

Trajectories of socio-emotional functioning in early-stage dementia: Implications for the individual with dementia and their family carer

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Abstract

Background and objectives: Changes in socio-emotional functioning in people living with dementia (PLWD) are common; however, little is known about the broader effects these may have on wellbeing. This study examined socio-emotional functioning over time and associations with the wellbeing of PLWD and their family carers.

Method: One hundred and one individuals with a diagnosis of dementia and their respective carers completed the Social Emotional Questionnaire (assessing emotion recognition, empathy, social relationships and social behaviour) alongside measures of dementia severity, cognition, mood, stress, and relationship quality. Sixty-six dyads were reassessed on the same measures at 12 months post-baseline, and 51 dyads again at 20 months post-baseline.

Results: When rated by the PLWD, there was no change in socio-emotional functioning over time; however, carers reported a significant decline over time. For both carers and the PLWD, poorer wellbeing measures were indicative of worse socio-emotional functioning at Time 1, though only dementia type, quality of life and relationship quality impacted upon the trajectory of socio-emotional decline over time.

Conclusions: Changes in social and emotional functioning are evident early in the course of dementia and worsen within 20 months. Both carer characteristics and those of the PWLD affected reporting of social and emotional functioning. These data are useful for guiding the provision of appropriate education and care.

Keywords: social, emotional, function, dementia, carers, change over time, social neuroscience

INTRODUCTION

Dementia, or major neurocognitive disorder, is associated with changes in multiple cognitive domains such as impairments in language ability, executive functions, and memory and concomitant difficulties with everyday functioning (APA, 2013). Changes in social functioning are also found in people living with dementia (PLWD) but these are less widely researched than general cognition and physical functioning. Indeed this lack of research into social function changes in clinical conditions naturally extends into clinical practice (Kelly et al., 2017). Failure to assess social functioning and report these difficulties to the PLWD and their families may limit their ability to self-manage the illness (Vernooij-Dassen & Jeon, 2016). This goes against more recent formulations of health and wellbeing, noting the ability to adapt and self-manage being integral (Huber et al., 2011).

In Alzheimer's disease (AD) difficulties in general understanding of social situations including reading emotions in other people's faces, remembering people's names and the identities of people who care for them are common (Bora et al., 2016; Greene & Hodges, 1996). In vascular dementia (VaD), there is more of a mixed pattern depending on what areas of the brain have been affected by vascular injury, though it is also common to see changes in social functioning (Shimokawa et al., 2000). In all dementias, as the disease process progresses there is generally more widespread impairment, including in the area of social functioning. It is often argued that these changes in social cognition are brought about purely by changes in general cognition such as changes in language ability, executive function and memory; however there is evidence that social function changes occur outside of, and sometimes independently of, general cognitive changes (Shimokawa et al., 2000). Relatedly, social networks and the association of these to cognition and social function have also been examined. Better social structures such as being married and reporting greater frequency of contact with friends were each independently related to less memory decline over time (while memory was not associated with future social structure) (Zahodne et al.,

2019), indeed this protective factor of social contact has been repeatedly demonstrated (see Livingston et al., 2020).

Regardless of the timeline, changes in social functioning and behaviour can place strain on the relationship between the PLWD and those providing care. Shimokawa et al (2001) found that poor emotion recognition ability was related to greater interpersonal relationship problems and difficulties in terms of management for staff in aged care facilities. Similarly strain on family carers of people with dementia is also evident. Nelis et al (2011) explored the extent to which *awareness* of social and emotional function is reduced in early stage dementia and the effect of this on the carer, and found that lower awareness of social function in the PLWD was related to carer stress and poorer perceived quality of relationship. Further, carer stress is higher when PLWD have social dysfunction in the areas of initiation of hobbies and likewise when they are socially isolated (Giebel et al., 2016).

Little extant research has examined social functioning in the early stages of dementia, nor has there been any investigation of *changes over time* and the impact of these changes on PLWD or on their carers. Previously, we have shown that *self-awareness* (measured by the extent of discrepancy between self- and informant reports) of social functioning may be a key factor in carers' wellbeing (Clare, Nelis, Whitaker, et al., 2012; Nelis et al., 2011); however the data were examined from a discrepancy perspective rather than using the raw data for social functioning, and the study did not explore changes in social functioning over time, the impact of these on the PLWD or carer, or the impact on the relationship between the two. In a more recent study performance measures of social cognition (emotion recognition tasks) were positively correlated with carer-reported deficits in social function; however, two-thirds of carers either underestimated or overestimated social function difficulties. Further, carer-reported social functioning was found to mediate the relationship between the performance-based measure of social cognition and caregiver burden (Spitzer et al., 2019). Taken together, these studies show firstly that there are discrepancies between perceptions of social functioning reported by PLWD and their carers, secondly, that

appraisal of these difficulties by carers influences carer burden, and thirdly, carer burden can also influence appraisal of social function. What is not yet known is the effects of possible changes over time and their relationship to carer burden.

This study examines social and emotional function in early stage dementia and how this changes over time. Secondly it will address whether these changes are related to dementia characteristics such as the type of dementia, severity of neuropsychiatric symptoms and cognition. Finally, it will examine the relationship between social and emotional function and quality of life for the PLWD, quality of the relationship between the PLWD and care partner, and carer stress.

MATERIALS AND METHODS

Design

The current study examines socio-emotional functioning in a community-dwelling sample of people with early-stage dementia who participated in the Memory Impairment and Dementia Awareness Study (MIDAS: Clare, Nelis, Martyr, Roberts, et al., 2012). This longitudinal, multimethod study of awareness assessed 101 participants (and carers) at entry, after 12 months ($n = 66$) and again after approximately 20 months from entry ($n = 51$). Ethics approval was granted by the relevant University and North Wales Research Ethics Committees (05/WNo01/45). As part of previous analyses of data in MIDAS, *awareness* of social functioning in the PLWD was examined at a single time point in relation to quality of life (Nelis et al., 2011). The current study examines self- and carer-reported socio-emotional functioning and the factors that are associated with this over time.

Participants

One hundred and one individuals with early-stage dementia ($M_{age} = 78.66$, $SD = 7.75$) and their carers ($M_{age} = 68.39$, $SD = 14$) were identified through six memory clinics across North Wales, United Kingdom. Participants were eligible if they met criteria for ICD-10 (WHO, 1992) diagnosis of Alzheimer's disease (AD), vascular dementia (VaD) or mixed AD and VaD.

Participants were required to be in the early stages of the disease as indicated by scoring 18 or above on the Mini-Mental State Examination (MMSE; Folstein et al., 1975). PLWD were excluded from the study if they were concurrently experiencing major depressive disorder or psychosis, or had a history of brain injury or any other neurological condition. In addition, to be eligible to participate each PLWD needed a family member or close friend in frequent contact willing to participate; we refer to these collectively as ‘carers’. People living with dementia were aged between 51 and 91 years at Time 1 and had 8-19 years of education. Descriptive statistics for the sample at Time 1, Time 2, and Time 3 are presented in Table 1. There are no significant differences in demographic variables between those in the study at Time 1 versus Time 3 (Clare, Nelis, Martyr, Whitaker, et al., 2012).

Table 1 about here

Measures

The following measures from the MIDAS study were examined in the present analysis.

The original 30-item Social Emotional Questionnaire (SEQ; Bramham et al., 2009) was administered (self- and carer-report) and factor analyses conducted (see Nelis et al., 2011) resulting in the final inclusion of 24 items across 3 factors; Emotion Recognition and Empathy (ERE), Social Relationships (SR) and Prosocial Behaviour (PB). Total scores (for 24 items) and the 3 factors are included in the analyses. There are 11 items relating to the ability to understand and relate to others emotions including recognition of the five basic emotions (happiness, sadness, fear, anger and disgust), 7 items to address engagement and maintenance of relationships and 6 items examining public behaviour such as aggression and criticism. Items are responded to on a five point scale of strongly agree to strongly disagree. The SEQ has demonstrated reliability and validity in brain injury patients (Bramham et al., 2009), and has been validated for use with people with dementia (Nelis et al., 2011).

The Mini-Mental State Examination (MMSE: Folstein et al., 1975) and Neuropsychiatric Inventory – Questionnaire (NPI-Q: Kaufer et al., 2000) were used to examine cognition and dementia severity, respectively. The MMSE demonstrates adequate internal consistency ($\alpha = 0.68-0.96$) retest reliability (0.80-0.95) and construct validity (convergent, specificity and sensitivity) (see Tombaugh & McIntyre, 1992 for review). The Quality of Life – Alzheimer’s Disease was used to measure self-reported QoL of PLWD and has shown adequate reliability ($\alpha = 0.83-0.90$) and validity (QOL-AD: Logsdon et al., 2000). The Hospital Anxiety and Depression Scale (HADS: Snaith & Zigmond, 1994) examined self-reported (PLWD) mood (symptoms of anxiety and depression) and has been reported to be reliable ($r = 0.86-0.91$; Spinhoven et al., 1997) and valid (0.68-0.77; Bjelland et al., 2002). The Relative Stress Scale (RSS: Greene et al., 1982) was completed by carers and demonstrates adequate internal consistency ($\alpha = .85$) and validity. The 12-item General Health Questionnaire (GHQ-12: Goldberg, 1992) was completed by carers to examine their levels of mood and stress, it demonstrates good internal consistency ($\alpha = .86$) and validity 0.65-0.93 (0.65-0.93; Romppel et al., 2013). Finally, the Positive Affect Index (PAI: Bengtson & Schrader, 1982), a measure of quality of relationship, was completed by both the PLWD and the carer (see Clare, Nelis, Whitaker, et al., 2012 for information on the adaptation of this measure for people with dementia). This scale has been used with PLWD, showing good internal consistency ($\alpha = 0.81$) and re-test reliability ($r = 0.66$) (Woods, 2009).

Procedure

Researchers attended the participant’s home where the PLWD and the carer were assessed separately. Assessments were conducted over 1-3 sessions as required. Informed consent was obtained at each time point from both the PLWD and the carer.

Statistical analyses

Correlations and *t*-tests were used to examine relationships between demographic variables and socio-emotional functioning. Logistic regression was used to test for differences between those who

remained and withdrew from the study. Random effects regression analyses examined change in socio-emotional functioning over time, and also the influence of other variables on this change. This method tolerates different numbers of measurements for different individuals over time, unequal intervals (months between assessment) and correlated and non-constant variability (Laird & Ware, 1982). Participant identification number was the participant variable, SEQ test score designated as the dependent variable and time interval (fixed effect) entered as a covariate. Three models (fixed slope, fixed intercept; fixed slope, random intercept; random slope, random intercept) were fitted in each case and parameters estimated using maximum likelihood for comparisons of model fit. To select the best model the Bayesian Information Criterion (BIC) was used (Schwarz, 1978), with a lower BIC indicative of a better fit. For both variables (SEQ self and informant) the fixed slope random intercept model had the best fit and was used for all further analyses. Following model selection, restricted maximum likelihood (REML) was used for parameter estimation. Individual change in socio-emotional functioning over time was also examined using reliable change indices.

RESULTS

Age and gender influences on socio-emotional function at Time 1

Spearman's correlations revealed no significant relationship between age and SEQ individual domains or total score (ERE $\rho = -.09, p = .38$; SR $\rho = -.03, p = .80$; PB $\rho = .18, p = .08$; SEQ total $\rho = .22, p = .83$). Independent samples t-test revealed a significant effect of gender on self-reported socio-emotional functioning, $t_{(81.43)} = 2.19, p = .031$, with females with dementia self-reporting better social functioning ($M = 97.83, SD = 8.15$) than males with dementia ($M = 93.36, SD = 11.64$).

Predictors of missing data at follow-up

A binomial logistic regression was performed to ascertain the effects of age and education, as well as our main outcome variables at Time 1 on the likelihood that participants remained in the study at Time 3. The model was not statistically significant, $\chi^2_{(13)} = 16.64, p = .22$. Upon examining individual

variables and their contribution, age of the PLWD at Time 1 was the only significant predictor of remaining in the study at Time 3, $Wald_{(1)} = 4.25, p = .039$. See Table 2.

Table 2 about here

Socio-emotional functioning over time

Random effects regression analyses (linear mixed-effects models) were conducted to examine patterns of change in social functioning (SEQ) over time (see Table 3, model *a*). A significant linear decrease in total SEQ score over time of 0.32 points per month was observed ($\beta = -0.32, 95\% \text{ CI: } -0.52 \text{ to } -0.12, p = .002$) from a baseline mean of 88.96 (95% CI: 86.22-91.71) (Table 3). PLWD also self-reported a decrease in total SEQ score over time ($\beta = -0.04, 95\% \text{ CI: } -0.19 \text{ to } -0.11, p = 0.63$) from a baseline mean of 96 (95% CI: 94.01 to 97.97), though this was not significant (see Table 5 model *a*, and Figure 1).

Figure 1 about here

Table 3 about here

Alternative analyses to examine change over time

Carer reported SEQ total scores were examined to determine what proportion of PLWD improved in socio-emotional functioning over time versus declined over time. A reliable change index was calculated (Evans et al., 1998) for SEQ using Cronbach's alpha of 0.76 (reliability estimate from Nelis et al., 2011) resulting in a change score of greater than 9.4 being required for confidence that movement in SEQ score was not due to unreliability of measurement. Approximately 10% of PLWD reliably improved in their socio-emotional functioning over time, 63% remained unchanged and 27% reliably declined. Table 4 displays descriptive statistics for the three groups.

Table 4 about here

Regression analysis examined baseline predictors of total SEQ score (carer rated) at Time 3. SEQ at baseline was entered at the first step and accounted for 42.5% (adjusted r^2) of the variance in SEQ

score at Time 3, $F_{(1, 48)} = 37.18$, $p < .001$. Other variables entered (cognition, mood, quality of relationship, and carer stress) were all excluded.

Influence of dementia characteristics on socio-emotional functioning

Random effects regression analyses (linear mixed-effects models) were conducted to examine patterns of change in social functioning (SEQ) at baseline (Time 1) and over time in relation to dementia characteristics (see Table 3). First, dementia type was examined. Those with AD had an average SEQ score of 91.9 at baseline, and this was lower for both those with VaD and Mixed dementia ($\beta = -6.32$, CI: -12.52 - -0.12 and $\beta = -5.71$, CI: -12.98 - 1.57 respectively. Those with AD declined at a rate of 0.55 points per month, which is significantly greater than those in the Mixed dementia group (Mixed vs AD, $\beta = 0.74$, CI: 0.21- 1.26).

At baseline (Time 1), greater dementia symptomatology (NPI symptom number) or greater dementia severity (NPI severity) was associated with lower SEQ total scores (-2.63, CI: -3.55 - -1.71 and -1.19, CI: -1.56 - -0.81). Over time, as symptoms increase the decline in the trajectory of SEQ score becomes less steep (0.13, CI: 0.07 – 0.18), and this is also the case for dementia severity (0.05, CI: 0.02 – 0.08). There was no effect of cognition (MMSE) on SEQ at baseline, nor was there a significant impact of cognition on the trajectory of SEQ over time.

Relationship between socio-emotional functioning and PLWD wellbeing

The wellbeing (mood and quality of life) of the PLWD was examined in relation to self-reported socio-emotional functioning using linear mixed-effects models (see Table 5). At baseline, higher scores on mood symptomatology (total HADS score) were associated with lower SEQ total score (-0.62, CI: -0.90 - -0.35), whereas better scores on quality of life were associated with higher SEQ total scores (0.65, CI: 0.31 – 0.99). There was no impact of mood (total HADS) on the trajectory of SEQ over time, whilst higher quality of life scores were associated with a decline in SEQ total score over time (-0.03, CI: -0.03- -0.01).

Table 5 about here

Relationship between socio-emotional functioning and carer wellbeing

The wellbeing (mood, stress and level of distress) of the carer was examined in relation to carer-reported socio-emotional functioning using linear mixed-effects models (see Table 6). At baseline (Time 1), higher mood symptomatology (GHQ scores) was associated with lower SEQ total scores (-0.43, CI: -0.84 - -0.03). Greater carer stress was also associated with decreased SEQ total scores at baseline (-0.56, CI: -0.77 - -0.35), as was greater carer distress (NPI distress) (-0.89, CI: -1.18 - -0.61). Over time as mood improves, the worsening of SEQ total score slows (0.04, CI: 0.00 - 0.08), though there was no significant impact of carer stress nor carer distress on the trajectory of SEQ.

Table 6 about here

Relationship between socio-emotional functioning and relationship quality

Perceived relationship quality according to both the PLWD and their carer was examined in relation to socio-emotional functioning as rated by the carer using linear mixed-effects models. At baseline (Time 1) a better relationship quality score (PAI) according to the carer was associated with higher SEQ total scores (1.19, CI: 0.64 - 1.73). Similarly, a better relationship quality score according to the PLWD was also associated with higher SEQ total scores (0.81, CI: 0.35 – 1.27). There was no significant impact of relationship quality according to the carer on the trajectory of SEQ over time (Table 6), although as relationship quality according to the PLWD increased over the time the trajectory of SEQ total score declined (-0.05**, CI: -0.09 - -0.01) (see Table 5).

The agreement between the quality of the relationship as reported by the PLWD and the carer was moderate and significant at Time 1 ($r = .462, p < .001$), though not at Time 3 ($r = .220, p = .120$). At both time points the carers ratings of quality of the relationship are more closely associated with the informant-rated socio-emotional functioning of the PLWD, admittedly also rated by the carer (Time 1 $z = 2.19, p = .03$; Time 3 $z = 2.02, p = .04$ two-tailed).

DISCUSSION

Changes in social functioning are often present in PLWD. This study is the first to the authors' knowledge to have examined trajectories of self- and carer-reported social and emotional functioning in people with early-stage dementia and the factors that influence these changes. Further, and of importance, we examined the effect of changes in social and emotional functioning on the wellbeing of both the PLWD and the carer, as well as the perceived quality of the relationship between the two.

The finding that changes in social and emotional functioning are evident early in the course of the disease and worsen within 20 months is useful for guiding the provision of appropriate care. On average this reduction was approximately one point every three months, and over the duration of the study, 27% of the group demonstrated a reliable reduction in social and emotional functioning of greater than 9 points. Social and emotional functioning at Time 1 was the only significant predictor at Time 3, suggesting that signs of change are recognisable very early in the course the disease. Further, we found that those in the VaD and those in the Mixed dementia group had lower social functioning at baseline compared with those with AD. Together, these findings have significant implications for clinicians who conduct diagnosis and provision of care thereafter. Specifically, it indicates that screening for early changes in social and emotional functioning should routinely form part of diagnostic testing for dementia, and where these changes are seen, the PLWD and their family should be provided with information that will help them manage impairments in the future.

It is not surprising that self- and carer-rated reports of social and emotional functioning were discordant, with extensive evidence that people living with dementia show changes in awareness of self, and may have difficulty reporting accurately on their impairments (Banks & Weintraub, 2008; Rankin et al., 2005). For example, they have been shown to have impaired awareness of difficulties on domains such as socio-emotional function and memory (Banks & Weintraub, 2008; Graham et al., 2005). Meanwhile, in other areas such as functional ability PLWD

have been found to be accurate, while their carers often underestimate ability (Martyr & Clare, 2018). Indeed, discrepancies between self- and informant reports can be influenced by many factors including the ability itself (Banks & Weintraub, 2008). Clare et al. (2012) found discrepancies between reports were greatest for everyday function, followed by memory and less so for social-emotional functioning in those with early stage dementia. Further, lower levels of self-awareness are associated with the type of dementia, greater age, lower MMSE scores, poorer recall and naming scores, lower anxiety and the use of home care services (Banks & Weintraub, 2008; Clare et al., 2011; DeFeis et al., 2019). The wellbeing of the carer also affects the reliability of reporting, with carer burden and stress having been shown to elevate reports of impairment in the care receiver (Clare et al., 2011; Martyr & Clare, 2018), suggesting that we should interpret the discordance cautiously. Changes in awareness over time related to cognition (Clare et al., 2011) and changes in the perceived quality of the relationship are also likely to influence reporting, and this was supported by our findings. Specifically, we found that self-reported relationship quality as reported by PLWD and the carer is more closely associated at Time 1 than it is 20 months later, potentially also supporting the finding of a reduction in self-awareness over time and the influence of this on relationship dynamics.

Greater symptom severity and higher number of neuropsychiatric symptoms observed at Time 1 were associated with lower socio-emotional functioning, though this was not found for cognition. While socio-emotional functioning continued to decline over time, as dementia symptoms and severity increased, the decline in socio-emotional functioning slowed. From the perspective of the PLWD poorer mood at Time 1 was indicative of lower socio-emotional function, though mood did not affect changes in socio-emotional functioning over time. As would be expected, higher quality of life was related to better socio-emotional function at Time 1; similarly where quality of life remains good, the decline in socio-emotional function slows. For carers, poorer mood and higher levels of stress and distress were associated with reports of lower socio-emotional functioning in the person they care for at Time 1. Over time socio-emotional functional decline

slowed as mood improved, while stress and distress were not shown to relate to socio-emotional function over time. This may represent increasing levels of adjustment to the caring role and the potentially greater acceptance of the changes they are witnessing in the person they provide care for. It is also possible that with time, carers access and benefit more from support services. It is however worth noting that the levels of stress reported by carers in the current sample are still relatively low given the rating scale ranges from 0-60 (Greene et al., 1982) though comparable to similar studies ($M = \sim 20$) (Ulstein et al., 2007). For both carers and PLWD, higher perceived relationship quality was associated with higher socio-emotional functioning at Time 1. Taken together it is worth considering that where we did find relationships between measures, they were all self- or informant-report, and for the only objective measure of function (cognition, tested behaviourally) there was little association with socio-emotional functioning over time. There are at least two considerations to be made here. Firstly, we need to question the historical use of general cognition tests to predict social functioning in neurological groups, particularly when it has been established that tests of general cognition cannot always access impairments in the social realm (e.g., Spikman et al., 2012). Secondly, we need to consider the level of objectivity that can be achieved when relying heavily on self- and informant-reports (Clare et al., 2011; Martyr & Clare, 2018; Spitzer et al., 2019), particularly where there are overlapping constructs that are being measured. Therefore, these data speak to the need for more objective measurement of social functioning in dementia research (e.g., Kelly & McDonald, 2020), but also suggest that clinical assessment of social function in the early stages of diagnosis will better prepare carers for what is to come.

The information that is provided to carers and PLWD about the symptoms, and what to expect as the disease progresses is crucial. Quinn et al. (2019) demonstrated that beliefs carers held about dementia (dementia representations) impacted upon carer well-being, satisfaction with life and stress; specifically, those who identified dementia symptoms as being associated with age or dementia diagnosis were doing better. Not only does knowledge of disease cause, symptoms and

prognosis often help with medical care and help-seeking (Kiser et al., 2012; Shinan-Altman & Werner, 2017), it is also associated with reduced societal stigma (Herrmann et al., 2018) and the ability of paid and family carers ability to provide more compassionate care for longer (Quinn et al., 2019). Thus, assessment and identification of social-emotional problems early in dementia care may reduce stress and burden, and improve the carer's ability to provide compassionate care for longer.

Limitations

Several limitations of the current study need consideration. First, attrition is inevitable and expected in longitudinal studies, particularly those with older PLWD. Attrition was approximately 50% of participants over 20 months, and age at Time 1 was the main predictor of this attrition. Despite this we approached our main research question regarding changes in socio-emotional functioning over time using random effects regression analyses. This method is designed to manage attrition at different rates across time, as well as differing measurement intervals and correlation in data between time points (Laird & Ware, 1982; West, 2009), providing reasonable confidence in our conclusions. Larger n at Time 1 may also have enabled more fine-grained analysis of the various components within the SEQ and how each changes over time. Second, findings presented here are based on secondary data analyses. Because of the retrospective nature of the analyses, no a priori sample size or power calculation was conducted. Finally, both PLWD and carer data were analysed separately. An alternative analytical approach could be the Actor Partner Interdependence Model (Kraemer & Jacklin, 1979) which is designed to statistically account for interdependence within interpersonal relationships. However, this is only suitable where we have, and intend to analyse the same measures for both actor and partner. It also assumes that one person (x) *causes* effect on the other (y) (Kenny, 2018), for which we would not universally expect to be the case in the PLWD/carer relationship.

Clinical implications

The study relies predominately on self- and informant-rated questionnaires potentially

introducing bias. There are now performance-based measures of social function (e.g., Kelly & McDonald, 2020) available which were designed specifically for dementia assessment, and as such may serve as more objective measures of change in social function over time. Similarly, while the factor base of the SEQ was re-examined to be suitable for this population, Sommerlad and colleagues (2017) have since also developed a measure of social function specifically for PLWD and their carers; future studies should consider using this tool alongside behavioural measures to reduce biases in reporting. Another useful addition to this type of study to capture any informant introduced bias may be a measure of relational bias (Bjørge et al., 2019). Finally, while still routinely used in clinical settings, the use of the MMSE does not allow for various components of cognition to be examined separately, and it is possible that these components differentially affect social function over time.

People with various forms of dementia invariably experience social function changes at some point of the disease process and these changes can cause distress for carers. Indeed here we have shown that changes in social function can be seen in shorter periods of time, over less than two years, and the factors that influence this trajectory. While here we report on questionnaire measures alone, and others (Spitzer et al., 2019) have included both self-report and behavioural measures of social changes, there is need for a more formal, behavioural assessment of these deficits in early dementia (Kelly & McDonald, 2020). Routine clinical assessment of social function and consideration of those associated variables that influence social function over time such as type of dementia, quality of life and relationship quality may not only be beneficial for differential diagnosis, but also for delivery of high quality, personalised care thereafter. Future research should examine whether empowering carers with knowledge of socio-emotional changes early in the course of the disease process improves quality of life and wellbeing for both the PLWD and their carer, and extends the ability of the carer to provide care in the home longer and for PLWD to remain living independently in the community for longer.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Banks, S., & Weintraub, S. (2008). Self-awareness and self-monitoring of cognitive and behavioral deficits in behavioral variant frontotemporal dementia, primary progressive aphasia and probable Alzheimer's disease. *Brain and Cognition*, 67(1), 58-68.
- Bengtson, V. L., & Schrader, S. S. (1982). Parent-child relations. In D. J. Mangon & W. A. Peterson (Eds.), *Research instruments in social gerontology: Social roles and social participation* (Vol. 2, pp. 115-185). University of Minnesota Press.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research*, 52(2), 69-77.
- Bjørge, H., Kvaal, K., & Ulstein, I. (2019). The effect of psychosocial support on caregivers' perceived criticism and emotional over-involvement of persons with dementia: an assessor-blinded randomized controlled trial. *BMC Health Services Research*, 19(1), 744.
- Bora, E., Velakoulis, D., & Walterfang, M. (2016). Meta-Analysis of Facial Emotion Recognition in Behavioral Variant Frontotemporal Dementia: Comparison With Alzheimer Disease and Healthy Controls. *Journal of Geriatric Psychiatry and Neurology*, 29(4), 205-211.
<https://doi.org/10.1177/0891988716640375>
- Bramham, J., Morris, R. G., Hornak, J., Bullock, P., & Polkey, C. E. (2009). Social and emotional functioning following bilateral and unilateral neurosurgical prefrontal cortex lesions. *Journal of Neuropsychology*, 3(Pt 1), 125-143. <https://doi.org/10.1348/174866408X293994>
- Clare, L., Nelis, S. M., Martyr, A., Roberts, J., Whitaker, C. J., Marková, I. S., Roth, I., Woods, R. T., & Morris, R. G. (2012). The influence of psychological, social and contextual factors on the expression and measurement of awareness in early-stage dementia: testing a biopsychosocial model. *International Journal of Geriatric Psychiatry*, 27(2), 167-177.
<https://doi.org/10.1002/gps.2705>

- Clare, L., Nelis, S. M., Martyr, A., Whitaker, C. J., Marková, I. S., Roth, I., Woods, R. T., & Morris, R. G. (2012). Longitudinal trajectories of awareness in early-stage dementia. *Alzheimer Disease and Associated Disorders*, *26*(2), 140-147.
<https://doi.org/10.1097/WAD.0b013e31822c55c4>
- Clare, L., Nelis, S. M., Whitaker, C. J., Martyr, A., Marková, I. S., Roth, I., Woods, R. T., & Morris, R. G. (2012). Marital relationship quality in early-stage dementia: perspectives from people with dementia and their spouses. *Alzheimer Disease and Associated Disorders*, *26*(2), 148-158. <https://doi.org/10.1097/WAD.0b013e318221ba23>
- Clare, L., Whitaker, C. J., Nelis, S. M., Martyr, A., Markova, I. S., Roth, I., Woods, R. T., & Morris, R. G. (2011). Multidimensional assessment of awareness in early-stage dementia: a cluster analytic approach. *Dementia and Geriatric Cognitive Disorders*, *31*(5), 317-327.
<https://doi.org/10.1159/000327356>
- DeFeis, B., Chapman, S., Zhu, C., Azar, M., Sunderaraman, P., Ornstein, K. A., Gu, Y., & Cosentino, S. (2019). Reduced Awareness of memory deficit is associated with increased medicare home health care use in dementia. *Alzheimer Disease and Associated Disorders*, *33*(1), 62-67.
- Evans, C., Margison, F., & Barkham, M. (1998). The contribution of reliable and clinically significant change methods to evidence-based mental health. *Evidence-Based Mental Health*, *1*(3), 70-72.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*(3), 189-198. [https://doi.org/10.1016/0022-3956\(75\)90026-6](https://doi.org/10.1016/0022-3956(75)90026-6)
- Giebel, C. M., Challis, D. J., & Montaldi, D. (2016). A revised interview for deterioration in daily living activities in dementia reveals the relationship between social activities and well-being. *Dementia*, *15*(5), 1068-1081. <https://doi.org/10.1177/1471301214553614>

- Graham, D. P., Kunik, M. E., Doody, R., & Snow, A. L. (2005). Self-reported awareness of performance in dementia. *Cognitive Brain Research*, *25*(1), 144-152.
- Greene, J., Smith, R., Gardiner, M., & Timbury, G. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. *Age and Ageing*, *11*(2), 121-126. <https://doi.org/10.1093/ageing/11.2.121>
- Greene, J. D., & Hodges, J. R. (1996). Identification of famous faces and famous names in early Alzheimer's disease. Relationship to anterograde episodic and general semantic memory. *Brain*, *119* (Pt 1), 111-128.
- Herrmann, L. K., Welter, E., Leverenz, J. B., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? *The American Journal of Geriatric Psychiatry*, *26*(3), 316-331. <https://doi.org/10.1016/j.jagp.2017.09.006>
- Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., & van der Meer, J. W. (2011). How should we define health? *BMJ*, *343*.
- Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *12*(2), 233-239. <https://doi.org/10.1176/appi.neuropsych.12.2.233>
- Kelly, M., & McDonald, S. (2020). Assessing social cognition in people with a diagnosis of dementia: Development of a novel screening test, the Brief Assessment of Social Skills (BASS-D). *Journal of Clinical and Experimental Neuropsychology*, *42*(2), 185-198. <https://doi.org/10.1080/13803395.2019.1700925>
- Kelly, M., McDonald, S., & Frith, M. (2017). A Survey of Clinicians Working in Brain Injury Rehabilitation: Are Social Cognition Impairments on the Radar? *The Journal of Head Trauma Rehabilitation*, *32*(4), E55-E65. <https://doi.org/10.1097/HTR.0000000000000269>

- Kenny, D. A. (2018). Reflections on the actor–partner interdependence model. *Personal Relationships*, 25(2), 160-170.
- Kiser, K., Jonas, D., Warner, Z., Scanlon, K., Bryant Shilliday, B., & DeWalt, D. A. (2012). A Randomized Controlled Trial of a Literacy-Sensitive Self-Management Intervention for Chronic Obstructive Pulmonary Disease Patients. *Journal of General Internal Medicine*, 27(2), 190-195. <https://doi.org/10.1007/s11606-011-1867-6>
- Kraemer, H. C., & Jacklin, C. N. (1979). Statistical analysis of dyadic social behavior. *Psychological Bulletin*, 86(2), 217-224.
- Laird, N. M., & Ware, J. H. (1982). Random-effects models for longitudinal data. *Biometrics*, 38(4), 963-974.
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., & Cooper, C. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413-446.
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2000). Quality of life in Alzheimer's disease: patient and caregiver reports. In S. M. Albert & R. G. Logsdon (Eds.), *Assessing quality of life in dementia* (pp. 17-30). Springer.
- Martyr, A., & Clare, L. (2018). Awareness of functional ability in people with early-stage dementia. *International Journal of Geriatric Psychiatry*, 33(1), 31-38. <https://doi.org/10.1002/gps.4664>
- Nelis, S. M., Clare, L., Martyr, A., Markova, I., Roth, I., Woods, R. T., Whitaker, C. J., & Morris, R. G. (2011). Awareness of social and emotional functioning in people with early-stage dementia and implications for carers. *Aging & Mental Health*, 15(8), 961-969. <https://doi.org/10.1080/13607863.2011.575350>
- Quinn, C., Jones, I., Martyr, A., Nelis, S. M., Morris, R. G., & Clare, L. (2019). Caregivers' beliefs about dementia: findings from the IDEAL study. *Psychology & Health*, 34(10), 1214-1230.

- Rankin, K. P., Baldwin, E., Pace-Savitsky, C., Kramer, J. H., & Miller, B. L. (2005). Self awareness and personality change in dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 76(5), 632-639.
- Romppel, M., Braehler, E., Roth, M., & Glaesmer, H. (2013). What is the General Health Questionnaire-12 assessing?: Dimensionality and psychometric properties of the General Health Questionnaire-12 in a large scale German population sample. *Comprehensive Psychiatry*, 54(4), 406-413. <https://doi.org/10.1016/j.comppsy.2012.10.010>
- Schwarz, G. (1978). Estimating the dimension of a model. *The Annals of Statistics*, 6(2), 461-464.
- Shimokawa, A., Yatomi, N., Anamizu, S., Ashikari, I., Kohno, M., Maki, Y., Torii, S., Isono, H., Sugai, Y., Koyama, N., & Matsuno, Y. (2000). Comprehension of emotions: comparison between Alzheimer type and vascular type dementias. *Dementia and Geriatric Cognitive Disorders*, 11(5), 268-274. <https://doi.org/17249>
- Shimokawa, A., Yatomi, N., Anamizu, S., Torii, S., Isono, H., Sugai, Y., & Kohno, M. (2001). Influence of Deteriorating Ability of Emotional Comprehension on Interpersonal Behavior in Alzheimer-Type Dementia. *Brain and Cognition*, 47(3), 423-433.
- Shinan-Altman, S., & Werner, P. (2017). Is there an association between help-seeking for early detection of Alzheimer's disease and illness representations of this disease among the lay public? *International Journal of Geriatric Psychiatry*, 32(12), e100-e106.
- Snaith, R. P., & Zigmond, A. S. (1994). *HADS: Hospital Anxiety and Depression Scale*. NFER-Nelson.
- Sommerlad, A., Singleton, D., Jones, R., Banerjee, S., & Livingston, G. (2017). Development of an instrument to assess social functioning in dementia: The Social Functioning in Dementia scale (SF-DEM). *Alzheimers and Dementia*, 7, 88-98. <https://doi.org/10.1016/j.dadm.2017.02.001>
- Spikman, J. M., Timmerman, M. E., Milders, M. V., Veenstra, W. S., & van der Naalt, J. (2012). Social cognition impairments in relation to general cognitive deficits, injury severity, and

- prefrontal lesions in traumatic brain injury patients. *Journal of Neurotrauma*, 29(1), 101-111. <https://doi.org/10.1089/neu.2011.2084>
- Spinhoven, P., Ormel, J., Sloekers, P., Kempen, G., Speckens, A., & Van Hemert, A. (1997). A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychological Medicine*, 27(2), 363-370.
- Spitzer, N., Shafir, T., Lerman, Y., & Werner, P. (2019). The Relationship Between Caregiver Burden and Emotion Recognition Deficits in Persons With MCI and Early AD. *Alzheimer Disease & Associated Disorders*, 33(3), 266-271.
- Tombaugh, T. N., & McIntyre, N. J. (1992). The mini-mental state examination: a comprehensive review. *Journal of the American Geriatrics Society*, 40(9), 922-935.
- Ulstein, I., Bruun Wyller, T., & Engedal, K. (2007). The relative stress scale, a useful instrument to identify various aspects of carer burden in dementia? *International Journal of Geriatric Psychiatry*, 22(1), 61-67.
- Vernooij-Dassen, M., & Jeon, Y.-H. (2016). Social health and dementia: the power of human capabilities. *International Psychogeriatrics*, 28(5), 701-703.
- West, B. T. (2009). Analyzing longitudinal data with the linear mixed models procedure in SPSS. *Evaluation & the Health Professions*, 32(3), 207-228.
<https://doi.org/10.1177/0163278709338554>
- WHO. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. World Health Organization.
- Woods, R. T. (2009). Relationship quality and quality of life in dementia. 19th International Congress of Gerontology, Paris.
- Zahodne, L. B., Ajrouch, K. J., Sharifian, N., & Antonucci, T. C. (2019). Social relations and age-related change in memory. *Psychology and Aging*, 34(6), 751-765.

Table 1. Sample characteristics

Variable	Time 1	Time 2	Time 3
<i>PLWD</i>	<i>n = 101</i>	<i>n = 66</i>	<i>n = 51</i>
	78.66	78.61	78.61
Age (SD)	(7.75)	(8.52)	(7.82)
Gender (female:male)	53:48	37:29	27:24
	11.68	11.98	11.76
Years of Education (SD)	(2.67)	(2.79)	(2.42)
Diagnosis <i>n</i> (AD:VaD:Mixed)	51:30:20	39:15:12	31:11:9
<i>Carer</i>	<i>n = 101</i>	<i>n = 66</i>	<i>n = 51</i>
	68.39	67.03	66.18
Age (SD)	(14.00)	(14.66)	(14.43)
Gender <i>n</i> (female:male)	64:37	42:24	35:16
Reside with PLWD <i>n</i> (Y:N)	74:27	42:24	32:19
Relationship <i>n</i> (partner:child:other relative:friend)	66:26:6:3	39:19:5:3	29:16:4:2

Table 2. Means (standard deviations) for demographic data and outcome measures **at Time 1** for those who remained versus withdrew at Times 2 and 3

Variable	Time 2		Time 3	
	Remained (<i>n</i> = 66)	Withdrew (<i>n</i> = 35)	Remained (<i>n</i> = 51)	Withdrew (<i>n</i> = 14)
<i>PLWD</i>				
Age	77.48 (1.04)	80.89 (0.96)	76.75 (1.10)*	79.43 (2.74)
Years of Education	11.98 (0.34)	11.11 (0.40)	11.76 (0.34)	12.93 (1.03)
Cognition (MMSE)	24.26 (0.35)	24.00 (0.46)	24.51 (0.39)	23.64 (0.82)
Mood (HADS)	10.23 (0.80)	9.18 (1.00)	10.22 (0.94)	10.86 (1.47)
Quality of Life	36.82 (0.61)	38.13 (0.99)	36.96 (0.71)	35.93 (1.23)
Quality of Relationship	24.11 (0.49)	25.29 (0.67)	27.78 (0.55)	25.14 (1.13)
Self-rated SEQ	49.00 (1.19)	46.88 (1.94)	49.27 (1.37)	48.93 (2.43)
<i>Carer</i>				
Age	66.48 (1.79)	71.97 (2.08)	65.06 (2.03)	70.14 (3.12)
Years of Education	11.86 (0.31)	11.34 (0.44)	11.94 (0.37)	11.64 (0.59)
General Health	13.52 (0.79)	12.45 (1.02)	13.08 (0.82)	15.43 (2.19)
Relative Stress Scale	20.81 (1.46)	17.86 (1.95)	20.26 (1.44)	23.21 (4.52)
NPI-Q - Total symptom score	4.59 (0.33)	4.06 (0.37)	4.57 (0.36)	4.86 (0.88)
NPI-Q - Total distress score	9.87 (0.99)	8.55 (1.34)	9.80 (1.01)	10.86 (2.87)
NPI-Q - Severity score	8.57 (0.78)	7.35 (0.96)	8.47 (0.82)	9.29 (2.15)
Quality of Relationship	22.61 (0.52)	23.83 (0.92)	22.55 (0.56)	22.71 (1.42)
Carer-rated SEQ	56.67 (1.70)	52.88 (2.27)	56.16 (1.87)	58.57 (4.37)

Note. NPI-Q = Neuropsychiatric Inventory Questionnaire; SEQ = Social Emotional Questionnaire; MMSE = Mini-Mental State Examination; HADS = Hospital Anxiety and Depression Scale. * Age of the PLWD at Time 1 was the only significant predictor of remaining in the study at Time 3 ($p = .039$).

Table 3. Linear mixed effects models for all socio-emotional total scores as rated by the carer and in relation to diagnostic characteristics

	Total SEQ (I)				
	<i>Unconditional</i>	<i>Diagnosis</i>	<i>NPI-Q symptoms</i>	<i>NPI-Q severity</i>	<i>MMSE</i>
	<i>a</i>	<i>b</i>	<i>c</i>	<i>d</i>	<i>e</i>
Intercept	88.96***(86.22-91.71)	91.89***(88.15 - 95.63)	100.52***(95.78-105.27)	98.62***(94.73-102.51)	72.58***(51.93-93.22)
Time (months)	-0.32**(-0.52- -.12)	-0.55***(-0.81 - -0.29)	-.92***(-1.28 - -.56)	-.75***(-1.09- -.41)	.95(-.37- 2.27)
AD	-	Ref	-	-	-
Vascular	-	-6.32* (-12.52 - -0.12)	-	-	-
Mixed	-	-5.71 (-12.98 - 1.57)	-	-	-
AD x Time	-	Ref	-	-	-
Vascular x Time	-	0.32 (-0.15 - 0.79)	-	-	-
Mixed x Time	-	0.74**(0.21 - 1.26)	-	-	-
NPI-Q symptoms	-	-	-2.63***(-3.55- -1.71)	-	-
NPI-Q symptoms x Time	-	-	0.13***(0.07-0.18)	-	-
NPI-Q severity	-	-	-	-1.19***(-1.56- -0.81)	-
NPI-Q severity x Time	-	-	-	.05**(0.02-0.8)	-
MMSE	-	-	-	-	0.68(-0.017-1.53)
MMSE x Time	-	-	-	-	-.05(-0.11-0.00)
Residual variance	87.85***(65.70-117.45)	83.88***(62.51 - 112.56)	95.36***(70.27-129.42)	97.53***(71.75-132.56)	86.88***(64.87-116.37)
Intercept variance	106.01***(68.65-163.71)	104.63***(67.71 - 161.67)	58.91**(31.01-111.90)	49.89**(24.18-102.93)	105.41***(68.22-162.87)

*** p<.001, **p<.01, *p<.05

Note. AD = Alzheimer's Disease, NPI-Q = Neuropsychiatric Inventory Questionnaire, MMSE = Mini-Mental State Examination
 Models a-b; T1 n = 98, T2 n = 67, T3 n = 50. Models c-e; T1 n = 98, T2 n = 66, T3 n = 24.

Table 4. Mean scores at baseline (standard deviations) for key variables in each SEQ group

		SEQ Improved <i>n</i> = 5	SEQ No change <i>n</i> = 32	SEQ Declined <i>n</i> = 14
PLWD	Age	74 (2.77)	76.06 (1.43)	79.29 (2.07)
	Mini-Mental State Examination	23.4 (1.17)	24.84 (0.50)	24.14 (0.76)
	Years of Education	11.2 (1.46)	11.84 (0.42)	11.79 (0.63)
	Hospital Anxiety Depression Scale	9.4 (2.60)	12.03 (1.21)	6.36 (1.41)
	Quality of Relationship	23.4 (0.51)	23.81 (0.77)	23.86 (0.95)
	Quality of Life	36.4 (1.96)	36.81 (0.99)	37.5 (1.15)
Carer	Age	66.2 (4.21)	65.63 (2.93)	63.36 (2.97)
	General Health Questionnaire	17.8 (2.61)	12.55 (0.99)	12.57 (1.62)
	Relative Stress Scale	28 (4.65)	18.55 (1.73)	21.29 (2.81)
	Quality of Relationship	21 (1.14)	22.81 (0.77)	22.5 (1.02)

Note. SEQ = Social Emotional Questionnaire

Table 5. Linear mixed effects models for all socio-emotional total scores as rated by the PLWD and in relation to their wellbeing

	Total SEQ (P)			
	<i>a</i>	<i>Mood</i> <i>b</i>	<i>Quality of life</i> <i>c</i>	<i>Relationship quality</i> <i>d</i>
Intercept	95.99***(94.01-97.97)	102.17***(98.92 - 105.42)	71.91***(59.21-84.61)	76.20***(64.79 - 87.61)
Time (months)	-0.04(-0.19- -0.11)	-0.07(-0.38 - 0.23)	1.19*(0.17-2.21)	1.20**(0.32 - 2.08)
Mood	-	-0.62***(-0.90 - -0.35)	-	-
Mood x Time	-	0.00(-0.02 - 0.03)	-	-
Quality of life	-	-	0.65***(0.31-0.99)	-
Quality of life x Time	-	-	-0.03*(-0.03- -0.01)	-
Relationship quality	-	-	-	0.81**(0.35 - 1.27)
Relationship quality x Time	-	-	-	-0.05**(-0.09 - -0.01)
Residual variance	47.97***(35.46-64.91)	49.28***(36.10 - 67.26)	47.72***(35.06-64.96)	49.73***(36.59 - 67.60)
Intercept variance	54.27***(34.03-86.57)	36.63**(20.30 - 66.09)	46.39***(27.79-77.45)	42.07***(24.48 - 72.31)

*** p<.001, **p<.01, *p<.05

Model *a*; T1 n = 99, T2 n = 66, T3 n = 48. Model *b*; T1 n = 99, T2 n = 65, T3 n = 23. Model *c*; T1 n = 97, T2 n = 65, T3 n = 23. Model *d*; T1 n = 97, T2 n = 64, T3 n = 23.

Table 6. Linear mixed effects models for all socio-emotional total scores as rated by the carer and in relation to their wellbeing

	Total SEQ (I)			
	<i>GHQ</i> <i>f</i>	<i>Stress</i> <i>g</i>	<i>NPI-Q distress</i> <i>h</i>	<i>Relationship quality</i> <i>i</i>
Intercept	94.49***(88.48 - 100.50)	99.36***(94.83 - 104.54)	97.62***(94.05 - 101.20)	61.61***(48.86 - 74.35)
Time (months)	-0.85**(-1.37 - -0.33)	-0.45 (-0.92 - 0.02)	-0.57***(-0.88 - -0.26)	0.52 (-0.51 - 1.56)
GHQ	-0.43*(-0.84 - -0.03)	-	-	-
GHQ x Time	0.04*(0.00 - 0.08)	-	-	-
Stress	-	-0.56***(-0.77 - -0.35)	-	-
Stress x Time	-	0.01 (-0.01 0.03)	-	-
NPI-Q distress	-	-	-0.89***(-1.18 - -0.61)	-
NPI-Q distress x Time	-	-	0.02 (-0.01 - 0.05)	-
Relationship quality	-	-	-	1.19***(-0.64 - 1.73)
Relationship quality x Time	-	-	-	-0.04 (-0.08 - 0.01)
Residual variance	87.42***(64.45 - 118.57)	101.85***(75.00 - 138.30)	95.70***(70.76 - 129.43)	95.79***(71.54 - 128.26)
Intercept variance	103.23***(84.82 - 164.39)	50.52**(24.48 - 104.26)	47.65**(23.29 - 97.49)	70.28***(-0.74 - 121.23)

*** p<.001, **p<.01, *p<.05

Note. GHQ = General Health Questionnaire, SEQ-I = Social Emotional Questionnaire-Informant, NPI-Q = Neuropsychiatric Questionnaire Model *f*; T1 n = 94, T2 n = 65, T3 n = 24. Model *g*; T1 n = 94, T2 n = 64, T3 n = 23. Model *h*; T1 n = 96, T2 n = 64, T3 n = 24. Model *i*; T1 n = 95, T2 n = 66, T3 n = 24.

Figure Caption

Figure 1. Mean self- (PLWD) and carer-reported scores for the three SEQ subscales at Time 1, Time 2 (12 months) and Time 3 (20 months). Higher scores indicate perceived better emotion perception, social relationships and behaviour. Error bars are standard error of the mean.

Figure 1

