribed by students in previous year, including noting observational data (environment, actions, NVC, temporal information)**
  - **Preliminary analysis (Open, Axial, tentative concepts)**
  - **Not shown to current students until completion of their axial coding**



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

DEMANDS

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OCCUPATION

- Declarative
- Problem solving
- Multi track
- Arranging tiles
- Word finding
- Social
- Flow & Sync

ENVIRONMENT

- Layout
- Structure

Shared World

Support with Kindness

Co-occupational Engagement

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)
Co-occupational 'telepathy'
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)

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

A Shared World

- 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 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)

Playful competition

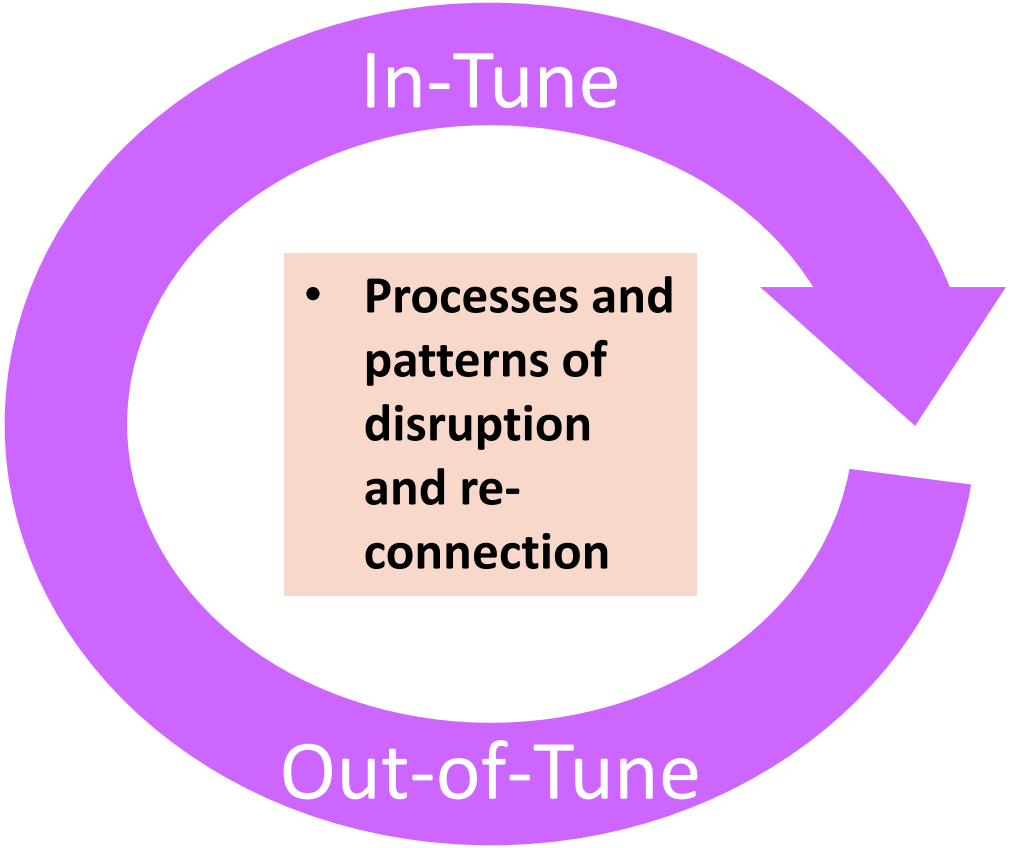
Jane: No cheating by the way (laughs)
(Arthur makes a face by sticking out tongue at Mary and then smiles)
Mary: That's alright I know you want to [win] (laughs)

Shared action

Jane and Arthur – counting the scores together

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

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

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

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)

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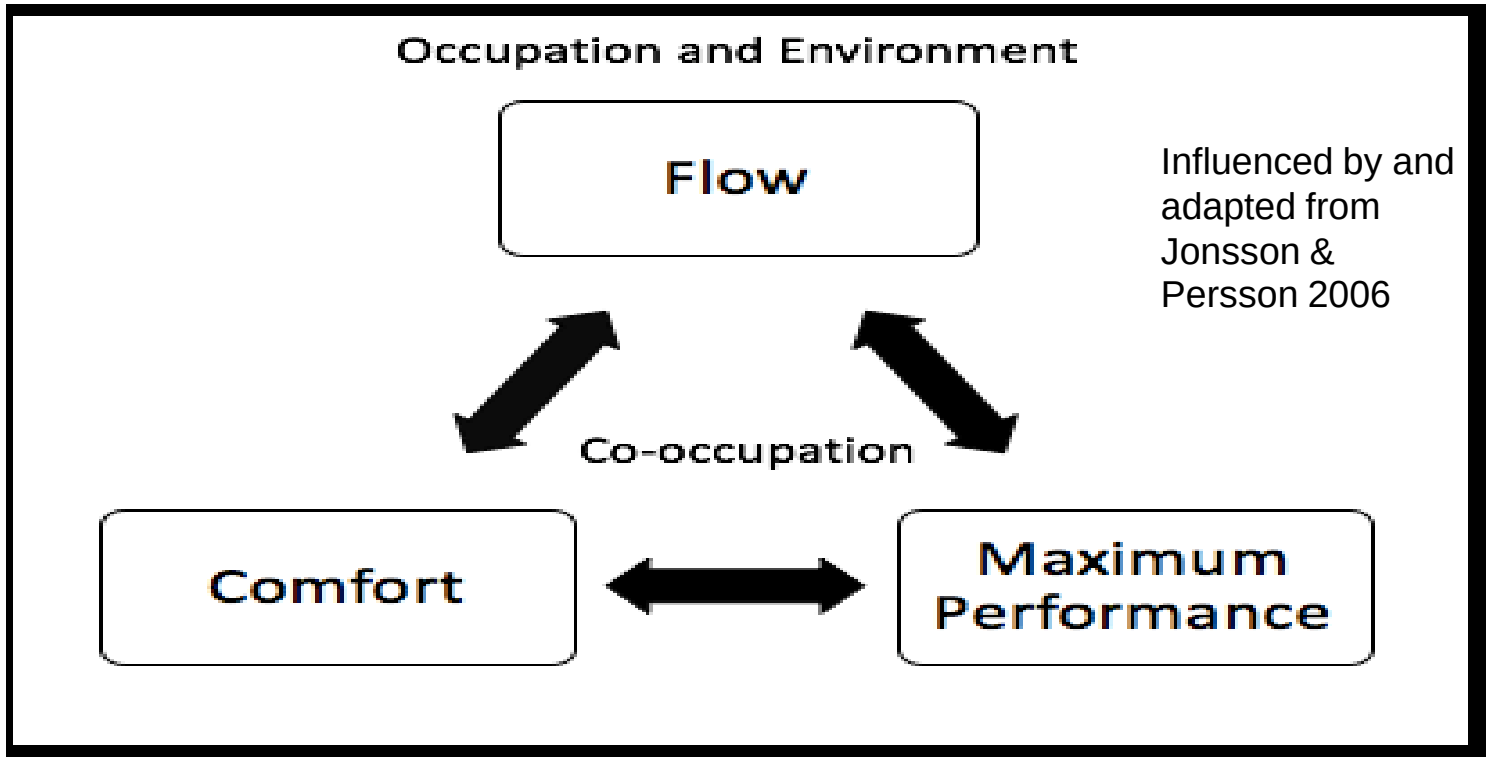
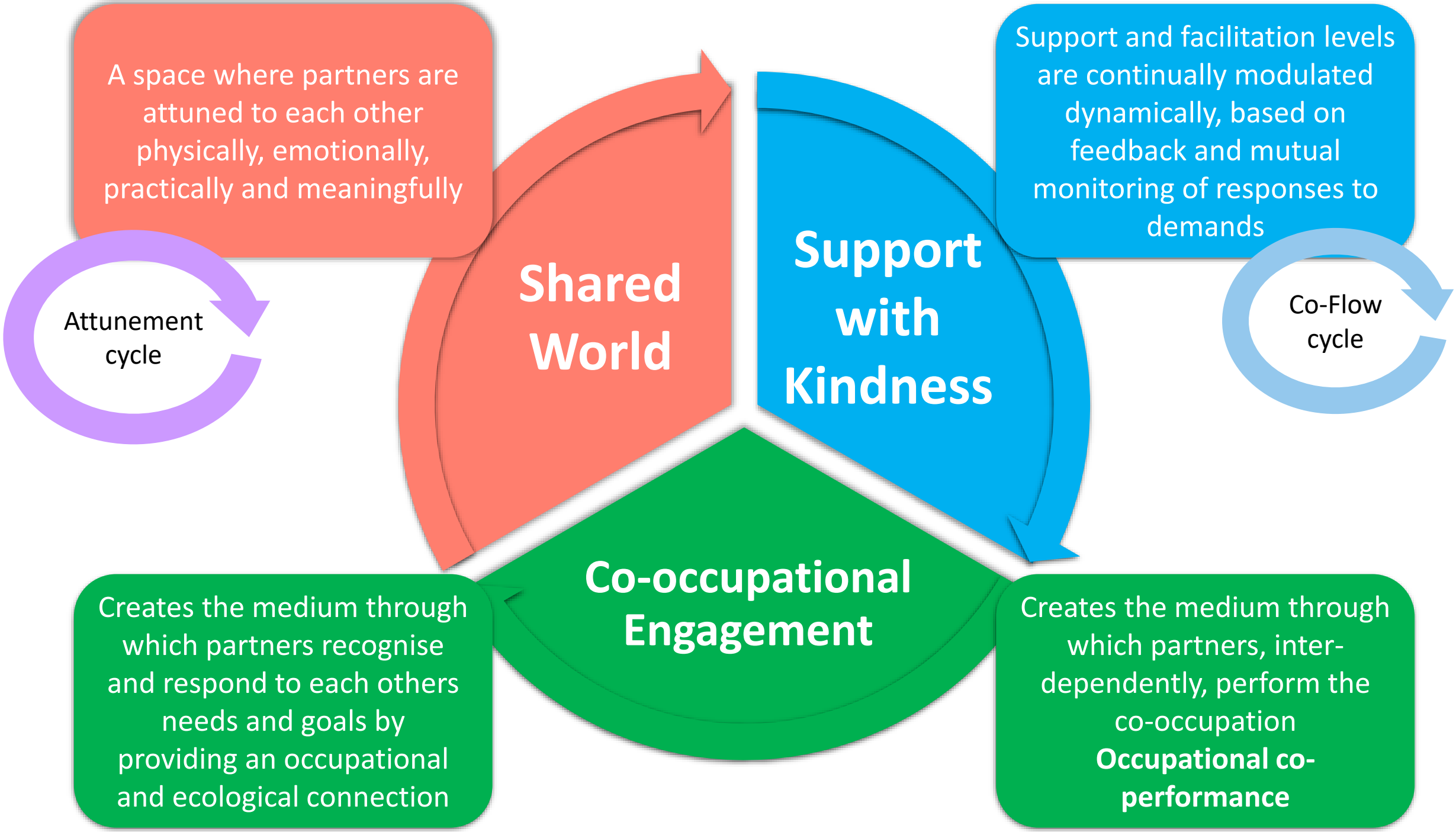


Co-Occupation Flow Cycle (Co-Flow)

Support with kindness

- 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


A space where partners are attuned to each other physically, emotionally, practically and meaningfully
Attunement cycle
Shared World
Support and facilitation levels are continually modulated dynamically, based on feedback and mutual monitoring of responses to demands
Co-Flow cycle
Support with Kindness
Co-occupational Engagement
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, inter-dependently, perform the co-occupation
Occupational co-performance

Conclusions

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- 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

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