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Physical activity patterns within dementia care dyads

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Abstract

Previous research has explored physical activity habits of people with dementia and their family carers separately, with little consideration of how physical habits are associated within dyads. Within this observational study, we sought to explore the relationship between people with dementia and their carers' physical activity, at a group level and at a dyadic level. Twenty-six participant dyads (person with dementia and their carer spouses) were asked to wear an accelerometer for 30 days continuously. Comparisons were made at a group level and a dyadic level. People with dementia did not participate in significantly more moderate to vigorous physical activity (M=15.44 mins/day; SD=14.40) compared to carers (M=17.95 mins/day; SD=17.01). Within dyads, there were moderately strong associations between daily moderate to vigorous physical activity (r=0.48-0.54), but not with overall activity levels (r=0.24). Despite physical activity habits remaining relatively low within people with dementia and caregivers, respectively, moderate to vigorous physical activity levels appear to be correlated within dyads. Understanding mutual influence on physical activity levels within dyads is an important pathway to promote an active lifestyle.

Keywords: physical activity, exercise, dementia, caregiver, dyad, spouse

Introduction

The World Health Organisation (WHO) has prioritized healthy ageing policies to help manage the growing health system costs of an ageing population and to maximise individual health (WHO, 2015). Physical activity is an important contributor to healthy ageing, with well-established health benefits to older adults (Chodzko-Zajko et al., 2009; Cunningham et al., 2020; Taylor et al., 2004). The WHO and UK physical activity guidelines recommend at least 150 minutes of moderate intensity physical activity (MVPA) a week for older adults (65+) (Bull & Expert Working Groups, 2010; World Health Organization, 2010), and suggest that “something is better than nothing” when recommending physical activity for older adults with chronic health conditions, such as dementia (Department of Health & Social Care, 2019).

Increased functional and cognitive impairment is associated with lower physical activity participation (Sport England, 2021; Wion et al., 2020) and hence it unsurprising that people with dementia participate in less physical activity than cognitively healthy older adults (Boyle et al., 2015; McArdle et al., 2019; Watts et al., 2016; Zanco et al., 2016). Walking appears to be the most popular form of physical activity in people with dementia (Farina et al., 2021; Winchester et al., 2013), though gardening is also frequently reported as a popular leisure time physical activity (Müller et al., 2021; Watts et al., 2013). Accelerometer data demonstrates that many PwD live largely sedentary lives (van Alphen, Volkers, et al., 2016) with little variability between days (Watts et al., 2016), particularly in non-walking physical activities (Abel et al., 2019).

The reduction of physical activity in people with dementia can be attributed to several potential barriers that extend past physical changes associated with old age. Thirty five

barriers, 26 motivators and 21 facilitators related to physical activity were identified in a systematic review of literature (van Alphen, Hortobágyi, et al., 2016). Evidence on this topic is however still relatively sparse, being predominantly derived from small samples in qualitative research. One emerging theme is the importance of family carers, herein referred to as carers, in providing support and motivation to facilitate and maximise physical activity in people with dementia (Farina et al., 2020; Hobson, 2017; van Alphen, Hortobágyi, et al., 2016).

Carers as a whole appear to participate in a limited amount of physical activity; being more likely to be physically inactive compared to non-carers (Stacey et al., 2019; Tseliou et al., 2019). Increased carer burden is associated with lower physical activity, particularly with leisure based activities (Hirano et al., 2011). This is supported by carers of people with dementia who identified lack of time and their caring role as key barriers to their physical activity (Farina et al., 2020). As highlighted in a recent systematic review, there is a general lack of evidence about physical activity of carers from the UK, including the levels of physical activity in this group (Horne et al., 2021).

People with dementia and their carers therefore both represent underactive groups, as a consequence of the condition. However, it is unclear to what extent the physical activity of the person with dementia is associated with carer physical activity and vice versa. One hypothesis is that increased dependence on carers leads to a change in roles, whereby habitual physical activities shift from the person with dementia to the carer (McArdle et al., 2019), such as one partner taking responsibility for all household tasks. As such, we might expect there to be greater low intensity physical activity in the carer to compensate for inactivity in the person with dementia. This may align with

evidence from non-cognitively impaired older adults, in which instrumental activities of daily living provide older women with the opportunity to remain active (Sheehan & Tucker-Drob, 2019; Wu et al., 2021). Increased caring responsibilities may however minimise the amount of time available for carers to participate in more purposeful physical activity (Farina et al., 2020; Malthouse & Fox, 2014). In parallel, the reliance on the carer to facilitate and support physical activity for the person with dementia (Farina et al., 2020; Hobson, 2017) may result in greater physical activities participated as a dyad. It is likely that such mechanisms will vary between individuals and over time, but at present there is no research exploring whether there is a quantifiable association of physical activity levels within carer-dementia dyads.

In this study, we seek to start to fill this gap in the literature by reporting the relationship between people with dementia and their carers' physical activity, at a group level and at a dyadic level. The study aims were to:

1. Describe and compare group level differences in physical activity between people with dementia and their spousal carers.
2. Determine whether there is an association between physical activity participation within carer-dementia dyads.

Materials and Methods

Design

This is a secondary analysis of observational data collected as part of a study in which we investigated the feasibility and acceptability of using activity monitors in people with dementia (Farina et al., 2019).

Participants

We enrolled community-dwelling, ambulatory, people with dementia (clinically diagnosed, self-reported), aged 65 and above. Whilst there were no criteria based on dementia severity, participants were required to have capacity to consent. There were no other restrictions on comorbidities, health status or dementia type. Participants were also required to have a co-habiting family carer who also participated. Participants were recruited from the geographic area of Sussex (South East England). Health Research Authority ethical approval was obtained by the London - Brighton & Sussex Research Ethics Committee.

As an explorative, secondary analysis, there was no formal sample size calculated for this study.

Procedure

Participants were identified either through self-referral or had previously expressed interest in participating in research studies. Informed consent was obtained from both the person with dementia and their carer independently by a trained researcher. Capacity to consent was assessed in all people with dementia. The researcher ascertained whether the person with dementia is able to, a) understand the purpose of the study, b) retain the information long enough to make a decision, c) weigh up the information, and d) communicate their decision. If the person with dementia was unable to do any of these, then they were deemed to lack capacity and excluded from the study. Both the person with dementia and the carer were asked to complete a series of questionnaires (see below) before being given the activity monitor. All participants were

provided with a device diary to make notes about when the device was removed, alongside guidance of the device functionality. After one month or withdrawal from wearing the devices (whichever came first), satisfaction with wearing devices was assessed (Farina et al., 2019). The activity monitors were collected at the end of testing and all participants were given a summary of their own physical activity participation after the completion of the study.

Setting

Data collection was conducted during the UK autumn months (September to November 2017). In the South East of England during that period, the average temperature was 11.3°C, with 30.1 days of rainfall totalling 149.3 mm of rain (Met Office, 2017). Two-thirds of all households in the South East have access to a greenspace of at least 20 hectares within two kilometres (McKernan & Grose, 2007).

Measures

The measures used in this study can be split into the activity monitor component and questionnaires.

Activity monitor: The GENEactiv Original (Activinsights Ltd., Cambridgeshire, UK) is a wrist worn acceleration sensor. The device has been shown to be acceptable to wear in community-dwelling people with mild-moderate dementia (Farina et al., 2019). The device has previously been shown to be valid measure of physical activity and sedentary time (Pavey et al., 2016; White et al., 2016) and is commonly used in older adult populations (Broekhuizen et al., 2016; Ramires et al., 2017; Rowlands et al.,

2014). In the present study, the GENEactiv Original was set to have a sampling frequency of 20Hz. Both the person with dementia and the carer were asked to wear the device on their non-dominant wrist for the duration of the study. Participants were encouraged not to remove or interact with the device. Participants did not have the ability to review their activity habits in real-time.

Three indices were extracted: 1) the average daily Euclidean Norm Minus One (ENMO) as a summary measure of acceleration, the value presented is the average ENMO over all the available data normalised per 24-hour cycles, with invalid data imputed by the average at similar time points on different days of the week. In this study, the average daily ENMO was used as an estimate of unspecified movement, and indirectly represents habitual physical activity; 2) average time spent in MVPA per day based on 5 second epoch size and a ENMO metric threshold of 100 milligrams (mg) setting bout duration of 1 minute and inclusion criterion of more than 80 percent, and; 3) average time spent in MVPA per day based on 5 second epoch size and a ENMO metric threshold of 100mg setting bout duration of 10 minutes and inclusion criterion of more than 80 percent. Differentiating between 1-minute and 10-minute bouts allows us to understand the differences between all MVPA instances and more purposeful MVPA (e.g., running, swimming), thus providing us an insight into the types of physical activity being participated in.

The data were processed using the GGIR package (version 1.5-12) (Hees et al., 2013) for R (R. Core Team, 2016) on RStudio software v1.2 (RStudio Team, 2020).

Questionnaires: A short set of questionnaires were administered to the person with dementia and their carer. The full list of measures is reported elsewhere (Farina et al., 2019), but the following were used in the analyses presented here:

- The Montreal Cognitive Assessment (MoCA) test (Nasreddine et al., 2005) – A short screening instrument of cognitive function. The MoCA was completed by the person with dementia only.
- The Rapid Assessment of Physical Activity (RAPA) (Topolski et al., 2006) - A short questionnaire used to assess physical activity levels in older adults. The questionnaire captures what older adults “usually do”. The measure provides standardised examples of what light, moderate and vigorous physical activity looks like. The measure was completed by the person with dementia and the carer as a self-report instrument. As per the original guidance, participants were defined as aerobically “regular active” if they reported as spending 30 minutes or more a day of moderate physical activities (5 or more days a week), or 20 minutes or more a day of vigorous physical activities (3 or more days a week).

Analysis

Data were presented descriptively (e.g., Median, Interquartile Range (IQR), Mean, Standard Deviation (SD)), with the carer and the person with dementia data reported separately.

Accelerometer data were initially presented as summary statistics over the duration of the study. Group differences (person with dementia and carer treated as seperate

groups) were compared through multiple regression, bootstrapped (1,000 samples, Bias Corrected and accelerated (BCa)). To compare the baseline RAPA, a Chi-square test was used to see whether the groups differed in being regularly active or not.

We wanted to test whether the physical activity levels of the dyadic pairs were more similar than when compared with data from non-dyads. Dyad comparisons were treated as distinguishable (i.e., the dyads are identifiable by the nature of their role and cognitive status) and only whole cases were used. Pearson product-moment correlation coefficients between dyad indices of physical activity were calculated, whilst using a t-test of the null hypothesis that the sample correlation was 0. We used the SPSS syntax developed elsewhere (Alferes & Kenny, 2009).

We also visualised daily data to highlight relationships between groups and within dyads. For the former, this was achieved by creating an average-of-averages of accelerometer indices for each weekday (i.e., Monday to Sunday) and plotting on bar chart. For dyadic data, daily physical activity of both the carer and person with dementia were plotted within a scatter plot. We did not statistically analyse such data as independent observations because it would have violated assumptions of independence of errors and avoids issues with inflated degrees of freedom or pseudoreplication (Lazic, 2010; Millar & Anderson, 2004).

Analysis was completed in SPSS, version 25 (IBM Corp., 2017).

Results

Of the 61 participant dyads contacted, 25 refused. Twenty-six participant dyads were recruited in the study. The average age of people with dementia was 79.8 years old (SD = 5.8) compared with carers who were 76.4 years old (SD= 5.9). The person with dementia had on average a mild severity of cognitive impairment (mean MOCA = 17.7, SD = 3.7). Both the persons with dementia and carer's subjective reported similar physical activity, being classified as "regular active" (n=12 vs n=10, respectively) based on the RAPA (χ^2=1.39, p=0.41). Further details are presented in Table 1. One dyad stopped wearing the device after one day and one carer refused to wear the device, thus the remaining 24 dyads had complete data for analysis. Other demographic information and wear time data are reported elsewhere (Farina et al., 2019). The dyads where we were unable to collect sufficient accelerometer data did not significantly differ on key demographics such as age and cognitive status (p>0.05).

Group-level differences on daily physical activity

Over the course of the study, carers were on average more active (mean daily ENMO) compared those with dementia (p=0.02). There was no statistically significant difference between the two groups for the 1-minute bout MVPA (p=0.57) or 10-minute bout MVPA (p=0.61). See Table 2.

Visualising the data on the average weekday of the study highlights that carers almost always participated in more physical activity than people with dementia. However, error terms were often wide and overlapping between groups. See Figure 1.

Dyadic comparisons

Mean daily ENMO (mg) demonstrated a weak, non-statistically significant, positive association within dyads (r=0.24, 95% CI = -0.13 to 0.62, p=0.17, t=1.41). For daily MVPA time, there was a significant positive association within dyads for greater than 1-minute bouts (r=0.48, 95% CI = 0.10 to 0.74, p=0.01; t=2.58) and 10-minute bouts (r=0.54, 95% CI = 0.17 to 0.77, p=0.006; t=3.01).

Dyadic comparisons on a daily basis are visualised in Figure 1. All accelerometer indices indicated a positive trend within dyads.

Discussion

This study set out to understand the relationship between people with dementia and their carer's physical activity. The study highlighted that whilst group-level differences in physical activity were observed, there was also an association within dyads.

When visualising data across weekdays, we observed that the carer was nearly always participated in more physical activity across all Actigraph indices on a given day. At a group-level, similar to other studies, physical activity participation is higher in carers than those that they care for (Mattek et al., 2019), based on the average ENMO/day index. Assuming that cognitive impairment does not inherently lead to less physical activity participation (Stubbs et al., 2014), our findings could be explained by increased carer's activity due to their caring role. Such an interpretation might also explain why there was no significant difference between the carers and persons with dementia in

terms of MVPA. Namely, the types of physical activity that might increase due to a carer's role, are likely to be considered light (e.g., household chores, walking). However, we cannot rule out potential floor effects in the MVPA data. Contextualising these data within the broader literature is difficult due to differences in populations and accelerometer indices. Both the person with dementia (Mean ENMO/day = 17.02 mg) and carer (Mean ENMO/day =20.48 mg) were less active compared to a larger cohort (n=785) of European older adults (mean age 68.6) that participated on average 28.1mg per day (SD=19.8)(Felez-Nobrega et al., 2023).

At a dyadic level, there was evidence of a linear association between the person with dementia and carer's physical activity, particularly for MVPA indices. This lends support to the notion that the motivation and support of physical activity from the carer (Farina et al., 2020; Hobson, 2017) may lead to increased purposeful physical activity within the dyad. Visualised daily data did not indicate that there is a compensatory mechanism; namely, that as the person with dementia is able to do less, the carer has to do more activity (McArdle et al., 2019). Factoring the role of gender in larger samples would be of value (Wu et al., 2021), as the mechanisms for physical activity might be different for men and women.

In both MVPA indices of physical activity, the associations were sufficient to indicate non-independence. In brief, non-independence indicates that the behaviour or characteristic of one is affecting the other's outcome, and can be attributed to compositional effects, mutual influence or common fate (Grawitch & Munz, 2004). Future research should consider adopting an Actor Partner Interdependence Model (APIM) in sufficiently powered dyadic studies (Shamali & Østergaard, 2019) to assesses

whether the degree to which the carer's outcome is influenced by their own characteristics (actor effect), or by the characteristics of the person with dementia (partner effect). APIM has been used in other populations (e.g. adolescent-parent, people with multiple-sclerosis-caregiver) to understand the role of salient psychosocial variables and demographic factors on physical activity participation within the dyad (Burns, 2019; Fakolade et al., 2018). The importance of revealing partner effects is that it could provide alternate routes to promoting physical activity through targeting the characteristics associated with the partner. Not framed in terms of the APIM, the Physical Activity Behaviour change Theoretical model in dementia (PHYT-in-dementia) builds upon generic behavioural change models yet recognises the uniqueness of dementia experiences (Di Lorito et al., 2019). Notably, the model highlights the importance of significant others (e.g., carer) in promoting physical activity in people with dementia, though it is proposed that this effect is bidirectional (Di Lorito et al., 2020). As such, there are potential benefits of developing physical activity interventions and public health messages aimed at both the person with dementia and carer. Such dyadic interventions do exist (de Dios-Rodríguez et al., 2023; Lamotte et al., 2017), though just because the intervention targets both carers and people with dementia, it does not necessarily result in a significant increase in physical activity when compared to controls (de Dios-Rodríguez et al., 2023).

This study has important limitations. First, we cannot ascertain why the person with dementia or carer were participating in physical activity, and whether the relationship between physical activity habits were causally linked. Second, due to the sample size and recruitment strategy we cannot assume that this population would reflect a larger

cohort of people with dementia and carers. Third, the sample size will have limited the statistical power to detect anything but large between group differences, and thus prevented us from controlling for confounding variables (e.g., age, sex, cognitive impairment). Larger studies in representative populations are needed. Fourth, the mean daily ENMO is not the most intuitive metric to interpret, though as it has benefits over applying thresholds to data which may have questionable validity depending on the population (Grimes et al., 2019). In line with this, we adopted a processing threshold to ascertain a metric of time spent participating in MVPA, but there is still debate about the best threshold to use in older adults (Fraysse et al., 2021). Fifth, carers were all co-habiting spouses and therefore the findings may not represent other dyadic relationships of care (e.g., child carers). Finally, the present study provides us with certain dimensions of physical activity (e.g., intensity, duration), but does not provide detail about the types of activity that are occurring independently or together, or whether it for leisure or non-leisure purposes.

This study provides confirmatory evidence of underactivity in older adults with dementia and carers, over a prolonged observation period. Whilst carers are more physically active than those that they care for, it appears that it is only more purposeful physical activity (MVPA) that is associated within dyads. Our research highlights that efforts to improve spousal carer physical activity may have the added benefit of improving physical activity habits of the person they care for. Future research should seek to better understand why such an association exists and consider whether this non-independence could be adopted as a means to promote activity in both groups.

Conflicts of Interest

The authors have no conflict of interest to report

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Table 1. Participant characteristics of people with dementia (n=26) and their carer (n=26).

	Person with dementia	Carer
Age, mean(SD)	79.8 (5.8)	76.4 (5.9)
Sex: Male, n(%)	16 (31.4%)	7 (26.9%)
Physical complaints: Yes, n(%)	16 (61.5%)	14 (53.8%)
Physical complaints that influence physical activity: Yes, n(%)	8 (30.8%)	6 (23.1%)
More than one fall in the past year: Yes, n(%)	9 (34.6%)	4 (15.4%)
Regularly active (RAPA): Yes, n (%)	12 (46.2%)	10 (38.5%)
Missing	1 (3.8%)	1 (3.8%)

Table 2. Average daily participation in physical activity across the study. Differences are reported between carers and persons with dementia.

	Person with dementia (n=25)				Carer (n=24)				Between-group comparison	
									Unadjusted	
	Mean (SD)	Median (IQR)	Min	Max	Mean (SD)	Median (IQR)	Min	Max	B	BCa 95%
Mean daily ENMO [mg]	17.02 (4.64)	17.25 (7.22)	7.27	27.52	20.48 (5.38)	19.85 (7.31)	11.12	31.94	-3.46	-6.18 to -0.75
MVPA time/day, 1-minute bouts [mins]	15.44 (14.40)	11.04 (23.39)	0.24	46.73	17.95 (17.01)	12.76 (19.53)	2.03	69.02	-2.50	-11.21 to 6.03
MVPA time/day, 10-minute bouts [mins]	4.03 (5.09)	2.54 (5.68)	0.00	18.11	4.92 (7.30)	1.49 (6.42)	0.00	24.20	-0.88	-4.25 to 2.39

BCa = Bias-corrected and accelerated, ENMO = Euclidean Norm Minus One, IQR = Interquartile range, MVPA = Moderate to Vigorous Physical Activity, SD = Standard Deviation

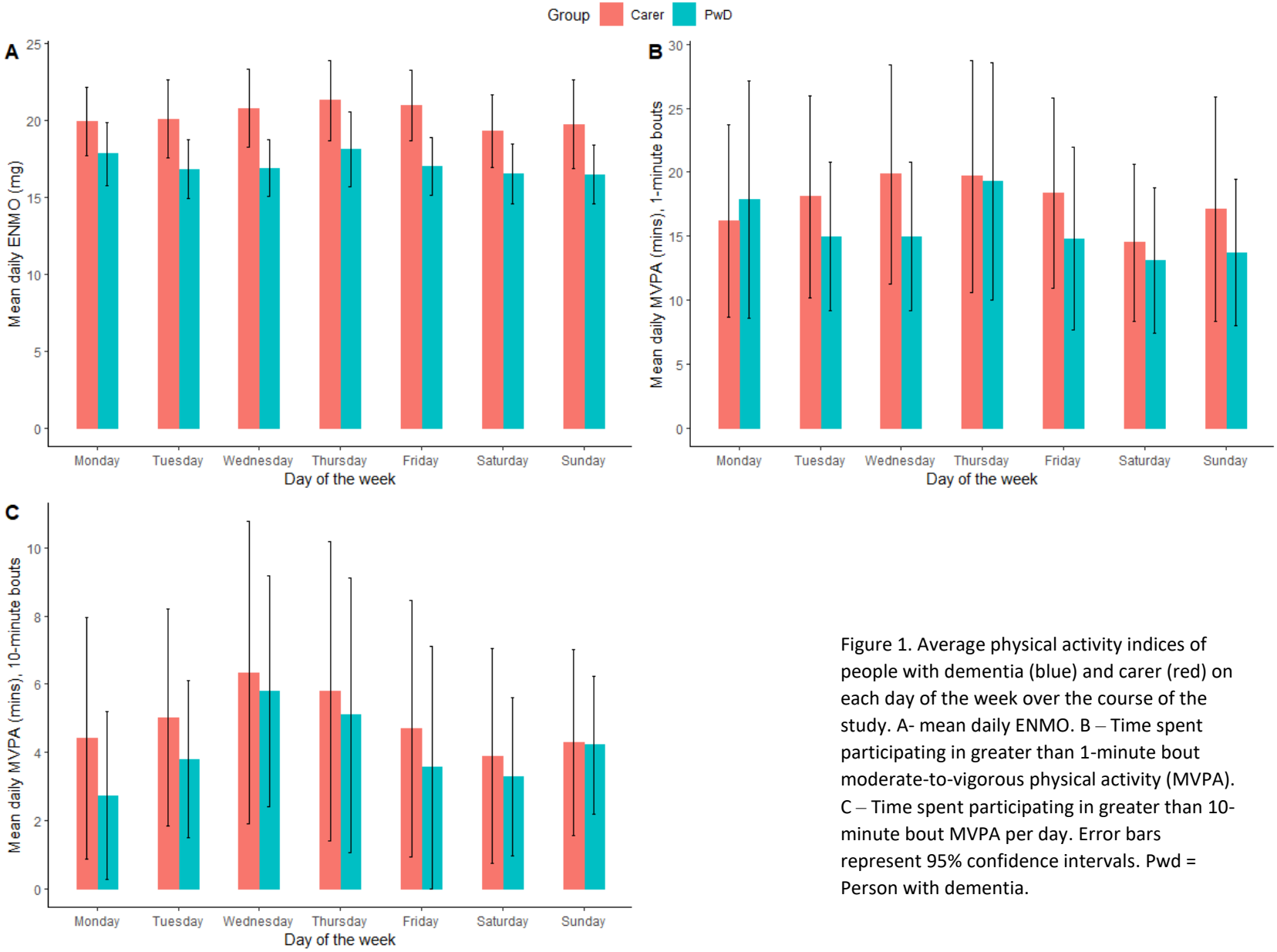

Figure 1. Average physical activity indices of people with dementia (blue) and carer (red) on each day of the week over the course of the study. A- mean daily ENMO. B – Time spent participating in greater than 1-minute bout moderate-to-vigorous physical activity (MVPA). C – Time spent participating in greater than 10-minute bout MVPA per day. Error bars represent 95% confidence intervals. Pwd = Person with dementia.

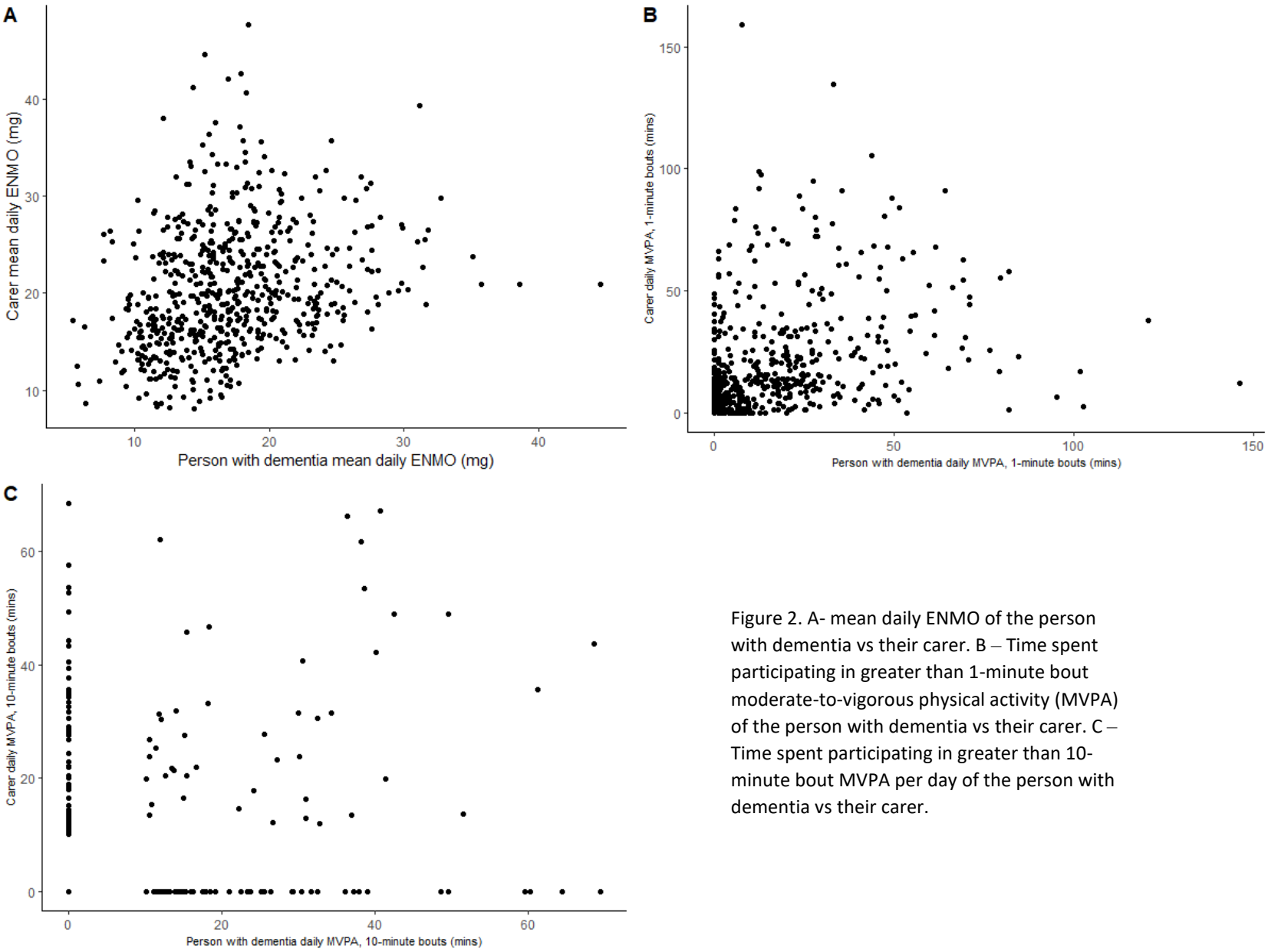

Figure 2. A- mean daily ENMO of the person with dementia vs their carer. B – Time spent participating in greater than 1-minute bout moderate-to-vigorous physical activity (MVPA) of the person with dementia vs their carer. C – Time spent participating in greater than 10-minute bout MVPA per day of the person with dementia vs their carer.