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Hypothesis: Dementia diminishes interdependence in health and quality of life among
spousal partners

Running head: Dementia diminishes interdependence

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Conflict of interest declaration

The authors declare that there is no conflict of interest.

IRB protocol/human subjects approval numbers

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Nyman, S., Hayward, C., Ingram, W., Thomas, P., Thomas, S., Vassallo, M., . . . Barrado-Martín, Y. (2018). A randomised controlled trial comparing the effectiveness of Tai Chi alongside usual care with usual care alone on the postural balance of community-dwelling people with dementia: Protocol for The TACIT Trial (TAi ChI for people with demenTia). *BMC Geriatrics*, *18*, e263.

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including: trial design; data collection, analysis, and interpretation; manuscript writing; and dissemination of results including the decision to submit the article. The chief investigator had final decision on these matters.

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Description of authors' roles

SRN: Developed the hypothesis, led on the empirical work reported (formulated the research question, designed the analyses, interpreted the results), wrote the first draft of the paper, and approved the final version.

CC: Analysed the data, conducted literature searches to support the paper writing, critically reviewed drafts, and approved the final version.

NG: Interpreted the results, critically reviewed drafts, and approved the final version.

Data availability

The electronic, quantitative trial data will be shared with bona fide researchers intending to use the data for non-commercial research purposes. Access to the following will be restricted to researchers who sign a confidentiality agreement and confirm their intention to use the data is for secondary data analysis for non-commercial research purposes using a Creative Commons licence: statistical analysis plan; trial protocol, and anonymised participant-level dataset and data documentation. Interested parties may make a formal request to access the electronic dataset, which will be approved / declined by the chief investigator in accordance with the Data Management Plan that will detail management of access, sharing, and preservation of the data. Any use of the electronic data set must be requested via Bournemouth University Library (bordar@bournemouth.ac.uk) who will collaborate with the chief investigator with regards to access.

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Hypothesis: Dementia diminishes interdependence in health and quality of life among spousal partners

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Introduction

We present a hypothesis that dementia may create a unique dynamic for spousal partners by diminishing their interdependence in health and quality of life. Below, we briefly review prior literature to explain the hypothesis and present some initial evidence in support from a trial dataset. We hope that researchers will test our hypothesis with their datasets, and that this article inspires further research into the relationship dynamics between people living with dementia and their partners and implications for their health and quality of life.

As the disease progresses, people living with dementia become increasingly dependent on family and friends for everyday activities and care. While some receive formal paid care, the majority of care provided for those living at home is by informal carers (also termed caregivers) and often family members including spouses (referred to as carers throughout here). Often, especially with older people, the distinction between those providing and those receiving informal care can become blurred making definitions of the caring role problematic. While definitions of carer vary, a consistent feature is the provision of unpaid care.¹ In the United Kingdom, it is estimated that over 61 per cent of people with dementia aged 60 and above live at home supported by over 700,000 carers to the value of £11.6 billion per annum.²

Data from the United Kingdom, France, and Germany suggest that approximately two thirds of carers of people living with dementia are spouses.³ Being a carer can impact on quality of life, defined as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”^{4, p.1405} Research with spouses suggests that over time the health and quality of life of both partners converge. Indeed, the health of each partner is interdependent on the other, and this interdependence is greater among older people.⁵ For example, 6-year longitudinal data from Europe suggest that as married couples age, a spouse’s quality of life,

cognition, and health is predictive of their partner's quality of life.⁶ Diary studies also suggest that daily emotions are contagious between married couples.⁷ Such interdependence in emotional and relational wellbeing has also been identified in non-spousal informal carers of relatives with a chronic illness, physical disability, or frailty due to ageing.⁸ Therefore, through daily interaction, emotion transmission, and shared behaviours and experiences,⁵ as with spouses generally, we might expect the perceived quality of life of people living with dementia to converge over time and become similar to that of their spousal carer. Similarly, quality of life among carers of people with various conditions has been found to be negatively associated with carer burden.⁹ Therefore, we might expect interdependence in quality of life to be directly and negatively associated with carer burden. i.e., if a person with dementia has low quality of life scores then we would predict not only lower scores of carer quality of life, but also higher scores of carer burden.

However, self-reports of health and quality of life require insight into one's own condition. Lack of insight, or anosognosia, refers to an individual's unawareness of the impact their medical condition has on their everyday functioning.¹⁰ Given that dementia is a degenerative neurological disease characterised by a chronic, global, and non-reversible loss of cognitive functioning,¹¹ an accompanying decline of insight into their condition is eventually identified in nearly all people living with dementia.¹⁰ In the context of quality of life, prior studies have found a discrepancy in quality of life ratings made by people living with dementia and proxy ratings from their carers. Some authors argue that a lack of insight by people living with dementia into the impact of their condition leads to this divergence in ratings.^{e.g.}¹² This would explain the stability of quality of life scores from people living with dementia over time but a gradual deterioration (in accord with expectation for a degenerative neurological disease) when reported in proxy by their carers.¹²

If people living with dementia become unaware of the impact of their condition, then their ability to report their level of quality of life in a manner that is congruent with their carer will also decline. Therefore, a lack of convergence in self-reported health and quality of life may develop among couples of a person living with dementia and their spousal carer.

Hypothesis

Our hypothesis is that dementia creates a unique context for spousal partners where interdependence in health and quality of life diminishes.

Initial evidence in support of the hypothesis

We conducted a secondary analysis of data on quality of life and carer burden from a randomised controlled trial with community-dwelling people living with dementia and their carers recruited as dyads.¹³ Self-reported quality of life from both dyad members, and carer burden, were collected at baseline and again six months later. As well as investigating the relationship between people with dementia and their spousal carers' quality of life, we were also interested in the relationship between quality of life of people with dementia and carer burden. This was because of the highly significant correlation between carer quality of life and carer burden,⁹ and the interest among researchers and policy makers to reduce carer burden to help support carers in their important role.¹ Thus, carer burden was our selected dependent variable for multivariate analyses to test our hypothesis of interdependence of health and quality of life between people with dementia and their spousal carers.

We used data at baseline and separately at the six-month follow-up in two sets of analyses. First, using baseline data, we tested the associations between quality of life of the person with dementia and their spousal carer's quality of life and carer burden. We then tested if quality of life of both the person with dementia and the spousal carer could predict

carer burden. Second, we tested the associations between quality of life of the person with dementia and their spousal carer's quality of life and carer burden at follow-up, using both baseline and follow-up data. We then tested whether quality of life of both the person with dementia and the spousal carer could predict carer burden at follow-up (see Supplemental Digital Content 1 for a full explanation of the method for this analysis).

Participants were recruited from 06/04/2017 to 17/07/2018, with the final follow-up completed on 30/11/2018. For the current analyses, 65 people living with dementia and their spousal carers provided data at baseline, and 54 at the 6-month follow-up. All couples were married and living together (see Table 1 for demographic details of participants at baseline and Supplemental Digital Content 2 - Table S1 for descriptive statistics for the variables at baseline and follow-up).

<<Table 1 about here>>

Carer burden at baseline

The output from the Pearson bivariate correlations is presented in Table 2. People living with dementia and carer quality of life at baseline were not significantly associated. For carer burden at baseline, the only baseline variable significantly ($p < 0.10$) associated with it was carer quality of life. Baseline measures from people living with dementia (quality of life and cognitive functioning) were not significantly associated with baseline carer burden.

Therefore, only baseline carer quality of life was entered into the regression that explained 43 per cent of the variance in carer burden at baseline ($F(1,61) = 47.82, p < 0.001, B = -52.54, SE = 7.60, \text{adjusted } R^2 = 0.43$).

<<Table 2 about here>>

Carer burden at follow-up

The results in Table 2 suggest that baseline and follow-up quality of life of people living with dementia were not significantly associated with carer quality of life at follow-up. For carer burden at follow-up, the only baseline variables significantly ($p < 0.10$) associated with it were carer burden and carer quality of life. Baseline measures from people living with dementia (quality of life and cognitive functioning) were not significantly associated with follow-up carer burden. For the variables at follow-up, the only variables significantly ($p < 0.10$) associated with carer burden at follow-up were carer quality of life and cognitive functioning of people living with dementia. The quality of life of people living with dementia was not significantly associated with carer burden at follow-up. Therefore, baseline carer burden, baseline and follow-up carer quality of life, and cognitive functioning of people living with dementia at follow-up were entered into the regression that explained 65 per cent of the variance in carer burden at follow-up ($F(4,43) = 22.30, p < 0.01, \text{adjusted } R^2 = 0.65$). Of the four variables entered, only baseline carer burden ($B = 0.57, SE = 0.11, p < 0.001$) and follow-up carer quality of life ($B = -23.02, SE = 8.20, p = 0.10$) significantly predicted carer burden at follow-up (baseline carer quality of life: $B = 5.42, SE = 10.00, p = 0.59$; follow-up people living with dementia cognition: $B = 0.00, SE = 0.12, p = 0.98$).

Discussion

In summary, the above analyses provide initial evidence from both baseline and follow-up data that reports from people living with dementia on their quality of life were not significantly associated with either carer quality of life or carer burden. Thus, in contrast to spouses in general, due to a lack of interdependence when a spousal partner has dementia, the quality of life of one partner cannot be predicted based on characteristics of the other. This also means that interventions designed to improve the health and quality of life of people

living with dementia and their carers may not necessarily benefit both partners. This has been observed in prior randomised controlled trials. For example, an intervention that increased walking among people living with dementia and their carers reported no benefit for people living with dementia but a reduction in carer burden.¹⁴ Additionally, in our Tai Chi intervention, we reported significantly higher quality of life among people living with dementia in the Tai Chi group relative to the control group but not their carers.¹³ This suggests that unless they are appropriately adapted, interventions for dyads may only be effective in improving the quality of life of either the person living with dementia or their carer but not both, even when both participate in the intervention.

Limitations of initial evidence and directions for future research

We acknowledge that our proposed explanation for a diminishment in interdependence between spousal carers was not tested in the above study. Therefore, alternative explanations are possible and future research could explore the mechanisms behind this relationship. Further, we recognise that the above initial dataset had limitations regarding the sample and measures used. This was a secondary analysis of people living with dementia and their carers recruited for a trial evaluating the efficacy of Tai Chi on postural balance.¹³ Therefore, the sample may not necessarily be representative of the general population of people living with dementia and their spousal carers. Future research with larger and more representative samples are needed that will afford subgroup analyses to fully test our hypothesis. Further, the number of years married / in partnership, and number of years living with dementia and severity of symptoms could be examined for their relationship with the degree of convergence in ratings of quality of life.

Future research might include additional variables. For example, relationships have been identified between carer burden and other variables including carer's perceived change

in identity in the person with dementia and relationship quality.¹⁵ Lastly, the measure of quality of life used in this study was relatively new and so did not readily lend itself to direct comparisons with prior studies. Future research could use both generic and dementia-specific measures of quality of life to test the similarity of their relationships with carer burden.

Conclusion

Our hypothesis is that dementia creates a unique dynamic for spousal partners by diminishing their interdependence in health and quality of life. We call on dementia researchers to collect data and conduct secondary data analyses to test our hypothesis and explore its implications for the health and quality of life of both people living with dementia and their carers.

List of Supplemental Digital Content

Supplemental Digital Content 1.docx (full explanation of the method)

Supplemental Digital Content 2.docx (Table S1 descriptive statistics)

Declaration of conflict of interests

The authors declare that there is no conflict of interest.

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Table 1. Demographic details of participants at baseline

	People living with dementia (n=65)	Carers (n=65)
Mean age (SD)	77.17 (7.66)	73.75 (8.37)
Gender		
Female	17	48
Male	48	17
Ethnicity		
White	63	64
Asian	1	1
Black	1	
Dementia diagnosis		
Alzheimer's	42	
Mixed	12	
Vascular	5	
Other	6	

Note: 34 couples were in the Tai Chi exercise intervention arm and 31 couples were in the control arm of the trial.

Table 2. Pearson correlations between baseline (B) and follow-up (FU) variables

	1. B-carer burden ^Ψ		2. FU-carer burden ^Ψ		3. B-carer quality of life ^π		4. FU-carer quality of life ^π		5. B-person with dementia quality of life ^π		6. FU-person with dementia quality of life ^π		7. B-person with dementia cognitive function ^π		8. FU-person with dementia cognitive function ^π		9. Trial arm	
	R	p	r	p	r	p	r	p	r	p	r	p	R	p	r	p	r	p
1 ¹																		
2 ²	.79	<.001																
3 ¹	-.66	<.001	-.49	<.001														
4 ³	-.62	<.001	-.66	<.001	.66	<.001												
5 ¹	-.05	.67	-.11	.44	.03	.83	-.09	.53										
6 ²	.06	.66	.07	.65	-.26	.06	-.01	.94	.40	<.001								
7 ¹	-.07	.59	-.06	.65	-.04	.77	.16	.26	-.27	.03	-.14	.30						
8 ³	-.28	.04	-.24	.09	.13	.37	.29	.04	-.14	.32	-.06	.68	.83	<.001				
9 ⁴	-.00	.97	.03	.85	.14	.27	-.05	.73	.21	.10	-.08	.58	-.26	.04	-.14	.32		

Notes: B = baseline, FU = follow-up. 1: N = 64, 2: N = 52, 3: N = 53, 4: N = 65. Values in bold indicate significance at $p < 0.10$.

^ΨLower score = better outcome; ^πHigher score = better outcome;

Methods

Design

This paper used data from the TACIT trial (TAi Chi for people with dementia); a randomised, assessor-blind, two-arm, parallel group, superiority trial investigating the effectiveness of Tai Chi to improve postural balance among community-dwelling people with dementia (blinded for review). The study was registered on ClinicalTrials.gov (ID: blinded for review) and the protocol has been published (blinded for review). The trial was approved by the xxxx Research Ethics Committee 4 (reference: blinded for review) and the Health Research Authority (xx project ID: blinded for review).

Setting

The study was conducted in three locations across the South of England. Participants enrolled in the trial were recruited via various sources such as National Health Service memory clinics, local charities and self-referral. The control group received usual care, while the intervention group received usual care plus a Tai Chi exercise intervention for 20 weeks. Irrespective of the random group allocation, all participants provided data at baseline and at a six-month follow-up in the same way. Details are described elsewhere (blinded for review).

Participants

We recruited dyads into the study, comprising a person with dementia and a carer. For the secondary analysis reported here, we only included dyads who were married. For the study overall, people with dementia who were eligible were: aged 18 or above, community-dwelling, had a diagnosis of a dementia (indicated on their medical record held by the NHS or general practitioner [GP]), physically able to do standing Tai Chi, and willing to attend weekly Tai Chi classes. Several exclusion criteria were applied: living in a care home; in

receipt of palliative care; severe dementia (score of 0-9 on the Mini Addenbrooke's Cognitive Examination ¹), had Lewy body dementia or dementia with Parkinson's disease, severe sensory impairment; already currently practising or were practising within the past 6 months Tai Chi or similar exercise on average once a week or more (Qi Gong, yoga, or Pilates); under the care of or referred to a falls clinic for assessment, currently attending a balance exercise programme (e.g. Otago classes); or lacked mental capacity to provide informed consent. Carers had to be: able to commit to supporting the person with dementia with data collection throughout the trial and in the intervention components if allocated to the intervention group, physically able to do standing Tai Chi, and willing to attend weekly Tai Chi classes. Carers were excluded if they had severe sensory impairment or lacked mental capacity to provide informed consent.

Measures

At baseline and the six-month follow-up, all data were collected in a home visit to both the person with dementia and carer together. A researcher was trained to conduct the data collection in a uniform manner at both baseline and follow-up and was blind to randomisation group; at follow-up dyads were asked not to reveal their group allocation and to conceal identifying items from the researcher (e.g. Tai Chi materials). At baseline, after both dyad members gave written informed consent, the person with dementia provided information by structured interview. This began with the Mini Addenbrooke's Cognitive Examination to assess global cognitive functioning to confirm eligibility ¹. The sum score of the 5-items was used (minimum to maximum possible scores of 0 - 30 with higher scores indicating greater cognitive function). The person with dementia then provided demographic data and completed further scales by structured interview.

People with dementia completed a measure of quality of life, the ICEpop CAPability measure for Older people (ICECAP-O) ². This 5-item scale produces a sum score that is then assigned weights (minimum to maximum possible scores of 0 – 1, with a higher score indicating greater capability). This measure of quality of life was chosen as it uses a broader scope of attributes identified by older people as important to quality of life (attachment, security, role, enjoyment, and control) ², and thus was more likely to be sensitive to psychological changes than a health-related measure of quality of life. Nonetheless, scores on the ICECAP-O have previously been associated with fall risk, general balance and mobility, and sensitive to cognitive status ³. It is also a measure recommended in guidelines on economic evaluation of fall prevention interventions ⁴. In addition, we have found the ICECAP-O to be a valid and reliable measure for use directly with people with dementia, with data supporting its convergent validity, discriminant validity, sensitivity to change, adequate factorial structure (blinded for review) and retest reliability (blinded for review).

Carers also provided demographic data by structured interview. They were then asked to self-complete the same ICECAP-O measure of quality of life and a measure of carer burden by hand away from the researcher and person with dementia. This was to promote honest reporting by carers without concern of their partner's reaction to their scores. Carer burden was assessed using the Zarit Burden Interview (short-form) ⁵. The sum score of this 12-item scale was used (minimum to maximum possible scores of 0 – 48 with higher scores indicating greater burden). It is the most commonly used tool for carer burden ⁶, and is shorter but just as reliable and valid as the full-length version ^{5 6}.

Statistical analysis

All analyses were conducted using IBM SPSS Statistics 25. Given the non-normal distribution of scores, before analyses were conducted, each variable except for baseline carer

burden and follow-up M-ACE was transformed using the fractional rank and inverse distribution functions method.⁷ The relationships between the variables at baseline and follow-up were then tested using bivariate Pearson correlations. The correlations were undertaken to explore the associations between people with dementia's quality of life and their spousal carers' quality of life and carer burden. Significant variables were then selected for entry into multiple linear regressions to test whether people with dementia's quality of life could predict carer burden. Baseline variables that were significantly associated with carer burden at baseline at $p < 0.10$ were selected to be entered into a multiple regression to predict baseline carer burden. Similarly, baseline and follow-up variables that were significantly associated with carer burden at follow-up at $p < 0.10$ were selected to be entered into a multiple regression to predict carer burden at follow-up. A p value of $p < 0.10$ was used as a more inclusive approach to ensure the key potential predictor variables were entered into the multiple regression. Six statistical assumptions for conducting multiple linear regressions were checked and all of them were met. These were as follows:

1. The relationships between the independent variables and the dependent variable were linear; checked via scatterplot.
2. There was no multicollinearity in the data; the independent variables were not too correlated (Pearson's $r = \leq 0.8$).
3. The values of the residuals were independent; checked via The Durbin-Watson statistic.
4. The variance of the residuals were similar; checked via scatterplot.
5. The values of the residuals were normally distributed; checked via visual inspection of the P-P plot that the dots were close to the line.
6. There were no influential cases biasing the model; no outliers were identified.

An important consideration for our analysis was that the data were from a randomised controlled trial. This meant that the data at follow-up could have been influenced by whether participants had been randomised to the intervention group (usual care plus Tai Chi) or control group (usual care only). To account for this, we included the variable of trial arm (intervention vs. control group) in the bivariate correlational analysis. If found to be significant ($p < 0.10$), we would then control for this variable by including it in the multiple linear regressions.

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Table S1. Mean (SD) baseline and follow-up scores on carer burden, quality of life, and global cognitive functioning.

	Baseline	Follow-up
Carer burden ¹	17.39 (8.20), n=64	19.90 (7.63), n=52
Carer quality of life ²	0.84 (0.11), n=64	0.76 (0.12), n=52
Person with dementia quality of life ²	0.89 (0.09), n=65	0.85 (0.11), n=53
Person with dementia global cognitive functioning ³	15.42 (4.61), n=65	13.85 (6.61), n=54

Notes: 1. Measured using the Zarit Burden Interview (short-form) (Bedard et al., 2001). The sum score of this 12-item scale was used (minimum to maximum possible scores of 0 - 48 with higher scores indicating greater burden). 2. Measured using the ICEpop CAPability measure for Older people (ICECAP-O) (Coast et al., 2008). The weighted sum score of this 5-item scale was used (minimum to maximum possible scores of 0 - 1, with a higher score indicating greater capability). 3. Measured using the Mini Addenbrooke's Cognitive Examination (Hsieh et al., 2015). The sum score of this 5-item assessment was used (minimum to maximum possible scores of 0 - 30 with higher scores indicating greater cognitive function).