

1 **Title: The impact of assistive technology on burden and psychological wellbeing in informal**
2 **caregivers of people with dementia (ATTILA Study)**

4 **Abstract**

5 INTRODUCTION, Assistive Technology and Telecare (ATT) may alleviate psychological burden in
6 informal caregivers of people with dementia. This study assessed the impact of ATT on informal
7 caregivers' burden and psychological wellbeing.

8 METHODS, Individuals with dementia and their informal caregivers were recruited to a randomized
9 controlled trial assessing effectiveness of ATT. Caregivers were allocated to two groups according to
10 their cared-for person's randomization to a full or basic package of ATT and were assessed on
11 caregiver burden, state anxiety, and depression. Caregivers' data from three assessments over six
12 months of the trial were analysed.

13 RESULTS, No significant between- or within-group differences at any time point on caregivers'
14 burden, anxiety, and depression levels were found.

15 DISCUSSION, Full ATT for people with dementia did not impact caregivers' psychological
16 outcomes compared to basic ATT. The length of follow up was restricted to six months.

17 *Keywords* dementia, assistive technology, telecare, informal caregiver, caregiver burden, mental
18 health

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77 **Research in Context:**

78 Systematic review: Electronic databases were searched for systematic reviews of interventions for
79 informal caregivers of people with dementia. Several reviews assessed interventions to improve carer
80 psychological outcomes but did not investigate second and third generation Assistive Technology and
81 Telecare (ATT). Our published systematic review identified three studies implementing telecare for a
82 person with dementia and assessing informal caregivers' outcomes, of which none were peer-
83 reviewed or randomised controlled trials (RCTs).

84 Interpretation: To our knowledge, ATTILA is the first RCT to assess the effectiveness of ATT for a
85 person with dementia on informal carers' psychological wellbeing. We have assessed its impact in a
86 large sample and provide insight into the short-term impact of its installation on psychological
87 wellbeing among caregivers.

88 Future directions: To confirm our findings, future studies should identify the minimum sample size
89 needed to detect an effect of ATT on informal carer outcomes and should carry out longer follow-up
90 assessments to determine whether carer benefits are manifest later.

91 **Highlights:**

- 92 • Informal caregivers of people with dementia have been found to have poor psychological
93 wellbeing
- 94 • We investigated the impact of a full package Assistive Technology and Telecare (ATT)
95 implemented for the cared-for person on informal caregivers' psychological wellbeing
- 96 • The psychological wellbeing of informal caregivers of people with dementia receiving a full
97 package ATT did not differ from that of caregivers of people with dementia not in receipt of a
98 full package of ATT

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102 INTRODUCTION

103 Caring for a person with dementia is associated with poor psychological and physical wellbeing ¹
104 placing greater psychological burden on the caregiver than caring for individuals with other chronic
105 conditions ². Interventions to prevent poor psychological outcomes and institutionalisation of the
106 person with dementia have been developed. Psychological support interventions that target informal
107 carers directly can be delivered face-to-face or over the telephone ³. A systematic review of 40 studies
108 found that interventions including a social component, with or without a cognitive component, were
109 more effective in improving psychological wellbeing than interventions without such components ⁴.
110 Small sample sizes and differences in the types of interventions might explain differences in study
111 outcomes. Over 200 interventions for caregivers have been tested in randomized trials and found to
112 have some efficacy on caregivers' outcomes ⁵. Telephone-based interventions to support caregivers
113 communicate between patient and the healthcare system appear to be effective in improving outcomes
114 ⁶. A recent meta-analysis has identified that telecare can improve health outcomes in caregivers ⁷.

115 An alternative to interventions targeting the caregivers directly are those aiming to remotely monitor
116 and manage the care recipient. Information communication technologies, such as those collecting,
117 capturing, storing, processing, transmitting, exchanging, and presenting information, and/or
118 communication, appear to facilitate delivery and access of healthcare to individuals with a chronic
119 disease ^{8,9}. Assistive Technology and Telecare (ATT) involves installing equipment to manage the
120 risks of living at home. Some ATT devices continuously, automatically and remotely monitor for real-
121 time emergencies and lifestyle changes ^{10,11}, others 'stand-alone' (e.g. electronic reminders, key
122 safes). While directed at the care recipient, these may also impact on caregiver outcomes by
123 improving sleep and reducing worry and stress by providing alerts to serious incidents such as falls,
124 cooking accidents, or wandering, thus enabling appropriate and timely intervention. A systematic
125 review of seven studies, three of which were of caregivers for individuals with dementia, showed that
126 telecare exerts a positive effect on caregiver stress and strain ¹². The reports that included caregivers
127 of dementia care recipients were not peer-reviewed publications, and as such, caution in interpreting
128 findings from this systematic review is warranted. Overall however, findings do suggest a trend

129 favouring the application of ATT for caregivers and care recipients, which needs to be investigated
130 further.

131 We conducted a pragmatic RCT as part of the larger Assistive Technologies and Telecare to maintain
132 Independent Living At home trial (ATTILA) ¹³. The ATTILA trial examined the clinical and cost-
133 effectiveness of ATT in supporting people with dementia to continue living safely within their own
134 homes and the impact of the intervention on caregiver psychological outcomes ¹³. This paper reports
135 on the impact of the intervention on informal caregiver outcomes ¹³. The aim of this sub-study of the
136 ATTILA trial was to compare the effect of a full ATT versus basic ATT package for people with
137 dementia on their caregivers' psychological outcomes.

138 **METHODS**

139 *Design*

140 This was a sub-study of the ATTILA randomized-controlled trial and used a quasi-experimental
141 design, examining the effect of receipt of ATT services on psychological outcomes of carers of people
142 with dementia ¹³ (Trial Protocol Reference ISRCTN86537017). Participants in the current study were
143 informal caregivers of people with cognitive difficulties or dementia who had been recruited to the
144 ATTILA trial ¹³.

145 *Participants*

146 In the ATTILA trial, participants were people with a diagnosis of dementia or cognitive difficulties
147 sufficient to suggest dementia, who met English Social Services' eligibility criteria for Fair Access to
148 Care Services (an eligibility framework in England for prioritising the use of adult social care
149 resources), were living in the community and had a working telephone line. Exclusion criteria were
150 current receipt of an ATT intervention (except for the provision of non-monitored smoke and carbon
151 monoxide alarms, key safes and pendant alarms) or previous installation of ATT that had not been
152 used, unlikely to comply with long term follow-up, participation in another interventional dementia
153 trial, or had an identified urgent need for a home care package due to immediate and severe risk to
154 participant or others. Informal caregiver participants were adults, who could be co-resident or non-

155 resident with the trial participant. The caregiver remained in the trial for the full 104-week trial
156 duration or until their care recipient left due to death or institutionalization or withdrawal from the
157 trial.

158 ***Intervention and control conditions***

159 Informal caregivers were allocated to the intervention or control arm according to the randomisation
160 group of their cared-for person. Participants with dementia in the ATTILA trial were randomised to
161 one of two conditions: 1. Intervention: a semi-structured needs assessment for ATT by a health or
162 social care professional, followed by installation of ATT devices and response services as indicated
163 by the assessment, or 2. Control: a semi-structured needs assessment for ATT by a health or social
164 care professional, followed by installation of devices restricted to a non-monitored smoke or carbon
165 monoxide alarm, key safe and pendant alarm where indicated.

194 ***Sample size***

195 The sample size was estimated on the expected effect size of the intervention on the primary outcome
196 (i.e. time to institutionalization) for the ATT recipients. No required number of participants was
197 identified for the caregiver sample.

198 ***Procedure***

199 Outcome rating scales were completed by caregivers at the same time points as scheduled data
200 collection for their care recipient: baseline (0 weeks), 12, 24, 52, and 104 weeks. Data were collected
201 on the care recipients and their respective caregivers. Caregivers completed the baseline data
202 collection at home, with or without the assistance of the data collection assistants. Further assessments
203 were mailed to caregivers or completed at the care recipients' follow-up appointments.

204 ***Descriptive data***

205 Data about the caregiver, their caring responsibilities, and their relationship to the participant were
206 collected, including: i) caregiver age, ii) frequency of caring responsibility (lives with the care
207 recipient, visits once per day, or visits less than once per day), iii) who lived with the care recipient

208 (spouse or partner, care recipient lives alone, or other). Data about the severity of the care recipient's
209 dementia symptoms were captured using the Standardised Mini-Mental State Examination (SMMSE)
210 ¹⁴.

211 *Caregiver outcome data*

212 Data were collected about caregiver outcomes on three scales at each time point:

213 1. Caregiver burden: The Zarit Burden Interview ¹⁵ is a 22-item scale assessing burden of caregiving.

214 Participants respond on a 5-point Likert-type scale ranging from 0 (never) to 4 (always), to generate a
215 single score with higher scores indicating greater burden. Scores 0-20 indicate little or no burden, 21-
216 40 mild to moderate burden, 41-60 moderate to severe burden, and 61-88 indicating severe burden.

217 2. Depression: Centre for Economic Studies Depression Scale-10 (CESD-10): A 10-item scale.

218 Participants respond on a 4-point Likert-type scale ranging from 0 (rarely/none of the time) to (3) all
219 of the time. A single score, ranging from 0-30 is calculated. A score ≥ 10 indicates depression.

220 3. State Anxiety: Short form of the state scale of the Spielberger State-Trait Anxiety Inventory [STAI;

221 ¹⁶]: A six-item scale where participants rate anxiety symptoms on a four-point Likert-type scale
222 ranging from 1 (not at all) to 4 (very much). A single score is calculated ranging from 20-80 points;
223 higher scores represent greater anxiety. A 'normal' score is 34-36 points.

224 *Data analysis*

225 We analysed the data with the Statistical Package for the Social Sciences (SPSS) version 25 (alpha
226 level = .05). Normality of the data was examined by visual inspection of the histograms and
227 conducting the Shapiro-Wilk test of normality. To establish the structure of the Zarit Burden
228 Interview in this sample a Principal Component Analysis (PCA) with an Oblimin rotation was
229 performed. We used the Kaiser-Meyer-Olkin test to check the suitability of the data for PCA,
230 followed by inspection of a scree plot to determine the number of factors.

231 *Selection of cases/ timepoints for inclusion in analyses*

232 There were several sources of attrition across time points including loss to follow up, death, or
233 institutionalisation of the care recipient. Because rates of attrition at the later time points reached

234 approximately 50% by week 104, analysis of the caregiver sample was restricted to baseline, week 12,
235 and week 24. Intention to treat analyses were conducted.

236 *Imputation*

237 To account for missing data across demographic variables and outcomes, we conducted multiple
238 imputation for baseline only, by including all predictors to fill the missing data. We used data from all
239 three examined time points (baseline, week 12, and week 24) within the same multiple imputation
240 model. We produced 10 imputed datasets ($m = 10$); each of the multiply imputed datasets was
241 analysed as usual, after which the 10 sets of results produced for each analysis were combined using
242 Rubin's rules¹⁷⁻¹⁹.

243 *Descriptive data, randomisation and loss to follow-up analyses*

244 Means and standard deviations were calculated for continuous data and frequencies and percentages
245 for categorical data. We conducted Linear Mixed Modelling (LMM) to analyse between-group
246 differences, change over time as well as interaction effects of group and time. An initial set of
247 analyses was conducted to examine the assumption that within-participants scores are highly
248 correlated by calculating the intraclass correlation (ICC). The second set of models included
249 covariates. Time was entered as a fixed effect for each LMM with participants' identification number
250 as random effect with the default variance components (VC) structure.

251 In addition to the main effects of group and time, the effects of the time-group interaction were
252 examined and interpreted where a significant interaction term indicating differential treatment
253 effectiveness was found. The decomposition of interaction effects for (i) group differences within
254 each time point and (ii) changes over time within each group individually were examined. Significant
255 effects were investigated using pairwise comparison with the estimated marginal means. The 95%
256 confidence intervals (CI) around the estimated marginal means on each outcome for each group were
257 also calculated. All LMM analyses in each section were adjusted for each of the demographic
258 variables presented in Table 1. Alpha level was set at 0.05.

259 RESULTS

260 *Participants*

261 495 people with dementia and, where available, their caregivers, were recruited to the trial. Of
262 participating caregivers, 354 provided data on age (control $n = 182$, intervention $n = 172$) and on
263 SMMSE scores for the person with dementia. The remaining 141 missing data for age and SMMSE
264 scores were imputed. Baseline caregiver and care recipient demographic characteristics are
265 summarised in Table 1 and baseline scores for each outcome are summarised in Table 2.

266 *Caregiver burden*

267 The Zarit Burden Inventory (ZBI) was analysed as total score, and as three-component factors
268 following a Principal Component Analysis. The three components were defined as: i) Component 1:
269 Negative appraisal of the care partner role, ii) Component 2: Adequacy as a care partner, iii)
270 Component 3: Caregiver Burden and Strain

271 Total scores and the three-component scores for the ZBI were not significantly different between the
272 control and intervention group at 12 or 24 weeks. There were no significant within-group or
273 interaction effects across all time points (see Table 2).

274 We also conducted post hoc subgroup analyses among live-in caregivers, and in caregivers who were
275 the spouse or partner of the cared-for person, in whom we might expect poorer psychological
276 wellbeing and levels of burden. Neither of these sub-group analyses revealed differences between the
277 two groups in any of these outcomes.

278 *Caregiver Depression and Anxiety*

279 Scores for CES D-10 (depressed mood) were not significantly different between the control and
280 intervention group and there were no significant interaction effects across all time points. Similarly,
281 scores for the STAI-6 (anxiety) did not significantly differ between the control and intervention group
282 and no significant interaction effects were found. Parameter estimates and adjusted mean scores for
283 each group at each time point are presented in Table 3.

284 We also conducted post hoc subgroup analyses among live-in caregivers, and in caregivers who were
285 the spouse or partner of the cared-for person, in whom we might expect poorer psychological
286 wellbeing and levels of burden. Neither of these sub-group analyses revealed differences between the
287 two groups in any of these outcomes.

288 **Discussion**

289 The impact of caring for someone with dementia on informal caregivers' health and wellbeing has led
290 to the development of interventions to reduce caregivers' burden²⁰. These interventions may have a
291 broader impact because alleviating caregivers' burden and psychological difficulties may reduce the
292 likelihood of the care recipient being institutionalised, resulting in lower social and healthcare costs.
293 In this sub-study of the ATTILA trial, we compared the impact of deploying the full or basic ATT
294 package in the home of the people with dementia on the psychological outcomes of their caregivers
295 (caregiver burden, depression, and anxiety) in the first 24 weeks following its installation.

296 Mean scores of caregiver burden, depression, and state anxiety did not differ between the caregivers
297 of trial participants in the intervention and control groups at follow-up. Sub-analyses on live-in
298 caregivers and those who were the spouse or partner of the cared-for person also revealed no effects
299 of the intervention on caregiver burden or psychological wellbeing. It is notable that the caregiver
300 burden levels, depression and anxiety remained stable during the course of the study. Although this
301 study was not conducted as a non-inferiority trial, the data suggest no negative impact of receiving the
302 ATT intervention on caregiver burden and psychological outcomes.

303 One explanation for the lack of impact on these outcomes is the relatively low baseline levels of
304 burden, depression, and state anxiety²¹. Mean burden in the intervention and control group for the
305 overall sample and the examined sub-groups were in the mild to moderate range. Similarly, mean
306 levels of depression in this sample were below the clinically relevant threshold on the CES D-10
307 scale, for which a score >10 indicates depression. For state anxiety, mean scores on this scale at
308 baseline were 40.3 (standard error 1.22) and 39.7 (standard error 1.28) for the control and intervention
309 group respectively. Therefore, participants might have had sufficiently high levels of anxiety at

310 baseline to benefit from the intervention. Previous studies have indicated higher levels of depression
311 and anxiety at baseline in their study populations. (see e.g. ²²), and a recent study using the same
312 instrument for assessing depression found higher scores, above the clinically relevant threshold, in
313 their sample ²³.

314 Alternatively, it is possible that the effects of the intervention may have been limited in effecting
315 change in these outcomes. Interventions specifically targeting caregivers may be more effective than
316 those aiming to support the cared-for person. Meta-analyses indicate that caregiver-directed
317 interventions have demonstrated effectiveness on average in reducing depression; effective
318 interventions include Cognitive Behavioural Therapy, cognitive reframing and educational
319 interventions ^{20,24-26}. Therefore, to optimize the benefits of the installation of ATT for both the care
320 recipient and the caregiver, it may be important to provide additional caregiver-directed practical and
321 psychosocial support. Effective and potentially low burden and low-cost modes of delivery of these
322 interventions include the use of telephone and internet ^{27,28}.

323 In the current sample, mean SMMSE scores indicated moderate levels of cognitive impairment in the
324 cared-for participant sample. There is some evidence to indicate that the severity of dementia is
325 related to levels of depression and anxiety, with only severe dementia leading to caregivers having
326 high levels of depression and anxiety ^{29,30}, although this relationship has not always been confirmed ³¹.
327 Furthermore, while we observed baseline between-group differences in SMMSE scores, the
328 magnitude of this difference was marginal with fewer than two points between the control and
329 intervention group. Additionally, in our analyses, we adjusted for SMMSE scores at baseline. It is
330 also possible that disease severity in the care recipient was not sufficiently severe to produce high
331 burden, depression, or anxiety scores at baseline in the caregivers such that they may have been
332 reduced by the intervention. It is of note that a small but significant difference was found between the
333 two groups with those receiving ATT having higher scores on the MMSE.

334 While the care recipients had been diagnosed with dementia, they were of mixed aetiology and
335 severity. Furthermore, there was a low risk of wandering in the sample at baseline, with 72% of
336 participants with dementia being classified as being at low risk of wandering, and half of participants

337 identified as having a low safety risk in their own home. It is possible that the effects of ATT on
338 caregivers' burden might be related to varying levels of cognitive impairment in the care recipient³²
339 and the type of dementia³³. Moreover, different dementia types manifest varying levels of
340 behavioural problems. Thus caring for someone with frontotemporal dementia, which tends to present
341 with greater behavioural problems than Alzheimer's disease, for example, may impact on caregiver's
342 burden and depression differently^{33,34}. Identifying what type of dementia aetiology (Alzheimer's
343 disease, vascular dementia, etc.) may inform the selection of the type of intervention that should be
344 applied to alleviate the caregiver's burden³².

345 A further potential explanation of the lack of impact of the intervention may be the limited fidelity of
346 technology deployment in relation to the recommendations arising from the needs assessment³⁵. A
347 moderate correlation was found between the intervention ATT deployed and the needs of the person
348 with dementia. If the ATT did not address the problems experienced by the individual and their
349 caregiver, it can be expected to have had limited impact on the carers' outcomes.

350 ***Strengths, limitations, and suggestions for future research***

351 This study provides the first insight into the potential impact of ATT interventions for people with
352 dementia on outcomes for their informal caregivers. Because of the design of the trial, after care-
353 recipients had left the study due to death or institutionalization, their informal caregivers were no
354 longer followed up. Thus, the attrition rate in caregivers after 24 weeks was considerable, precluding
355 analysis of caregiver data after this time point. It is possible that any effects of ATT on caregivers'
356 psychological wellbeing may take some time to manifest, beyond the limited time scale in this study.
357 Furthermore, the sample size for the ATTILA study was based on the study primary outcome (time to
358 institutionalization) rather than on caregivers' outcomes. It is possible that our analyses were
359 statistically underpowered to detect intervention effects.

360 Caregivers in this study had only limited characterisation such that age, sex, and cognitive ability
361 were not assessed. While it is reasonable to assume that randomisation would have ensured

362 appropriate distribution of these characteristics, such that they would be evenly distributed across the
363 two groups, it was not possible to examine these characteristics statistically.

364 In light of the limitations above, future work should determine the minimum sample size to detect an
365 effect of the ATT intervention based on expected effect size for caregiver outcomes. It may well be
366 that longer follow up times and additional support interventions for caregivers are necessary to effect
367 benefits for caregivers' outcomes. It may also be fruitful to examine at which stage of the condition
368 assistive technologies should be introduced so that the person with dementia and caregiver can derive
369 the maximum benefit; and to examine which ATT devices are most useful at different stages of
370 dementia.

371 *Conclusions and implications for practice*

372 This study provides insight into the potential impact on caregiver burden and psychological wellbeing
373 of providing people with dementia with a comprehensive package of ATT compared to a basic
374 package. No impact of ATT on caregiver burden, depression and anxiety was identified. Thus,
375 interventions aiming to specifically target caregiver wellbeing alongside the deployment of ATT may
376 be important for delaying institutionalization and associated costs. Effective interventions to reduce
377 the impact of caregiving may include caregiver directed psychological techniques as well as ensuring
378 that caregivers have an appropriate understanding of the role of ATT, and scope for change when
379 using ATT.

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