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The Relationship Between Caregiver Burden and Depression

Abstract

Objectives: To examine risk factors for the development of depressive symptoms. **Design:** Longitudinal analysis was completed for clients with 2+ assessments. Development of depressive symptoms was defined as a Depression Rating Scale score of 3+ on re-assessment. **Results:** Overall, 10.7% of clients experienced new depressive symptoms and clients with a caregiver who was feeling distressed, angry or depressed were 45% more likely to develop symptoms. **Discussion:** The onset of depressive symptoms is common in home care. Understanding the experience of the informal caregiver can assist clinicians in providing services to maximize the well-being of both the client and their caregivers.

Keywords: interRAI, depression, home care, informal caregiving, caregiver burden, standardized assessment, Resident Assessment Instrument for Home Care

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1 **INTRODUCTION**
2
3   Depression is the most common psychiatric disorder among community-dwelling older

4   adults, and 15% of older Canadians (65+) report symptoms of depression (Denihan, Bruce,

5   Coakley, & Lawlor, 1998). Late life depression can be difficult to detect, as it is often presented

6   with other chronic co-morbid conditions, which can result in under-detection and under-

7   treatment (Kales & Valenstein, 2002). A recent study found that 12% of Ontario home care

8   clients experience depressive symptoms at the time of enrolment, but prevalence estimates in

9   community-dwelling older adults vary between 7% and 49% (Markle-Reid et al., 2011;

10   Szczerbinska, Hirdes, & Zyczkowska, 2012). Approximately 26% to 44% of clients receiving

11   home care services have depression, however, it is often undertreated or not treated at all

12   (Markle-Reid et al., 2011). The difficulty in detecting depressive symptoms in late adulthood

13   may be due to the reluctance to admit psychological symptoms and failure to recognize several

14   symptoms of depression that often occur in older adulthood (e.g., lack of energy, sleep problems,

15   memory changes) (Cappeliez, 2014).

16   Poor physical health, sleep disturbances and being female have all been shown to be

17   important risk factors for depression in older adults (Cole & Dendukuri, 2003). Additionally,

18   limitations in completing instrumental activities of daily living (IADLs) and difficulties with

19   activities of daily living (ADLs) (Ormel, Rijsdijk, Sullivan, van Sonderen, & Kempen, 2002;

20   Szczerbinska et al., 2012) have been found to be associated with depressive symptoms in later

21   life. Loss of autonomy and cognitive impairment have also been found to be important risk

22   factors associated with depression with increasing age (Djundeva, Mills, & Wittek, 2015). An

23   inability to make decisions and an overall loss of autonomy often further exacerbates the effects

24 of functional limitations, which can lead to an even greater vulnerability in experiencing

25 depressive symptoms (Djundeva et al., 2015; Fiske, Loebach Wetherell, & Gatz, 2009).

26   There are also a number of factors that are protective against the development of

27 depressive symptoms. A higher level of education and socioeconomic status may act as a buffer

28 to late-life depression since more affluent individuals may experience fewer stressful events

29 relating to retirement and resource allocation (Fiske et al., 2009). McCusker and colleagues

30 (2007) found that clients with minor and major depressive symptoms were less likely to have a

31 spouse and more likely to have a caregiver that resided outside of the home (McCusker, Latimer,

32 Cole, Ciampi, & Sewitch, 2009), which emphasizes how emotional and social support can

33 reduce the risk for developing depressive symptoms. Older adults that are actively engaged in

34 valued activities within the community, and have religious and spiritual involvement are also at a

35 decreased risk of developing depression (Fiske et al., 2009).

36   In Canada, there are two million informal caregivers caring for older adults within the

37 community (Information, 2011). The majority of older adults that receive community based

38 home care are not able to cope without the assistance from an informal caregiver.

39 Approximately 16% of caregivers report feelings of distress, with these rates rising to 28% when

40 they are providing more than 21 hours of support per week. This rate continues to rise for

41 caregivers providing care for older adults experiencing symptoms of depression (32%), cognitive

42 impairments (37%) and for those displaying aggressive behaviours (52%) (Canadian Institute for

43 Health Information, 2010). These types of adverse effects contribute to increased caregiver

44 strain and stress which can result in the need for institutional care (Garlo, O'Leary, Van Ness, &

45 Fried, 2010). This level of strain and stress placed on informal caregivers, on top of the hours

46 required for their own paid employment puts them at a greater risk for caregiver burden.

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47   Caregiver burden refers to the long-term physical and psychological strain associated with caring

48   for another individual (Schulz & Sherwood, 2008). A study by Park and colleagues (2015)

49   found that clients with severe cognitive impairment, ADL and IADL dependency and behavioral

50   problems all contributed to increased caregiver burden (Park, Sung, Kim, Kim, & Lee, 2015).

51   Previous research has also shown that caregivers of depressed individuals are significantly more

52   likely to report poor quality of life and poor mental health compared to those caring for non-

53   depressed older adults (McCusker, Latimer, Cole, Ciampi, & Sewitch, 2007). Therefore, it is

54   important to begin to identify the relationships between symptoms of depression in the client and

55   the impact this has on caregiver burden in order to improve quality of life for both the client and

56   the caregiver. Increased knowledge in this area may allow for a greater amount of availability of

57   support services for caregivers in an attempt to prevent/reduce overall burden and decline in

58   individuals caring for older adults (McCusker et al., 2009).

59   In Ontario, approximately 700,000 individuals receive home care each year, with an

60   annual budget of $2.4 billion, accounting for 4.7% of the annual health care budget (Ontario

61   Ministry of Health and Long-Term Care, 2015). Publicly-funded home care is administered by

62   Local Health Integration Networks (LHINs) in Ontario, which work to coordinate the type and

63   amount of care that each client receives (Home Care Ontario, 2015). Currently, in Canada, little

64   is known about incident depression and the potential risk factors that may be associated with the

65   development of depression in older adults.   There have been studies published around incident

66   depression, however these have generally examined adults between the age of 18 and 65 years

67   (Wang et al., 2010), or have focused on healthy community-dwelling older adults (Strawbridge,

68   Deleger, Roberts, & Kaplan, 2002; Veronese et al., 2017). Additionally, there have been studies

69   that have examined predictors of a new depression diagnosis for older adults admitted to

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70   complex continuing care (Martin et al., 2008), however no studies have looked at this in a home

71   care population. Therefore there is a gap within the literature relating to the development of

72   incident depression in older adults receiving home care services and the important risk factors

73   associated with this development. The main goals of this study were to examine the incidence of

74   depressive symptoms in older home care clients (65+) in Ontario and the potential risk factors

75   associated with the development of these symptoms over time. We were also interested in

76   examining the relationship between the onset of depressive symptoms and the potential

77   association this may have with caregiver burden.

78
79   **METHODS**
80   *Data source*
81
82   The current study utilized secondary data collected on Ontario home care clients who were

83   assessed using the Resident Assessment Instrument for Home Care (RAI-HC). The RAI-HC is a

84   government mandated assessment completed on all home care clients expected to receive at least

85   60 days of care (Ministry of Health and Long-Term Care 2006). The RAI-HC is part of a family

86   of assessments that were developed by interRAI (www.interrai.org), a not-for-profit organization

87   of clinicians and researchers from over 30 countries. These instruments are used to help guide

88   care planning, measuring quality issues and outcomes of care (Morris et al., 1997).

89   The assessment contains just over 300 items which covers domains including physical

90   functioning, communication and sensory difficulties, cognitive and behavioral patterns,

91   psychosocial well-being and medication use (Landi et al., 2000). The individual items on the

92   RAI-HC have been found to be valid and reliable, with documented evidence of criterion validity

93   (Poss et al., 2008). The RAI-HC has also been found to have good inter-rater reliability (average

94   kappa: 0.74) (Morris et al., 1997), as well as test-retest reliability (J.P. Hirdes et al., 2008).

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95   The standard reassessment period for the RAI-HC in Ontario is every six to twelve

96   months, unless there is a change in clinical status that warrants an earlier re-assessment.

97   Assessments are completed by trained care coordinators (typically registered nurses) on a laptop

98   computer within the client's home. Completion of the assessment includes gathering

99   information from a variety of sources, including speaking with the client, their informal

100   caregivers, health care professionals (e.g., primary care physician), and the use of clinical

101   records, as needed. All completed assessments are submitted to the Canadian Institute for Health

102   Information (CIHI; www.cihi.ca), where they are stored in a national data warehouse. Prior to

103   the research team being given access to the data by CIHI, all personal identifiers were removed

104   from the assessments.

105   *Sample*

106   The sample included clients aged 65+ who had at least two assessments completed

107   between 2006 and 2014 (n = 504,284). This time frame represented the most recent Ontario data

108   available to the research team. Of the clients that had at least two assessments completed within

109   this time frame, the sample was then limited to clients that had two assessments completed

110   within 12 months, in keeping with the mandated six- to twelve-month reassessment interval in

111   Ontario (n = 163,527). In the event that a client had more than two assessments within a 12-

112   month time frame, the two most recent assessments were kept for analysis. The average time

113   between a client's two most recent assessments was 6.2 months (SD = 3.0). A preliminary trend

114   analysis was completed in order to examine the rate of incident depression across each of the

115   eight years of data included in the current analysis. We found very little variability over time in

116   these rates. We also examined basic demographic characteristics and found that incident

117   depression did not change over time as a function of age or sex (data not shown). Therefore, we

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118   felt it was appropriate to use all eight years of data and allow clients within this time frame to

119   populate our analytic cohort. The Research Ethics Board at Wilfrid Laurier University reviewed

120   and approved the design of this study (REB # 4654).

121   *Measures*

122   The main outcome variable of interest was the development of incident symptoms of

123   depression. The presence of symptoms of depression was determined based on the scoring of the

124   Depression Rating Scale (DRS), which is one of the six health index scales embedded within the

125   RAI-HC that are automatically generated on completion of the assessment. The DRS is a

126   summative scale that measures signs and symptoms of depression. It can range from zero to 14

127   and combines seven items relating to mood and seven items relating to behaviour. A cut-point of

128   three or greater was used to indicate at least mild/moderate depressive symptoms (Martin et al.,

129   2008). Compared to the Hamilton Depression Rating Scale, this cut-point has been shown to

130   maximize the sensitivity of the DRS (94%), with minimal loss of sensitivity (72%) within a

131   sample of nursing home residents (Burrows, Morris, Simon, Hirdes, & Phillips, 2000).

132   A client was considered to have developed incident depression if they experienced no

133   depressive symptoms on their first assessment (i.e., a DRS score of 0, 1 or 2) and depressive

134   symptoms on re-assessment (i.e., a DRS score of three or greater). Conversely, if a client did not

135   have depressive symptoms on their first assessment and remained without symptoms on re-

136   assessment, they were classified as not developing depressive symptoms. Since the current

137   analysis was only interested in looking at factors relating to the development of incident

138   depression, clients were also excluded from the analysis if their DRS score remained the same or

139   improved between the two assessments, or if their initial symptoms of depression got worse over

140   time.

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141   The other five health index scales embedded within the RAI-HC measure functional

142   performance, cognition, health instability and pain. The Activities of Daily Living (ADL) Self-

143   Performance Hierarchy Scale (ADL-SHS) examines a client's physical functioning on areas

144   around personal care, which include eating, locomotion, dressing and bathing. Functional

145   performance on this scale is rated from zero (independent) to six (total dependence), where a cut-

146   point of two or higher was chosen to indicate at least some assistance is needed to complete these

147   tasks. The ADL-SHS has been validated against the Barthel Index (Mahoney & Barthel, 1965).

148   The Instrumental ADL (IADL) Involvement Scale is a summative scale that includes items

149   relating to meal preparation, ordinary housework, maintaining finances, managing medications,

150   phone use, shopping and transportation. Each individual item is scored from zero (independent)

151   to three (activity performed by others), for a total scale score ranging from zero to 21, where a

152   cut-point of 14 or higher was chosen to indicate a greater level of impaired functioning in

153   performing these tasks. The Cognitive Performance Scale (CPS) contains items pertaining to

154   expressive communication, independence in eating, short-term memory and daily decision-

155   making. The CPS is a hierarchical scale ranging from zero (no impairment) to six (severe

156   impairment), where a cut-point of two or greater was selected to indicate at least mild

157   impairment. The CPS has been validated against the Mini Mental State Exam (MMSE) (Morris

158   et al., 1994) and the Montreal Cognitive Assessment (MoCA) (Jones, Perlman, Hirdes, & Scott,

159   2010). The four-point Pain Scale includes items relating to both the frequency and intensity of

160   pain, and is rated from zero (no pain) to four (severe, daily pain), where a cut-point of two or

161   higher was used to identify clients with severe and/or daily pain. Finally, the Changes in Health,

162   End-Stage Disease and Signs and Symptoms (CHESS) Scale is used to identify individuals

163   experiencing health instability, or who are at risk for morality. The scale ranges from zero (no

164   health instability) to five (severe health instability), where a cut-point of two or greater was used

165   to capture those experiencing moderate to severe health instability (J. P. Hirdes, Poss, Mitchell,

166   Korngut, & Heckman, 2014).

167   Several items on the RAI-HC collect information regarding a client's caregiver including

168   informal support services provided by the client's family, living arrangements, the relationship

169   between the caregiver and the client and total hours of informal care provided in the previous

170   seven days (dichotomized at the median). We also examined additional items related to the

171   overall status of the caregiver. These three items included whether the caregiver was satisfied

172   with the current supports they were receiving from family and friends (yes/no), whether the

173   caregiver felt they could no longer provide care for the client (yes/no) and if the caregiver was

174   experiencing any feelings of distress, anger or depression (yes/no).

175   *Analysis*

176   Home care clients that experienced incident depression were compared descriptively to

177   those that did not develop new depressive symptoms with respect to demographic characteristics

178   (e.g., age and sex), social and physical functioning, informal care receipt and the five health

179   index scales. All predictor variables were measured at the time of the first assessment.

180   Categorical variables were analyzed using chi-square statistics where p-values were used to

181   determine significance. All of the analyses comparing these two groups were based on the

182   client's first assessment. Due to the large sample size used in the current analysis, we chose not

183   to rely on p-values to determine statistical relevance, but rather calculated odds ratios (OR), and

184   95% confidence intervals (CI) to help better understand important factors relating to the

185   development of depressive symptoms over time. Based on previous literature, we chose to use

186   an OR representing a 15% change (i.e., OR ≥ 1.15 or ≤ 0.85) to identify clinically relevant factors

187   relating to the development of depressive symptoms. This percent change was chosen as it

188   represents the smallest clinically important difference between treatments for depression within

189   the literature (Lustman, Griffith, Freedland, Kissel, & Clouse, 1998). Logistic regression

190   analyses were then performed to examine potentially important risk factors related to incident

191   depression. Results from the univariate analysis and relevant literature were used to identify

192   potential covariates. These covariates included age, gender, marital status, language, client's

193   relationship to the caregiver, the Pain Scale score, the CHESS score, whether the caregiver felt

194   they were unable to continue providing care, whether they were satisfied with the supports they

195   were receiving and if they were experiencing feels of distress, anger or depression. The

196   preliminary model was then further explored to determine if multi-collinearity and confounding

197   existed before establishing the final model. Model fit was based on the Akaike Information

198   Criterion (AIC), where a lower AIC value indicates better model fit. All statistical analyses were

199   conducted using SAS software (version 9.4, SAS Institute Inc., Cary, NC, USA). This study

200   followed the guidelines set out by the STrenghening the Reporting of OBservational studies in

201   Epidemiology (STROBE) (von Elm et al., 2007).

RESULTS

203   At the time of the first assessment, the mean age of the sample was 83.6 years (SD = 7.7),

204   63.5% were female, 57.2% of clients were widowed, separated or divorced and just under half of

205   home care clients did not complete high school (49.1%). The incidence of depressive symptoms

206   in the sample was 10.7% (n=17,498). Clients over the age of 85 years had a 22% decreased risk

207   of developing depressive symptoms compared to younger clients (OR = 0.78; 95% CI: 0.74,

208   0.82). Clients that were never married were 30% less likely to develop depressive symptoms

209   compared to clients that were married (OR = 0.70; CI: 0.64, 0.76). Females were at an increased

210   risk for incident depression compared to males (OR = 1.18; CI: 1.14, 1.22). Home care clients

211   with a primary language other than English had a 22% greater risk of experiencing depressive

212   symptoms between their two most recent assessments (OR=1.22; CI: 1.17, 1.27) (Table 1).

213   Clients with daily or severe pain had a 29% increased risk of developing incident

214   depression compared to clients that had no pain or less than daily pain (OR = 1.29; CI: 1.25,

215   1.33). Additionally, clients with a CHESS score of two or more had a 1.26 greater risk of

216   developing symptoms compared to clients with only mild or moderate health instability (OR =

217   1.26; CI: 1.22, 1.30). Clients with moderate/severe impairment in ADLs had a 14% decreased

218   risk of developing depressive symptoms, which just missed the cut-point for clinical

219   significance. Clients with moderate/severe cognitive impairment had a 14% increased risk of

220   developing incident depression, which again just missed the cut for clinical significance (Table

221   1).

222   Of the clients with a primary caregiver, there was no clinically significant increase in risk

223   for developing incident depression if the caregiver did not reside with the client. However, if the

224   primary caregiver was a spouse, clients were more likely to experience depressive symptoms

225   compared to clients whose primary caregiver was someone other than a spouse (OR = 1.21; CI:

226   1.14, 1.30). The type of support provided by the primary caregiver (i.e., emotional, IADL or

227   ADL) was not found to have an effect on the development of depressive symptoms in this

228   sample. However, if the primary caregiver felt as though they were unable to continue providing

229   care for the client, clients were more likely to experience a greater risk of incident depression

230   (OR=1.26; CI: 1.20, 1.32). Similarly, if the caregiver was not satisfied with the supports they

231   were receiving from other friends/family members, the client was 40% more likely to have an

232   increased risk of developing depressive symptoms (OR = 1.40; CI: 1.29, 1.52). Finally, if the

233 primary caregiver expressed feelings of distress, anger or depression, home care clients had a

234 45% increased risk of experiencing new depressive symptoms between their two most recent

235 assessments (OR=1.45; CI: 1.40, 1.51). The hours of informal support provided by the caregiver

236 in the last 7 days was not significantly related to the development of depressive symptoms (Table

237 2).

238   In the logistic regression model, a client's relationship to their caregiver was found to not

239 be a significant predictor of incident depression and was therefore dropped from further analysis.

240 Variables relating to caregiver status (unable to continue care and not satisfied with supports)

241 were also eliminated due to multi-collinearity with the caregiver distress item, which was kept,

242 as it had better predictive ability compared to the other two variables. Additionally, multi-

243 collinearity was found between gender and marital status, which was not surprising. Within our

244 data, there was a higher frequency of widowed woman compared to widowed males. However,

245 we decided to keep both in the model so that the odds ratios would be adjusted for these

246 characteristics which could be potential confounders. In the final adjusted model, two factors

247 were protective, namely age (85+ group: OR=0.78; CI: 0.7, 0.82) and being unmarried (0.71; CI:

248 0.65, 0.78) or widowed/separated/divorced (0.87; CI: 0.83, 0.90). The risk of incident

249 depression was *increased* for women (1.29; CI: 1.24, 1.33), those experiencing daily pain (1.25;

250 CI: 1.21, 1.29) and among clients with severe health instability (1.20; CI: 1.16, 1.24). Finally,

251 having a caregiver that experienced symptoms of distress, anger or depression also increased the

252 risk of incident depression by 41% (1.41; CI: 1.35, 1.46), even after adjusting for all other factors

253 in the model (Table 3).

254

255   **DISCUSSION**

256   In this sample of Ontario home care clients, the annual incidence of depressive symptoms

257   was 10.7%. To our knowledge, there is no information on the incidence of developing

258   depressive symptoms for older adults receiving home care services. As such, the closest

259   estimates available relate to the prevalence of depression in community-dwelling older

260   Canadians and estimates range from 26% to 44% (Markle-Reid et al., 2011). This analysis

261   represents a critical first step in understanding how these clients are functioning and the

262   important risk factors associated with developing depressive symptoms.

263   Overall, variables relating to the primary caregiver appeared to be some of the most

264   important predictors. The presence of a caregiver expressing feelings of distress, anger or

265   depression was an important risk factor for development of incident depression in the client.

266   Clients were 41% more likely to experience depressive symptoms if they had a caregiver who

267   experienced feels of distress, anger or depression. Numerous studies have cited that the primary

268   caregiver is at an increased risk of developing distress/burden if they are caring for someone who

269   has depression (deAlmeida Mello et al., 2016; McCusker et al., 2007). However, to our

270   knowledge, there is no information regarding the development of incident depression *in the*

271   *client* and its relationship with caregiver burden. There is a link between stressful life events and

272   the development of depression in older adults, which may help to explain the relationship

273   between caregiver burden and incident depression in the home care clients. A meta-analysis by

274   Kraaij and colleagues (2002) reviewed 25 studies and examined the types of negative life

275   events/total number of events and the relationship they have with depression. Almost all of the

276   negative life events examined had at least a modest, yet significant relationship with depression

277   (Kraaij, Arensman, & Spinhoven, 2002). If the primary caregiver is experiencing a stressful life

278   event (e.g., caregiving role is becoming burdensome), the client may become aware of this and in

279 turn, experience feelings of depression. This is likely a cyclical process as the caregiver

280 becomes distressed, the client may feel like a "burden" on the caregiver and therefore become

281 depressed which may cause increased distress for the caregiver.

282   Additionally, we found an important relationship between new episodes of depressive

283 symptoms and the primary caregiver's relationship with the client. If the primary caregiver was

284 a spouse, clients were 21% more likely to experience depressive symptoms compared to clients

285 with a primary caregiver who was another relative/friend. Although this relationship was

286 important on its own, it was not significant after adjusting for all other variables in the model.

287 Informal caregiving is an important aspect of care that allows older home care clients to maintain

288 their quality of life and functional status while remaining at home. It seem that the caregiver's

289 well-being plays an important role in relation to the client and their mental health. Therefore, the

290 client-caregiver relationship does appear to be quite complex and further research is needed in

291 this area in order to better understand contributing factors relating to caregiver burden and their

292 potential effects on a client's mental health. With this knowledge, early interventions to help the

293 caregiver may be put in place which may reduce the likelihood of the caregiver feeling as though

294 they can longer provide care. It is therefore crucial for these interventions to occur as early as

295 possible in order to support the caregiver and assist the family with providing informal care to

296 their loved one for as long as is feasible for them.

297   Clients that were aged 85+ had a 22% *reduced* risk of developing depressive symptoms

298 over time compared to their younger counterparts. Generally within the literature, increasing age

299 has been found to be a protective factor against developing depressive symptoms. Roberts et al.

300 (1997) found that increasing age per se was not associated with an increased risk of depression in

301 adults aged 50+. They found that age does not seem to be a cause of depression, but rather the

302   association of other age-related changes (e.g., difficulties completing ADLs, chronic health

303   conditions, etc.) may be contributing to depressive symptoms in older adulthood (Roberts,

304   Kaplan, Shema, & Strawbridge, 1997). Generally within the literature, being female has been

305   cited as a risk factor for incident depression (Cole & Dendukuri, 2003; Luppa et al., 2012). In

306   the current study, we found that females had a 29% increased risk of developing depressive

307   symptoms compared to males, even after adjusting for all other covariates. It has been suggested

308   that environmental factors in regards to social roles (e.g., supports received, life events, etc.) and

309   the ability to cope with these factors play an important role in the differences observed between

310   genders in the development of depressive symptoms (Luppa et al., 2012). Additionally, females

311   are more likely to discuss any psychological or physical issues they are experiencing with a

312   physician, which may bring a greater awareness to the depressive symptoms they are

313   experiencing (Piccinelli & Wilkinson, 2000).

314   The majority of clients in the sample spoke English as their primary language (80%),

315   with roughly 16% of clients speaking something other than English or French as their primary

316   language and this increased their risk for developing depressive symptoms in the univariate

317   analysis. This has been supported in the literature (Cairney & Krause, 2005). Although Canada

318   is officially considered a bilingual country, the majority of Canadians speak English as their

319   primary language; therefore, having a primary language that is neither of the two official

320   languages may put individuals at a higher risk of exclusion and potentially at greater risk for

321   experiencing depressive symptoms (Cairney & Krause, 2005).

322   The current study has several strengths including the large sample size and longitudinal

323   design. Additionally, we utilized data collected using the RAI-HC, which is a standardized

324   assessment used in multiple regions of Canada and the US. Since the RAI-HC is used with each

325 home care client on admission, with follow-up assessments occurring every 6-12 months, clients

326 are screened as they enter home care and periodically thereafter so if depressive symptoms are

327 present, it provides home care professionals with valuable information that can be used for care

328 planning.

329   A potential limitation to the current study was the selection of assessments used for the

330 analysis. We decided to use a client's two most recent assessments to examine the development

331 of depressive symptoms over time. We recognize that a client may have developed depressive

332 symptoms during an earlier time frame and therefore would have been excluded from our

333 analysis. However, we felt it was inappropriate to use older data since signs/symptoms of

334 depression happening in the past likely would have been recognized by the home care clinician

335 and some type of intervention or treatment may have been implemented. We therefore focused

336 on the most recent data for each person in order to capture depressive symptoms that likely had

337 not been subjected to extensive treatment at the time that the assessment were completed.

338 Additionally, the current analysis was limited to only examining the variables available in the

339 RAI-HC assessment. Although we were able to capture the majority of known risk factors in the

340 literature, there were some that we were not able to examine, including spirituality, socio-

341 economic status and a previous history of depression. Finally, our study relied on a summary

342 scale to identify the presence of symptoms of depression. We were unable to determine a

343 clinical diagnosis, since there is a single item on the RAI-HC that indicates the presence of "any

344 psychiatric disorders", which would include a diagnosis of depression but would also include

345 other mental health issues. However, the DRS has been shown to be a valid and reliable scale

346 for measuring depressive symptoms in older home care clients (Fisher, Seow, Brazil, Smith, &

347   Guthrie, 2015; J.P. Hirdes et al., 2002; Koehler et al., 2005) and has good predictive validity for

348   identifying a true clinical diagnosis (Martin et al., 2008).

349   Little is currently known about the development of depression in older adults, and one

350   strategy to address prevention is to have a better understanding of the important risk factors that

351   are associated with this outcome. The relationship between clients and their informal care

352   providers seems to be quite complex and not well understood. If a caregiver is experiencing

353   burden in their role, this may have an impact on the mental health of the client they are caring

354   for, which may lead to the client developing depressive symptoms. By identifying early signs of

355   caregiver burden, this may allow for timely interventions (e.g., respite) to be put in place to assist

356   the caregiver and maximize their capacity to continue in their caregiving role. Therefore, the

357   role of home care becomes extremely important in terms of early detection and interventions for

358   both the client and family.

359   Home care clinicians have an extremely important role in providing care to the client and

360   their family. Through ongoing assessment and continued communication to understand the

361   needs of the person and their family, these professionals have a strong role to play in flagging for

362   symptoms of depression and working with the family to ensure their needs are being met. In this

363   way, the home environment can be optimized to ensure the best possible quality of life for the

364   home care client and those caring for them.

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The Relationship Between Caregiver Burden and Depression

Table 1: Demographic and other characteristics comparing clients who did and did not develop incident symptoms of depression

Characteristic	All (n =163,527)	Did not develop new depressive symptoms (n =146,029)	Developed new depressive symptoms (n = 17,498)	Unadjusted OR (95% CI)
		% (n)		
Age groups				
Mean age (SD)	83.6 (7.7)	83.4 (7.7)	82.9 (7.7)	
65-74 years	14.4 (23,572)	14.2 (20,739)	16.2 (2,833)	Reference
75-84 years	38.1 (62,306)	37.8 (55,145)	40.9 (7,161)	0.95 (0.91, 1.00)
85+ years	47.5 (77,649)	48.0 (70,145)	42.9 (7,504)	0.78 (0.74, 0.82)
Sex				
Male	36.5 (59,631)	36.9 (53,824)	33.2 (5,807)	Reference
Female	63.5 (103,893)	63.1 (92,205)	66.8 (11,691)	1.18 (1,14, 1.22)
Marital status				
Married	37.8 (61,771)	37.4 (54,640)	40.8 (7,131)	Reference
Never married	4.2 (6,872)	4.3 (6,306)	3.2 (566)	0.69 (0.63, 0.75)
Widowed/separated/divorced	57.2 (93,568)	57.5 (83,907)	55.2 (9,661)	0.88 (0.85, 0.91)
Other	0.8 (1,316)	0.8 (1,176)	0.8 (140)	0.91 (0.76, 1.08)
Level of education completed				
Post-secondary	11.5 (14,253)	11.5 (12,790)	11.1 (1,463)	Reference
College/trade	17.0 (21,100)	17.1 (18,914)	16.6 (2,186)	1.01 (0.94, 1.08)
High school	22.5 (27,893)	22.6 (25,055)	21.5 (2,838)	0.99 (0.93, 1.06)
Less than high school	49.1 (60,910)	48.8 (54,188)	50.9 (6,722)	1.09 (1,02, 1.15)
Primary language				
English	80.7 (131,960)	81.0 (118,276)	78.2 (13,684)	Reference
French	2.9 (4,806)	2.9 (4,291)	2.9 (515)	1.03 (0.94, 1.14)
Other	16.4 (26,761)	16.1 (23,462)	18.9 (3,299)	1.22 (1.17, 1.27)
Activities of Daily Living (ADL) Self-Performance Hierarchy Scale				
No/mild impairment (0-2)	84.8 (138,702)	84.6 (123,579)	86.4 (15,123)	Reference
Moderate/severe impairment (3-6)	15.2 (24,825)	15.4 (22,450)	13.6 (2,375)	0.86 (0.82, 0.91)
Instrumental Activities of Daily Living (IADL) Involvement Scale				
No/mild difficulty (0-13)	47.4 (77,523)	47.4 (69,195)	47.6 (8,328)	Reference
Moderate/severe difficulty (14-21)	52.6 (86,004)	52.6 (76,834)	52.4 (9,170)	0.99 (0.96, 1.03)
Cognitive Performance Scale				
Intact/mild impairment (0-1)	46.7 (76,301)	47.0 (68,661)	43.7 (7,640)	Reference
Moderate/severe impairment (2-6)	53.3 (87,208)	53.0 (77,353)	56.3 (9,855)	1.15 (1.10, 1.18)
Pain Scale				
No pain/less than daily pain (0-1)	49.6 (81,067)	50.3 (73,377)	44.0 (7,690)	Reference

The Relationship Between Caregiver Burden and Depression

Characteristic	All (n =163,527)	Did not develop new depressive symptoms (n =146,029)	Developed new depressive symptoms (n = 17,498)	Unadjusted OR (95% CI)
		% (n)		
Daily/severe pain (2-3)	50.4 (82,459)	49.7 (72,651)	56.0 (9,808)	1.29 (1.25, 1.33)
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale				
Mild/moderate health instability (0-1)	61.4 (98,441)	62.0 (88,773)	56.5 (9,668)	Reference
Severe health instability (2-5)	38.6 (61,806)	38.0 (54,367)	43.5 (7,439)	1.26 (1.22, 1.30)

The Relationship Between Caregiver Burden and Depression

Table 2: Comparison of characteristics of the primary caregiver for clients with and without the development of incident depression

Characteristic	All (n =163,526)	Did not develop new depressive symptoms (n =146,028)	Developed new depressive symptoms (n = 17,498)	Unadjusted OR (95% CI)
		% (n)		
Primary caregiver lives with the client				
No	49.3 (79,204)	49.5 (71,058)	47.4 (8,146)	Reference
Yes	50.7 (81,595)	50.5 (72,544)	52.6 (9,051)	1.09 (1.05, 1.12)
Primary caregiver's relationship to client				
Other relative	8.2 (13,105)	8.3 (11,865)	7.2 (1,240)	Reference
Spouse	30.1 (48,438)	29.9 (42,967)	31.8 (5,471)	1.21 (1.14, 1.30)
Child/child-in-law	56.0 (90,067)	56.0 (80,488)	55.7 (9,579)	1.14 (1.07, 1.20)
Friend/neighbor	5.7 (9,219)	5.8 (8,309)	5.3 (910)	1.05 (0.96, 1.14)
Support provided by the primary caregiver				
Primary caregiver provides emotional support				
No	52.0 (83,689)	51.8 (74,475)	53.6 (9,214)	Reference
Yes	48.0 (77,136)	48.2 (69,150)	46.4 (7,986)	0.93 (0.90, 0.96)
Primary caregiver provides IADL support				
No	61.9 (99,622)	61.8 (88,711)	63.4 (10,911)	Reference
Yes	38.1 (61,203)	38.2 (54,914)	36.6 (6,289)	0.93 (0.90, 0.96)
Primary caregiver provides ADL support				
No	76.8 (123,539)	76.7 (110,181)	77.7 (13,358)	Reference
Yes	23.2 (37,286)	23.3 (33,444)	22.3 (3,842)	0.95 (0.91, 0.98)
Primary caregiver status				
Primary caregiver feels they are unable to continue providing care				
No	90.8 (148,472)	91.0 (132,908)	89.0 (15,564)	Reference
Yes	9.2 (15,055)	9.0 (13,121)	11.0 (1,934)	1.26 (1.20, 1.32)
Primary caregiver is not satisfied with the supports they are receiving				
No	96.8 (158,291)	96.9 (141,537)	95.8 (16,754)	Reference
Yes	3.2 (5,236)	3.1 (4,492)	4.2 (744)	1.40 (1.29, 1.52)
Primary caregiver expresses feelings of distress, anger or depression				
No	82.6 (135,099)	83.3 (121,564)	77.4 (13,535)	Reference
Yes	17.4 (28,428)	16.7 (24,465)	22.6 (3,963)	1.45 (1.40, 1.51)
Informal hours of care in the last 7 days				
13 hours or less	62.1 (101,591)	62.4 (91,042)	60.3 (10,549)	Reference
Greater than 14 hours	37.9 (61,936)	37.6 (54,987)	39.7 (6,949)	1.09 (1.06, 1.13)

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Table 3: Multivariate logistic regression model examining potential risk factors associated with incident depression

Variables in model	Adjusted OR (95 % CI)
Age	
65-74	Reference
75-84	0.93 (0.89, 0.97)
85+	0.78 (0.74, 0.82)
Gender	
Male	Reference
Female	1.29 (1.24, 1.33)
Marital status	
Married	Reference
Never married	0.71 (0.65, 0.78)
Widowed/separated/divorced	0.87 (0.83, 0.90)
Other	0.91 (0.76, 1.09)
Language	
English	Reference
French	1.02 (0.92, 1.12)
Other	1.18 (1.13, 1.23)
Pain Scale	
No pain/less than daily pain	Reference
Daily/severe pain	1.25 (1.21, 1.29)
CHESS scale	
No health instability	Reference
Severe health instability	1.20 (1.16, 1.24)
Caregiver experiences feelings of distress, anger or depression	
No	Reference
Yes	1.41 (1.35, 1.46)