Social Networks and Loneliness in people with Dementia of the Alzheimer-type

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Abstract word count: 233

Manuscript word count: 3650

Abstract

Objectives: Modifiable lifestyle risk factors are of great interest in the prevention and management of Alzheimer's disease (AD). Loneliness and social networks may influence onset of AD, but little is known about this relationship in people with AD. The current study aimed to explore the relationship between loneliness and social networks (social measures) and cognitive and psychopathology decline (AD outcomes) in people with AD.

Methods: Ninety-three participants with mild-moderate AD were recruited from memory clinics, in a cross-sectional study. Social networks (measured by the Lubben Social Network Scale), feelings of loneliness (measured by De Jong Loneliness Scale), cognition (measured by the Standardized Mini Mental State Examination) and psychopathology (measured by the Neuropsychiatric Inventory) were assessed in an interview setting. Two multiple regressions with Bootstrap were conducted on cognition and psychopathology as outcome variables. Family and Friends subsets of social networks and loneliness were entered as predictors and age, gender and depression as covariates.

Results: The friendship subset of social networks was significantly related to cognition (independent of age, gender, depression, loneliness and family subset of social network): B = .284, p = .01. Neither loneliness nor social networks predicted psychopathology (ps > .05).

Conclusions: Maintaining or developing a close friendship network could be beneficial for cognition in people with AD. Alternatively, greater dementia severity may lead to fewer friends. More research on the direction of this relationship in people with AD is needed.

KEY WORDS – Alzheimer, Dementia, Loneliness, Social Network, Cognition,

Psychopathology, and Neuropsychiatry.

KEY POINTS:

- This is one of very few studies exploring social network and loneliness in people with Alzheimer's disease.
- A larger social network made up of friends was associated with better cognition (independent of age, gender, depression, loneliness and family social network) in people with AD.
- Feelings of loneliness or social networks were not associated with psychopathology symptoms in people with AD.
- The findings highlight the need to develop and sustain friendships in people with AD, regardless of whether this is a cause or effect of poorer cognition.

Introduction

According to the most recent World Alzheimer Report, 46 million people are estimated to be living with Alzheimer's Disease (AD) globally, with figures increasing to 131.5 million by 2050 [1]. With no cure for AD and current pharmacological interventions only treating the symptoms [2,3], research that focuses on non-pharmacological ways of preventing or slowing down the disease progression is of great significance.

Research into the association between social networks and loneliness on the onset of dementia, has gained rapid interest recently [4–9]. Social networks are determined objectively by quantifying relationships and social interactions via the size of one's social network [6], the frequency and nature of interactions with friends and family [10], the number of social and leisure activities one is involved in [9], presence of a partner [11] and number of close relationships [12]. Loneliness, however, is a subjective measurement of how lonely one feels - loneliness is that distressing feeling that occurs when one's social needs are not met by the quantity and quality of one's existing social relationships[13]. Loneliness is normally measured via self-report ([4,7,14,15,16,17]).

Previous research into the relationship between social networks and dementia have shown that quality is better than quantity. For example, Amieva et al. (2010), found that feeling satisfied with social interactions and perceived reciprocity was protective of dementia over 15 years, but the size and nature of social networks was not associated with dementia risk. Furthermore, having a confidant was found to be protective of dementia in a 12 year cohort study [19]. Of note, neither of these studies measured loneliness, but one could assume that feeling satisfied with social interactions and having a confidant could reduce feelings of loneliness.

Other studies have investigated the effects of loneliness on dementia onset. Holwerda

and colleagues (2012) found that in healthy older adults were more likely to develop clinical dementia after three years if they *felt* lonely, rather than *being* lonely at baseline[20]. Similarly, a longitudinal study from Wilson and colleagues (2007) found that older adults who felt lonely were more than twice as likely to develop an AD-like dementia syndrome, than those who were not lonely. However, in this study, loneliness was not related to AD pathological markers or cerebral infarction among participants who died and in whom brain autopsy was performed[21]. Finally, in a recent longitudinal study of 6,677 middle-aged and older adults without dementia at baseline, loneliness, not being married and having fewer close relationships were discovered to be risk factors for dementia, but not the extent of contact with friends and family[8].

Studies exploring feelings of loneliness in people who already have dementia are rare, probably because it is difficult to ascertain whether someone with cognitive problems can accurately evaluate how lonely they are feeling. However, it has been argued that people with mild-moderate AD are very good at providing detailed self-reports of their quality of life [22]. Holmen and colleagues[23] distinguished between emotional and social loneliness - social loneliness corresponds to the absence of meaningful friendships and is connected to boredom and passivity, whereas emotional loneliness is a loss or absence of confiding in and imitating attachment to a special and beloved person. They found that social loneliness was more common in older adults with dementia, than older adults without dementia, but there was no difference in emotional loneliness. Social loneliness increased with dementia severity, but the opposite was found with emotional loneliness. Although, the study attempted to document loneliness in people with all stages of dementia, one might argue that the questions might not have been understood in a moderate-severe dementia sample. Haj and colleagues[24] found that participants with AD were significantly more lonely (measured using the 3-item UCLA Loneliness Scale) than healthy controls and this was positively correlated with more

hallucinations. Although the link between loneliness and hallucinations in people with AD was assessed, other neuropsychiatric symptoms of AD were not explored.

In the present study, we aimed to explore the relationship between social networks/loneliness and global cognition/psychopathology in older adults diagnosed with mild-moderate AD. We were interested in the size of close relationship networks, frequency of contact and nature of network (e.g. family or friends) to provide an all-round measure of social networks. For loneliness, we aimed to measure loneliness in a comprehensive and indirect fashion in order to avoid social bias. We explored the relationship between these social measures and global cognitive ability. Furthermore, as AD also results in neuropsychiatric changes, and not only cognitive changes, we explored the relationship between social network/loneliness and psychopathology. It is hoped that by understanding the relationship between loneliness, social networks and dementia associated symptoms therapeutic implications may be developed.

Materials and Methods

Design

The current study was explorative and cross-sectional in design. It assessed social networks, loneliness, cognition and neuropsychiatric symptoms among the recruited AD population. The study explored relationships between these variables. The predictor variables included social networks (two types: friends and family) and loneliness, whilst outcome variables included global cognition and neuropsychiatric symptoms. Confounders included age, gender and depression.

Ethical approval

Ethical approval was obtained from NHS National Research Ethics Service Committee London (Bromley) and the study was carried out in accordance to the Declaration of Helsinki[26].

Participants

Ninety-three participants (51 female; 42 male) were recruited from East Sussex memory clinics in England. Participants recruited had an existing diagnosis of AD (according to ICD-10 criteria; [27]). We only recruited people with mild-moderate dementia and excluded participants with severe dementia to reduce confounding effects of cognitive decline on the comprehension of the questions in the measures.

Inclusion criteria consisted of the following: a) a diagnosis of AD made between 6-24 months prior to enrolment in the study in order to ensure homogeneity of the sample; b) a Standardised Mini-Mental State Examination (SMMSE[28]; score of 12-26, indicating mild-moderate AD); c) aged 55 years and above; d) on stable dose of an acetylcholinesterase inhibitors for at least one month; e) had the capacity to consent (assessed by an old age psychiatrist); and f) their caregivers informants agreed to attend the interview. To avoid any confounding effects of disease and medication and to ensure a homogenous sample, the exclusion criteria included: a) all non-AD dementia (e.g. Lewy body, frontal-temporal, vascular); b) receiving antipsychotic medication; c) receiving antidepressant medication; d) residential/nursing home placement; e) previous or current history of severe mental health problems including anxiety, depression, psychosis and personality disorder. Informed

consent was taken from both participants and caregivers to ensure capacity to make an informed decision was not compromised.

Measures

The 12-item **Standardised Mini-Mental State Examination (SMMSE)**[28] assesses global cognition according to orientation of time and place, memory, attention and concentration, expressive language and praxis. Scores are out of 30, with higher scores indicating better cognitive functioning. SMMSE scores indicate dementia severity: mild 20-26; moderate 10-20; and <10 severe.

The **Neuropsychiatric Inventory (NPI)**[29] assesses psychopathology in people with dementia completed by caregiver informants. NPI consists of 12 neuropsychiatric symptoms prevalent in people with dementia: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, sleep and appetite. The frequency of each symptom domain and total NPI scores were calculated.

Cornell Scale for Depression in Dementia[30] is a measure of depression in patients with dementia. A total score of 0-6 rules out major depression, greater than 10 indicates a probable presence of major depression, and greater than 18 indicates that major depression is almost definitely present.

The **Lubben Social Network Scale – 6 item (LSNS-6)**[12] evaluates one's social ties within two social network subscales: family and friends. Each subscale consists of three questions. The three questions aim to determine the frequency of contact with relatives/friends, how many relatives/friends one feels at ease with to discuss personal matters and how many relatives/friends one would contact for help. Thus, the scale is based on both the size of the social network and the frequency of contact with that network. The score is an equally weighted sum of the items. Each subscale score ranges 0-15 and the total score ranges 0-30. Higher scores indicate more social ties. Total scores less than or equal to 12 and subscale scores less than or equal to six identifying those at risk of social isolation.

The **De Jong Gierveld 11-item loneliness scale**[31] measures feelings of loneliness. Participants need to indicate 'yes' or 'no' on whether or not they agree with the 11 statements (e.g. "I miss having a close friend"). Total loneliness score range is 0-11 and can be categorized into four levels: not lonely (score 0-2), moderately lonely (score 3-8), severely lonely (score 9 or 10), and very severely lonely (score 11).

Procedure

Demographic data, current health status, medication and past medical history were obtained from the participants' medical notes. Participants and their caregivers were required to attend one interview lasting between 45-60 minutes in a memory clinic. The measures were administered in the following order: SMMSE, NPI, the Cornell Depression scale, LSNS-6 and the De Jong Gierveld scale.

Statistical Analyses

All data was entered into IBM Statistical Package for the Social Sciences (SPSS) version 24 to be analysed. Descriptive data for all continuous variables is presented as minimum (min), maximum (max), mean (M), median (Mdn), and standard deviation (SD), whilst categorical variables are presented as frequencies and percentages. All descriptive and demographic values were rounded off to two decimal places, but all summary statistics are reported at three decimal places.

We carried out multiple regression to assess the relationships between loneliness and social networks on our outcome variables (global cognition and psychopathology). Bootstrap (described further here[32]) was performed, due to concerns of whether assumptions for a regression were met. The Bootstrap was performed on a 1000 samples, at 95% confidence intervals (bias corrected and accelerated type) and a simple sampling method.

Two hierarchical, multiple regressions were carried out on each of the outcome variables. Due to age, gender and depression possibly confounding the results, we entered these in the regression analyses too. Block 1 included age, gender and Cornell score; block 2 included De Jong Loneliness, Family LSNS-6 and Friends LSNS-6 scores. Forced entry was used for each block. The outcome variables were SMMSE and NPI total score for each of the multiple regressions.

Results

Exclusions

One participant's data indicated that he might have major depression (Cornell score > 10), thus his data was excluded from the analysis, leading to a sample size of 92.

Demographics

Participants were on average 82.61 years old (SD = 6.27). Nearly 67% of participants were living with someone, approximately 18% lived alone and received care, and approximately 15% lived alone and did not receive care. More than half of the participants were married (60%). Many were in the moderate stage (63%) of dementia, compared to the mild stage (37%) and none were in the severe stage. All participants were on cholinesterase inhibitors, with the majority on Donepezil (66%). See Table 1 for detailed demographic information.

[INSERT TABLE 1 HERE]

Descriptive Statistics

The results from the LSNS-6 measure shows that participants in this study were on average not socially isolated (M > 12; see Table 2), but there was large variance in the data (SD = 5.91; see Table 2 for Mdn and min/max scores of all measures). On closer inspection of the LSNS-6 subscale data, participants tended to be socially isolated in the Friends subscale, but not the Family subscale. Results from De Jong indicated that on average the participants in this study did not feel lonely (M= 2.02, SD =2.10; mean 0-2 indicates not lonely). On average, psychopathology was relatively low amongst our sample (NPI total

score M = 3.16, SD = 4.11; Table 2); however, a large variance was observed in these scores too (SD = 4.11). Agitation, anxiety and irritability were the most common disturbances observed (see Table 3 for a breakdown of NPI behaviours).

[INSERT TABLE 2 HERE]

[INSERT TABLE 3 HERE]

Multiple Regression Results: Effects of Age, Depression, Loneliness and Social Networks on Global Cognition

The results of the multiple regression with Bootstrap showed that, overall, Model 1 (consisted of age, gender and depression as predictors) was not a good predictor of global cognition and only explained 2.1% of the variance: R^2 change = .021, F change (3, 88) = .638, p = .592. Model 2 (which also included loneliness, Family and Friends) was almost a significantly better predictor of global cognition than Model 1, accounting for 10.6% of the variance: R^2 change = .084, F change (3, 85) = 2.676, p = .052. Although Model 2 was a better fit of the data overall, neither model fitted the data significantly ($^{\text{Model 1}}F(3, 88) = .638$, p = .592; $^{\text{Model 2}}F(6, 85) = 1.675$, p = .137) and a large amount of variance was unaccounted for.

Out of all the predictors entered into the multiple regression, Friends was the only predictor found to be significant of global cognition and this was a positive correlation: B = .284, SE Bias = .107, p = .01, BC 95% CI = .078 to .492. This relationship is independent of

all other predictors (see Table 4 for results on remaining coefficients). Thus, the more close friends our participants had, the higher their global cognition.

[INSERT TABLE 4 HERE]

Multiple Regression Results: Effects of Age, Gender, Depression, Loneliness and Social Networks on Dementia Psychopathology.

The results (Table 5) show that Model 1 (age, gender and depression as predictors) was a significant predictor of psychopathology and explained 49.6% of the variance: R^2 change = .496, F change (3, 88) = 28.911, $p < .001$. Model 2 (which also included loneliness, Family and Friends) was not significantly different than Model 1 and explained 52% of the variance in psychopathology: R^2 change = .023, F change (3, 85) = 1.368, $p = .258$. Both models fitted the data significantly: $^{\text{Model 1}}F(3, 91) = 28.911$, $p < .001$; $^{\text{Model 2}}F(6, 91) = 15.321$, $p < .001$).

On closer inspection of the coefficients with Bootstrap, depression was the biggest predictor of psychopathology – more depressive symptoms were related to more psychopathology symptoms overall ($p = .001$). Age was also related to psychopathology – there was a trend for older participants to have fewer symptoms, however, this was not significant ($p = .06$). None of the other variables were significant predictors of psychopathology (ps > .05).

[INSERT TABLE 5 HERE]

Discussion

The study explored the relationship between social factors (loneliness and social networks) and dementia indicators (global cognition and psychopathology) in nighty-three volunteers already diagnosed with mild-moderate AD. The key finding was that a larger social network consisting of close friends, was related to higher global cognition in people with AD. No significant results were found for family social networks, suggesting that having more friends is more important for global cognition than having more family ties. The relationship between friendship and cognition was independent of age, gender, depression, loneliness and family social ties. Feelings of loneliness were not related to global cognition. Furthermore, only depression was related to psychopathology symptoms but not feelings of loneliness, social networks, age or gender. These findings provide unique, preliminary data on the relationship between social measures and dementia indicators in people already diagnosed with AD dementia.

The findings somewhat contradict Boss and colleagues[4] findings, where feelings of loneliness have been shown repeatedly to relate to cognitive decline in older adults. However, the findings are in line with other research showing that individuals who live alone and have limited social ties are more prone to developing dementia later on in their life[5,6,8,33].

The novel finding of this study is that in participants with AD, social networks made up of friends had better cognition than those who had social networks predominantly made up of relatives. Friends are often chosen, whereas family members are not, allowing more opportunity for detrimental relationships within the family. In support of this, Schuster and

colleagues[34] found that negative interactions with a spouse were more detrimental on mental health than negative interactions with friends or other relatives. Criticism and other emotionally hurtful behaviour may be most likely to occur in close relationships, such as those with spouse and family members [35,36], whereas friends may refrain from such behaviours. Family are also more likely to be caregivers of the people with dementia [37] and demonstrate high Expressed Emotion (EE; highly critical and overinvolved), especially when they hold stigmas about dementia [38]. High EE in caregivers has been shown to have negative impacts on the person being cared for [39]. Indeed, the quality and not quantity of relationships has been found to be more important in reducing the risk of dementia [18]. Furthermore, in a study of Mexican older adults aged 50+, only those aged 71-80 years benefitted from social support[40]. Our participants had an average age of 80+ and therefore this interpretation is likely.

Various mechanisms for why social networks may protect against cognitive decline have been put forward [4,41]. Social ties may be beneficial to cognition due to increased levels of social interaction and intellectual stimulation[33]. Increased social interaction has been found to lead to increased neural stimulation and has a positive impact on cognition [42–45]. Pathways such as healthy lifestyles, psychological factors and physiological mechanisms may mediate social ties and cognition[46]. Stress is thought to be neurodegenerative, particularly in the hippocampus, and frequent social contacts, increased social integration and engagement may help to moderate the effect of stress on the central nervous system [46]. Furthermore, depression is thought to be a mediator between loneliness/social isolation and cognitive decline [4,47], however, as we excluded people with depression and further controlled for depression scores in the analyses, we can confidently say that the relationship between friendships and cognition was not mediated by depression in our sample.

No relationship was found between any of our social measures (social networks and loneliness) and psychopathology. To our knowledge, this is the first study to date to explore this relationship in people with AD. However, the reasons for why no significant results were found may be largely due to the low NPI scores observed. Neuropsychiatric symptoms are more common in individuals with severe AD (Charernboon & Phanasathit, 2014), who we excluded from the study. We also excluded anyone with severe psychiatric disturbances, thus it is difficult to make any firm conclusions here. However, we felt this was necessary in order to not confound the results. Future research may consider using more sensitive measures of psychopathology. Depression was found to be a predictor of psychopathology in this study, which is logical considering depression is one of the psychopathology symptoms measured in the NPI.

Limitations of our study included a lack of a control group and not using a comprehensive cognitive battery. Future research must include these. However, the principle limitation of the current study was that it was a cross-sectional study. Therefore, we cannot attribute cause or effect status to any of our variables of interest. Previous longitudinal studies, suggest that loneliness and a lack of close relationships are risk factors for cognitive decline in older adults [8,18]. However, there is also evidence that dementia causes social withdrawal and feelings of loneliness [48]. Expressive dysphasia, or word finding difficulty, commonly found in people with dementia, could make social engagement difficult and distressing for the person with dementia and as a result they may avoid social gatherings all together [49]. Furthermore, friends and family may also withdraw and not make as much effort to stay in touch, because it may be too upsetting for them and they may hold stigmatized views of people with dementia [50]. Therefore, although we found that a larger friendship group was related to lower cognition scores, it is difficult to determine which came first. Prospective studies are necessary to determine if loneliness and social networks predict

the prognosis of AD. However, a recent study, that used one of the largest samples to date with one of the longest follow-up intervals, showed that loneliness was associated with 40-50% increased risk of dementia, after controlling for social isolation, behavioural, clinical and genetic risk factors for dementia and depressive symptoms. Sensitivity analyses showed that this finding was unlikely due to reverse causality[51]. Although this study included a comprehensive measure of loneliness and measured social isolation in terms of how socially integrated the participants were, it did not differentiate between the effect of different types of social networks (e.g. friends or family). Thus, our study complements this work, but future longitudinal research is required to determine if different types of social networks can protect against cognitive decline.

Finally, regardless of the direction of the link, our study showed that with declining cognition, people with AD have fewer close friends - this could have marked impact on the quality of life of people with AD. In a recent systematic review and meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia, factors reflecting relationships and social engagement were associated with better quality of life[52]. Thus, supporting friendships for people with dementia may be viable in promoting quality of life.

Conclusion

The current study provided preliminary results on the relationship between social networks/loneliness and cognition/psychopathology. Due to some limitations, the direction of this relationship cannot be determined and potentially due to limited use of cognitive measures, the relationship between loneliness and cognitive decline was not observed. Nonetheless, the study applied comprehensive measures of loneliness and social networks,

filling the gap where previous studies have used more simpler measures [7,11]. The study clearly showed that the size and frequency of contact with friendship groups is related to cognition. It suggests that having good friends could be important for cognition in people already diagnosed with AD.

The results of the study are significant given the lack of research on social networks/loneliness in people with AD. Further longitudinal and randomised control trial studies are needed to support our preliminary findings of friendships potentially being protective of cognitive decline. Interventions that promote friendships in people with AD should be researched and developed.

Acknowledgements

The study was sponsored by Sussex Partnership NHS Foundation Trust. We are grateful to all the participants and caregivers who took part in the study, statisticians at Brighton and Sussex Medical School for their statistical advice on this paper, and staff at Sussex Partnership NHS Foundation Trust for their help in participant recruitment. A conflict of interest exists between the authors of Brighton and Sussex Medical School and one of the editors of the International Journal of Geriatric Psychiatry, Professor Sube Banerjee, as they are colleagues at the Centre for Dementia Studies. Additionally, Dr Tabet has received consultancy payment from Roche and Eli Lilly and Speakers Fees from GE Healthcare.

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Tables

Table 1. Participant demographics

		Frequency	%
Gender			
	Male	41	44.6
	Female	51	55.4
Dementia stage			
	Mild	34	36.96
	Moderate	58	63.04
	Severe	0	0
Lives with someone			
	Lives with spouse	55	59.78
	Lives with partner	2	2.17
	Lives with family member	4	4.35
	Total	61	66.30
Lives alone			
	Support from relatives or friend	11	11.96
	Support from carer	6	6.52
	Lives alone	14	15.22
	Total	31	33.70

Marital status			
	Married	55	59.78
	Widowed	34	36.96
	Single	3	3.26
	Divorced	0	0
Medication			
	Donepezil	61	66.30
	Rivastigmine	19	20.65
	Galantamine	10	10.87
	Memantine	2	2.17

NB. % = percentage of participants.

Table 2. Descriptive data of scores on social, behavioural, cognitive and mood measures.

	Min	Max	M	Mdn	SD
Social ties					
LSNS-6 family	0	15	7.91	8	3.11
LSNS-6 friends	0	15	4.98	5	3.94
LSNS-6 total	0	27	12.89	13	5.91
Loneliness					
De Jong total	0	9	2.02	1	2.10
Cognition					
SMMSE	12	26	20.41	21	3.66
Psychopathology					

NPI total	0	21	3.16	2	4.11
Depression					
Cornell	0	9	2.29	2	1.95

NB. Min = minimum score; Max = maximum score; M = mean average score; Mdn = median; SD = standard deviation score; LSNS-6 = Lubben Social Network Scale-6 item; SMMSE = Standardised Mini Mental State Examination; NPI = Neuropsychiatric Inventory.

Table 3. Frequency and percentage of participants with NPI behaviours

	Frequency	**%**
Delusions	6	6.52
Hallucinations	7	7.61
Agitation	40	43.48
Depression	29	31.52
Anxiety	39	42.39
Elation	2	2.17
Apathy	1	1.09
Disinhibition	1	1.09
Irritability	32	34.78

Aberrant motor behaviour	3	3.26
Sleep disturbance	6	6.52
Change in appetite	10	10.87

NB. % = percentage of participants with NPI behaviours.

Table 4. Summary of multiple regression with Bootstrap on global cognition

	B	**Bias**	**SE Bias**	***p* (2-tailed)**	**BCa 95% CI**	
					Lower	**Upper**
Model 1						
Age	.064	-.004	.060	.304	-.044	.175
Gender	.603	.008	.789	.450	-.979	2.108
Depression	-.173	.000	.223	.436	-.602	.270

Model 2						
Age	.063	-.004	.063	.340	-.042	.173
Gender	.316	.021	.788	.698	-1.433	1.964
Depression	-.089	-.015	.238	.693	-.556	.332
Loneliness	.068	.004	.243	.771	-.456	.543
Family social ties	.014	-.001	.145	.924	-.266	.315
Friend social ties	.284	-.007	.107	.010	.078	.492

NB. B = unstandardized beta coefficient; Bias = bias corrected and accelerated beta; SE B = standard error of bias corrected and accelerated beta; BCa 95% CI = bias corrected and accelerated 95% confidence interval.

Table 5. Summary of multiple regression with Bootstrap on psychopathology

	B	**Bias**	**SE Bias**	***p* (2-tailed)**	**BCa 95% CI**	
					Lower	**Upper**
Model 1						

Age	-.157	.005	.079	.045	-.329	-.026
Gender	-1.172	.084	.721	.134	-2.856	.394
Depression	1.420	.001	.225	.001	1.003	1.843
Model 2						
Age	-.151	.005	.079	.060	-.315	-.014
Gender	-.947	.089	.703	.226	-2.547	.558
Depression	1.492	-.003	.238	.001	1.039	1.928
Loneliness	-.241	-.010	.212	.267	-.643	.149
Family social ties	.111	-.004	.113	.334	-.101	.328
Friend social ties	-.162	.002	.093	.113	-.374	.027

NB. B = unstandardized beta coefficient; Bias = bias corrected and accelerated beta; SE B = standard error of bias corrected and accelerated beta; BCa 95% CI = bias corrected and accelerated 95% confidence interval.