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8 **Predicting psychological distress of informal carers of individuals with major**
9 **depression or bipolar disorder**

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21 **ABSTRACT**

22 Caring for someone with a mental illness is associated with high levels of burden and
23 psychological distress. Understanding these factors could be important to prevent the
24 development of physical and mental health problems in carers. The purpose of the present
25 study was to determine the contribution of coping styles and social support in predicting the
26 psychological distress reported by informal carers (IC) of individuals with major depression or
27 bipolar disorder. IC ($n = 72$) of adults with a diagnosed depressive illness were recruited from
28 mental health organizations within the community setting. Carers completed the General
29 Health Questionnaire, Brief COPE, and Social Support Questionnaire. Multiple linear
30 regression analysis revealed that 63% of the variance in psychological distress could be
31 accounted for by adaptive and maladaptive coping styles and perceived quantity and
32 satisfaction with social support. Satisfaction with social support ($\beta = -0.508$, $P < 0.001$) and
33 maladaptive coping ($\beta = 0.369$; $P < 0.001$) were significant predictors of psychological
34 distress. These findings suggest that interventions should consider coping styles, specifically

35 the interaction between maladaptive behaviours and enhancement of quality of support, to
36 assist carers to manage psychological distress, especially earlier in the caring role.

37

38 **KEY WORDS:** coping behaviour, carer, depression, social support.

39

40 **INTRODUCTION**

41 Depression is a leading contributor to the global burden of disease (Mey et al., 2014),
42 affecting approximately 350 million individuals across the world (WHO, 2016). Depression is
43 a mood disorder that exists as two distinct affective disorders, unipolar depression and
44 bipolar depression, which express similarities in terms of their low mood states and common
45 treatment strategies (Rastelli et al., 2013; Rogers & Agius, 2012). These mood disorders
46 greatly contribute to the medical and financial strain placed on the National Health Service
47 (McCrone et al., 2008; Simon, 2003). They have a negative impact not only on the individual
48 but also on partners, friends, and family members involved in their care (Crowe & Lyness,
49 2013; Grover et al., 2012; Johnson, 2000; Stjernswärd & Östman, 2008). Individuals who
50 provide this care voluntarily, regularly, and outside of the umbrella of primary care are
51 considered 'informal carers' (IC) (Goodwin & Happell, 2007; Lawn & McMahon, 2014). Being
52 an IC of someone with mental illness is associated with high levels of burden (Chambers et
53 al., 2001; Grover et al., 2012; Stjernswärd & Östman, 2008) and psychological distress
54 (Crombie et al., 2007; Holmes & Deb, 2003; Östman & Hansson, 2004; Shah et al., 2010).
55 Researchers have argued that caring for individuals with depressive mood disorders carries
56 significantly greater burden and distress in comparison to various other physical illnesses
57 (Ogilvie et al., 2005). This could be due to a complexity of such conditions as a result of their
58 varied, intense, and intangible emotions, states which are invisible to the human eye
59 (Molyneaux et al., 2011) that could result in disagreements between carers and medical
60 professionals. The variability of mood disorders over time means carers are often forced to
61 adapt their role without guidance or advice (Chambers et al., 2001; Rosenwax et al., 2014;
62 Schulze & Rossler, 2005; Winefield, 2000), and experience emotional and physical
63 exhaustion (Chambers et al., 2001; Jardim & Pakenham, 2010), frustration, resentment, and
64 anger (Spangenberg & Theron, 1999; Weimand et al., 2013), and a moral obligation to
65 provide constant support (Grover et al., 2012; Östman et al., 2005; Weimand et al., 2013).
66 Evidence shows IC to be at high risk of developing depression (Wittmund et al., 2002; Song
67 & Singer, 2006), although studies suggest coping style and social support to be important
68 mediators in their well-being.

69 Coping is a complex, multidimensional process that involves managing cognitive and
70 behavioural process to meet the internal and external demands of stressful situations
71 (Folkman & Moskowitz, 2004). IC are routinely forced to cope with stressful, challenging, and
72 unpredictable situations (Mackay & Pakenham, 2011; Weimand et al., 2013), and must deal
73 with these situations while regulating their own emotions (Folkman et al., 1986). This greatly
74 impacts their perceived capability to meet the demands of the caring situation (Carter, 2002).
75 Coping styles can generally be classified to be maladaptive or adaptive (Carver; 1997; Moore
76 et al., 2011; Thompson et al., 2010). Adaptive coping styles refer to those that are
77 constructive and increase an individual's ability to deal with the demands of a stressful
78 situation, while maladaptive coping refers to negative and dysfunctional methods that
79 increase stress and fail to improve an individual's ability to manage the demands of the
80 situation (Lazarus, 1999; Zeidner & Endler, 1996). Adaptive coping is more likely to result in
81 positive outcomes and enhance functioning; for example, active coping, positive reframing,
82 planning, humour, acceptance, religion, and the use of emotional and instrumental support
83 (Carver, 1997; Carver et al., 1989). Conversely, while offering temporary relief to the
84 stressor, maladaptive coping typically decreases functioning; for example, wishful thinking,
85 emotional withdrawal, avoidance and substance abuse use.

86 The coping style employed is strongly influenced by how the individual appraises the
87 situation (Lazarus & Folkman, 1984). Vasudeva et al. (2013) observed more maladaptive
88 coping styles in IC of patients with schizophrenia and bipolar disorder when the burden of
89 caregiving was reportedly greater. Mackay and Pakenham (2011) found carers who tended
90 to use maladaptive coping styles had poorer general health and experienced greater distress
91 than those who use more adaptive coping styles. This suggests that adaptive coping styles
92 can assist to alleviate psychological distress faced by carers in a constructive manner, while
93 maladaptive styles are problematic (Alpert, 2014; Kartalova-O'Doherty & Doherty, 2008).

94 Social support can act as a form of adaptive coping (Rees, 2007), and theoretically
95 takes four distinct forms: informational, tangible, esteem, and emotional support (Rees &
96 Hardy, 2000). For example, seeking social support, including one or more of these forms, is
97 considered an adaptive form of coping (Saunders, 2003; Song & Singer, 2006; Thoits, 1986).
98 Many IC report insufficient support and are unsure of how to obtain more (Douma et al.,
99 2006), with lower levels being associated with maladaptive coping styles (Coomber & King,
100 2012) and high levels of psychological distress (Wijndaele et al., 2007). Enhancing
101 perceptions of social support has proved effective in ameliorating the burden faced by carers
102 in the context of caring for an individual with an eating disorder (Coomber & King, 2012;

103 Raenker et al., 2013), and therefore, provides a strong case for IC of individuals with
104 depressive illnesses.

105 The caring literature has previously focussed on the IC role of patients with cancer
106 (Thomas et al., 2002), dementia (Gilliam & Steffen, 2006), Alzheimer's disease (Cooper et
107 al., 2008), Parkinson's disease (McLaughlin et al., 2011) stroke survivors (Greenwood et al.,
108 2009; McGurk et al., 2011) and in a broad spectrum of mental illnesses (Kartalova-O'Doherty
109 & Doherty, 2008; Mackay & Pakenham, 2011). Although mental illnesses have similarities,
110 every mental illness is different and will occur along a continuum of severity. Therefore,
111 caution must be taken when generalizing coping styles and social support of carers with
112 different conditions (Peterson, 2009). To the best of our knowledge, no studies have
113 attempted to examine the psychological distress of IC of individuals with depressive
114 illnesses. Specifically, a lack of research exists examining the experiences of IC within
115 voluntary third-sector organizations. These are non-governmental, non-for-profit
116 organizations consisting of charity, voluntary, and community alliances. Understanding how
117 best to support these carers is vital in assisting mental health practitioners in order to prevent
118 the development of physical and mental health problems, as they provide fundamental
119 support essential in improving the well-being and the treatment and recovery of the affected
120 individual (Kartalova-O'Doherty & Doherty, 2008; Winefiled, 2000). The consideration of how
121 the duration of care influences carer psychological distress has also been somewhat
122 overlooked in previous studies. Consequently, the purpose of the present study was to
123 determine the contributions of coping styles and social support to the psychological distress
124 reported by IC of individuals, specifically with major depression or bipolar disorder, recruited
125 from voluntary third-sector organizations. It was hypothesized that carer psychological
126 distress was linked to predominantly maladaptive coping styles being used, in combination
127 with lower levels of satisfaction with the support they are receiving.

128

129 **METHOD**

130 **Participants**

131 A quantitative, cross-sectional design was adopted to assess the psychological distress,
132 coping styles, and social support of IC. A total of 72 IC (F = 51) of adults with a depressive
133 illness were recruited from third-sector mental health organizations throughout England and
134 Wales, such as Depression Alliance and Rethink Mental Illness. These carers do not have
135 access to coping and social support services as they would in a clinical settings within
136 England and Wales, where support services are embedded within patient treatment plans.

137 Inclusion criteria were: (i) carer of a person with a diagnosed depressive illness (major
138 depression $n = 53$, bipolar disorder $n = 19$); (ii) well-established caring role; minimum of
139 1 year in role, through familial tie and/or cohabitation; and (iii) aged 18 years or over. The
140 majority of carers were over the age of 40 years (61%), and 74% currently lived with the
141 person they cared for. Participants failing to meet the inclusion requirements were excluded
142 from analysis (Table 1).

143 **Instrumentation**

144 A questionnaire was chosen to gain knowledge and understanding, while avoiding sensitive
145 conversation topics so respondent anonymity was maintained. The questionnaire
146 administered obtained descriptive information, including age, sex, and duration of caring role.
147 The details obtained were limited to those required to confirm that the inclusion criteria were
148 met and ensuring participant anonymity, as required by the university ethics committee. The
149 General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988) was used to identify
150 poorer health and perceived psychological distress. Those reporting a score of >15 indicated
151 that the participant experienced some psychological distress, and a core >20 indicated
152 severe problems and psychological distress (Goldberg & Williams, 1988). Coping styles were
153 measured using the Brief COPE (Carver, 1997), a 28-item questionnaire addressing adaptive
154 (problem-focussed) or maladaptive (dysfunctional) forms of coping, with respondents rating
155 each item according to those they use. The Social Support Questionnaire-6 (SSQ6) (Sarason
156 et al., 1987) assesses an individual's perception of the quantity of social support (QSS) and
157 satisfaction with social support (SSS) they receive. The shortest versions of these validated
158 questionnaires were used in order to reduce participant burden and enhance response rates.
159 Cronbach's alphas for the questionnaires and subscales in the current study were 0.93
160 (GHQ-12), 0.83 (Brief COPE, adaptive subscale), 0.85 (Brief COPE, maladaptive subscale),
161 0.86 (SSQ6, QSS), and 0.98 (SSQ6, SSS), respectively, ranging from acceptable to high
162 (Nunnally, 1978).

163 **Procedure**

164 Following ethical approval from the university ethics committee, mental health organizations
165 ($n = 12$) were contacted. The procedures used are shown in Figure 1. The proposed study
166 was put forward to the organizations' executives, where suitability to their service users was
167 considered, relevant subgroups were contacted, and information regarding the proposed
168 research was disclosed. To ensure data protection and anonymity, as required by the
169 university ethics committee, the organizations were the principle controllers; they had access
170 to the populations sampled in terms of questionnaire distribution and collection. All service

171 users of these organizations were free to engage or not engage at their own discretion
172 (Gillham, 2008). Response rates varied considerably across organizations; however, due to
173 anonymity requirements, the actual numbers of individuals per organization was unknown. All
174 participants were provided with study information sheets, and signed consent forms (Fig. 1).

175 **Data analysis**

176 Statistical analysis was conducted using SPSS version 20 (SPSS, Chicago, IL, USA).
177 Distributions for all scales, except SSS (skewness = -0.992, kurtosis = -0.372), were
178 acceptable. Transformation of this variable yielded similar outcomes, and so the use of the
179 original variable was deemed appropriate due to issues with transformed data (Tabachnick &
180 Fidell, 2013). The tolerance value and the variance inflation factor (VIF) showed no issues of
181 multicollinearity (tolerance >0.10, VIF <10), and a linear relationship was evident. A review of
182 the Mahalanobis distances revealed no outliers above the critical value, as specified by
183 Tabachnick and Fidell, (2013). While casewise diagnostics revealed one case to be below
184 the standard residual value of -3.0 (-3.165), the Cook's distance was below 1.0 (0.82),
185 indicating little impact on the overall regression. Correlations between psychological distress,
186 duration of carer role, and sufferers' age were performed. Multiple linear regression analysis
187 identified the variables that contributed to the level of psychological distress of carers.
188 Variables were deemed significant if they $P < 0.05$ (Pallant, 2008). Partial correlations
189 controlling for duration of support were also conducted.

190

191 **RESULTS**

192 Descriptive statistics of each of the independent and predictor variables are presented in
193 Table 1. While some variables achieved midpoint mean values on the scales, maladaptive
194 coping styles tended towards the lower end of the scale, and SSS tended towards the upper
195 limit. The latter was also higher than the QSS, although the distributions were similar.

196 Results of the regression analysis are presented in Table 2. The overall model revealed that
197 63% of the variance in psychological distress was accounted for by the coping and social
198 support variables (adjusted $R^2 = 0.63$, $F(4,67) = 30.87$, $P < 0.001$). SSS was the strongest
199 contributor to the model ($\beta = -0.508$), being inversely related and accounting for 25% of the
200 total variance in psychological distress. Maladaptive coping styles were positively related to
201 psychological distress, accounting for 14% of the total variance. The significant beta value for
202 SSS indicated that for every one-point decrease in SSS, there was a 0.5 increase in
203 psychological distress. Conversely, for every one-point increase in maladaptive coping, there

204 was a 0.37 increase in psychological distress. Adaptive coping styles and QSS failed to
205 make a significant contribution to the model.

206 To test for the effect of duration of carer role, a Pearson correlation was performed with
207 psychological distress, which revealed a significant negative relationship ($r = -0.25$,
208 $P < 0.05$). The analysis, using standard multiple linear regression, was repeated to introduce
209 and control for this 'unexpected' outcome, and revealed no substantive change in the overall
210 model or the principle predictors: maladaptive coping styles and SSS.

211

212 **DISCUSSION**

213 The purpose of the present study was to determine the contribution of coping styles
214 and social support in predicting the psychological distress reported by IC of individuals with
215 major depression or bipolar disorder obtained through third-sector voluntary organizations.
216 Importantly, consideration of the duration of caring role was made. In line with previous work
217 (Crombie et al., 2007; Holmes & Deb, 2003; Östman & Hansson, 2004), caring for someone
218 with a mental illness was associated with a tendency for higher levels of psychological
219 distress, evidenced by 46% of the sample meeting the criteria of either psychological distress
220 (scores between 15 and 20, 23%) or severe problems and psychological distress (scores
221 >20 , 23%). This is a greater proportion than would be expected in a general population
222 sample, where psychological distress is thought to affect between 5% and 27% of adults
223 (Drapeau et al., 2012), and mental illness affects approximately 25% of adults each year
224 (Mental Health Foundation, 2016). It was noted that 74% of this sample resided with the
225 person they cared for, and this could explain the higher levels of psychological distress
226 observed. Increased respite care could act as a buffer for IC who reside with the person they
227 support (Jardim & Pakenham, 2010), although this was not explored in the current study.

228 **Maladaptive coping styles**

229 Results of the regression analysis revealed maladaptive coping styles to be a
230 significant predictor of increased psychological distress, which is in agreement with the
231 findings of other published studies (Coomber & King, 2012; Kartalova-O'Doherty & Doherty,
232 2008; Mackay & Pakenham, 2011). Mackay and Pakenham (2011) found that IC ($n = 87$) of
233 individuals with non-specific mental illnesses, who relied on predominantly maladaptive
234 coping styles, had poorer general health and experienced greater psychological distress.
235 Maladaptive coping has also been found to be associated with higher levels of psychological
236 distress in IC of those with an eating disorder (Coomber & King, 2012). Caring is based on
237 the individual's perceived competency to meet the demands of the situation (Carter, 2002;

238 Trouillet et al., 2011), and the coping style employed is influenced to a certain extent by the
239 carer's ability to deal with the problem and regulate their emotions (Lazarus & Folkman,
240 1984). Lazarus (1999) acknowledged that coping is likely to be highly ineffective in situations
241 of high stress, and so carers' use of maladaptive coping styles could be a combination of the
242 challenging and highly-stressful caring role, and the perception that they were unable to meet
243 the demands of their caring situation (Mackay & Pakenham, 2011; Weimand et al., 2013),
244 while also seeking a form of short-term relief. The significant contribution of maladaptive
245 coping styles to increased carer psychological distress could be due to carers having entered
246 into their caring role unprepared (Mackay & Pakenham, 2011), and so have to 'get on with it'
247 and learn to cope through trial and error methods as situations arise (Chambers et al., 2001;
248 Cree, 2003; Kartalova-O'Doherty & Doherty, 2008). However, the question of cause and
249 effect, specifically whether the psychological distress triggers maladaptive coping or the latter
250 increases subsequent distress, remains unclear from the data, and would require
251 consideration through longitudinal studies.

252 **Adaptive coping styles**

253 In contrast, and in line with previous research (Pakenham et al., 2007; Song & Singer,
254 2006), adaptive coping styles were not related to reduced carer psychological distress. Song
255 and Singer (2006) observed that adaptive coping styles (in particular, approach coping) failed
256 to significantly predict a reduction in depressive symptoms of family carers ($n = 351$).
257 Furthermore, Pakenham *et al.* (2007) considered how adaptive coping styles, such as
258 acceptance, problem solving, and seeking social support, could predict global distress, where
259 all adaptive methods failed to be significant contributors. According to Folkman and Mosowitz
260 (2004), a carer's use of adaptive coping styles will not necessarily lead to a permanent
261 resolution of the problem, which could account for the disconnect between adaptive coping
262 styles and psychological distress in the current study.

263 **Social support**

264 Although QSS and SSS were both negatively associated with psychological distress,
265 the regression analysis revealed only the latter to be a significant predictor. SSS was the
266 strongest significant predictor in the model of the psychological distress faced by IC
267 supporting an individual with a depressive illness. The findings of the present study are
268 consistent with those of other authors; for example, Wijndaele *et al.* (2007) observed overall
269 social support to be negatively associated with perceived levels of distress. Greater SSS has
270 also been associated with significantly lower levels of distress in IC ($n = 101$) of adults with
271 mental illness (Mackay & Pakenham, 2011). This might be due to the strong stress-buffering

272 effects social support has as a valuable coping resource (Rees, 2007; Song & Singer, 2006).
273 Furthermore, Pakenham *et al.* (2007) found that a large social support network (QSS) failed
274 to significantly predict global distress in young carers. The lack of significance may be
275 explained as carers who receive support from various support groups are also reported to
276 have smaller social networks (Mannion *et al.*, 1996), indicating they possess few local
277 contacts. The reasons for smaller local support groups include circumstances that limit free
278 time and the availability of other similar IC, due to a trend towards becoming reclusive and
279 friends becoming dismissive or unavailable (Chambers *et al.*, 2001; Stjernswärd & Östman,
280 2008).

281 When the level of SSS, as perceived by the recipient, is high, this could protect
282 against raised psychological distress, and thus, they would not necessarily look to seek
283 additional support. Those with low SSS might seek to enhance this, but personal and
284 environmental constraints could limit opportunities. In addition, the establishment of satisfying
285 sources of support might require a longer timeframe commitment. However, these findings
286 are in contrast to Song and Singer's (2,006) where no relationship was found between social
287 support and carers' depressive symptoms, and also Coomber and King's (2012), where SSS
288 did not contribute to the prediction of psychological distress of IC of individuals with eating
289 disorders. Various reasons could exist for these differences: illness of patient, age of sample,
290 the recruitment strategy and/or the current sample being limited to the voluntary third sector. .
291 Previous studies have included individuals from numerous environments, such as
292 educational institutes and clinical settings, where various forms of social support could be
293 more accessible and plentiful. Social support was also measured using three subscales:
294 instrumental, emotional, and satisfaction with social support, over a longer, 1-year timeframe
295 (Song & Singer 2006). Future studies that provide an in-depth understanding of this dynamic,
296 as well as the distinct forms of social support, as proposed by Rees and Hardy (2000)
297 (informational, tangible, esteem, and emotional), are required.

298 **Duration of care**

299 Duration of the caring role showed a weak, negative relationship with psychological
300 distress, suggesting lower levels in those who have been in the role for longer periods. In
301 contrast, Hirst (2005) reported a positive relationship between duration of care and higher
302 levels of distress, although the nature of the sample, accuracy in recall, and response bias
303 cannot be excluded as possible explanations for this difference. When the duration of the
304 caring role was introduced into the model, little change was observed in the importance of
305 SSS and maladaptive coping in their predictive effect on psychological distress. This

306 indicated that efforts to achieve enhanced SSS and recognition of maladaptive coping
307 strategies could be useful to all carers, irrespective of the length of time they have been in
308 the role.

309 **Strengths and limitations**

310 The main strength of the present study was that it has explored psychological distress,
311 coping and social support in a group of individuals who play a vital role in the support and
312 care of people with depression, recruited exclusively through the voluntary sector. To the
313 best of our knowledge, no previous studies assessing IC distress have recruited participants
314 from third-sector voluntary organizations, incorporating a wide range of mental health
315 charities across England and Wales. The inclusion of those carers, from what could be
316 considered an 'invisible population' (Lawn & McMahon, 2014), has allowed insight into the
317 psychological distress they faced away from a clinical inpatient environment, as in previous
318 research, making our study unique. Employing recruitment methods solely from a community
319 setting, although more arduous, could also be regarded as more generalizable to the wider
320 carer community. Finally, a specific group of carers has been considered, as opposed to
321 generalizing mental illness with the inclusion of multiple conditions. This is particularly
322 important, as mental illness varies in nature and severity (Peterson, 2009).

323 Although the present study has a number of strengths, it also has limitations.
324 Engagement of those carers experiencing high levels of psychological distress might be low,
325 as suggested by Lazarus (1999), and this possible effect would need to be explored. The use
326 of mental health organizations to recruit might have excluded those individuals more socially
327 isolated, while including carers receiving some form of related social support. To control for
328 the variety of organizational social support, it could be useful to consider the use of 'within
329 mental health organization' studies, where carers have access to similar social support
330 networks. Additional information on the carer's level of support from, and engagement with,
331 voluntary organizations might be useful for understanding this factor. Likewise, the present
332 study's reliance on third-sector organizations with varied recruitment procedures made a
333 prior response rate difficult to predetermine, and makes replication of this study more difficult.
334 Finally, as the sample in the present study is diverse in terms of participants' age range and
335 the length of time cared for, future research is needed using a larger sample to compensate
336 for the breadth of age groups and length of time cared for.

337 **Implications for practice**

338 As carers are routinely forced to cope with stressful, challenging, and unpredictable
339 situations (Mackay & Pakenham, 2011), a key outcome for clinical practice would be the

340 development of carer-focussed interventions that assist carers to manage their perceptions
341 of psychological distress and those that encourage them to adopt a variety of coping styles
342 (Tennakoon et al., 2000) that they can adapt to their unique carer role (Folkman &
343 Moskowitz, 2004). Further consideration by health-care professionals of the coping profile at
344 a more individual level is important to improve carer health and well-being (Campos et al.,
345 2014). Facilitation of carer support groups would provide carers the opportunity to share their
346 coping experiences and learn from one another through peer support (Campos et al., 2014;
347 Stjernswärd & Östman, 2008). It is important that health practitioners make carers feel
348 supported, as by doing so, carers are more likely to trust the decisions made (Ayra, 2014).
349 Confiding in and sharing experiences with other carers with similar caregiving experiences
350 are invaluable forms of quality social support (Chambers et al., 2001; Weimand et al., 2013),
351 offering carers an alternative understanding of how to cope with the demands of their caring
352 role (Chen & Greenberg, 2004). In addition, QSS has the potential to result in more
353 successful patient recovery (Chambers et al., 2001; Moore et al., 2011), lessening demands
354 on health-care systems (Hill et al., 2007; Van Exel et al., 2007). It will also assist in
355 preventing carers themselves from falling ill (Stjernswärd & Östman, 2008). In light of this
356 sample, the data suggest that interventions should be applied soon after the initiation of the
357 caring role and that they continue in the long term through various avenues. These might
358 include education; small, local, IC groups; referral to voluntary sector organizations; and
359 clinically-led carer support groups, with an emphasis on providing quality support, as judged
360 by the carer.

361 **Conclusion**

362 In summary, SSS and maladaptive coping styles interact with the level of
363 psychological distress experienced by carers of depressed individuals. Strategies to enhance
364 SSS would seem logical to reduce distress, although changing maladaptive coping styles
365 might be more complicated because of its cause-and-effect dynamic with psychological
366 distress, and because maladaptive coping styles for some individuals might prove 'adaptive'
367 for others. The cross-sectional design of the present study suggests that the interaction
368 between these variables plays an important role in carers' mental well-being, and this
369 understanding needs to be extended in a variety of ways. Future research should implement
370 and test the effect of coping style modification and social support strategies on the
371 psychological well-being of IC. Further development of this work to understand the
372 individual's experiences over time would be an important step in the understanding of carers'
373 psychological distress, social support, and use of maladaptive and adaptive coping styles.

374

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378

379 **REFERENCES**

380 Alpert, P.T. (2014). Who's caring for the caregiver? *Home Health Care Management &*
381 *Practice*, 26(4), 266-268.

382
383 Ayra, D.K. (2014). Role of family carers in compulsory mental health treatment. *International*
384 *Journal of Social Psychiatry*, 60(1), 3-5.

385
386 Campos, F.A.L., Sousa, A.R.P.D., Rodrigues, V.P.D.C., Marques, A.J.P.D.S., Dores,
387 A.A.M.D.R. & Queirós, C.M.L. (2014). Peer support for people with mental illness. *Revista de*
388 *Psiquiatria Clínica*, 41(2), 49-55

389
390 Carter, P.A. (2002). Caregivers' descriptions of sleep changes and depressive symptoms.
391 *Oncology Nursing Forum*, 29(9), 1277-1283.

392
393 Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the
394 brief cope. *International Journal of Behavioral Medicine*, 4(1), 92-100.

395
396 Carver, C.S., Scheier, M.F. & Weintraub, J.K. (1989). Assessing coping strategies: A
397 theoretically based approach. *Journal of Personality & Social Psychology*, 56(2), 267-283.

398
399 Chambers, M., Ryan, A.A. & Connor, S.L. (2001). Exploring the emotional support needs and
400 coping strategies of family carers. *Journal of Psychiatric & Mental Health Nursing*, 8(2), 99-
401 106.

402
403 Chen, F.P. & Greenberg, J.S. (2004). A positive aspect of caregiving: The influence of social
404 support on caregiving gains for family members of relatives with schizophrenia. *Community*
405 *Mental Health Journal*, 40(5), 423-435.

406
407 Coomber, K. & King, R.M. (2012). Coping strategies and social support as predictors and
408 mediators of eating disorder carer burden and psychological distress. *Social Psychiatry &*
409 *Psychiatric Epidemiology*, 47(5), 789-796.

410

411 Cooper, C., Katona, C., Orrell, M. & Livingston, G. (2008). Coping strategies, anxiety and
412 depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric*
413 *Psychiatry*, 23(9), 929-936.

414

415 Cree, V.E. (2003). Worries and problems of young carers: Issues for mental health. *Child &*
416 *Family Social Work*, 8(4), 301-309.

417

418 Crombie, I., Irvine, L., Elliott, L. & Wallace, H. (2007). Carers of people with mental health
419 problems: Proposals embodied in current public mental health policy in nine countries.
420 *Journal of Public Health*, 28, 465-481.

421

422 Crowe, A. & Lyness, K.P. (2013). Family functioning, coping, and distress in families with
423 serious mental illness. *The Family Journal*, 22(2), 186-197.

424

425 Douma, J.C.H., Dekker, M.C. & Koot, H.M. (2006). Supporting parents of youths with
426 intellectual disabilities and psychopathology. *Journal of Intellectual Disability Research*,
427 50(8), 570-581.

428

429 Drapeau A, Marchand A, Beaulieu-Prévost D. (2012). *Epidemiology of Psychological*
430 *Distress*. In: L. L'Abate (Ed.) *Mental Illnesses - Understanding, Prediction and Control*. Rijeka:
431 *In Tech*.

432

433 Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A. & Gruen, R.J. (1986).
434 Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes.
435 *Journal of Personality & Social Psychology*, 50(5), 992-1003.

436

437 Folkman, S. & Moskowitz, J.T. (2004). Coping: Pitfalls and promise. *Annual Review of*
438 *Psychology*, 55(1), 745-774.

439

440 Gillham, N. (2008). *Developing a questionnaire*. (2nd ed.). London: Continuum.

441

442 Gilliam, C.M. & Steffen, A.M. (2006). The relationship between caregiving self-efficacy and
443 depressive symptoms in dementia family caregivers. *Aging & Mental Health*, 10(2), 79-86.

444

445 Goldberg, D. & Williams, P. (1988). *A user's guide to the General Health Questionnaire*.
446 Slough: NFER-Nelson.

447

448 Goodwin, V. & Happell, B. (2007). Consumer and carer participation in mental health care:
449 The carer's perspective: Part 2- barriers to effective and genuine participation. *Issues in*
450 *Mental Health Nursing*, 28(6), 625-638.

451

452 Greenwood, N., Mackenzie, A., Cloud, G.C. & Wilson, N. (2009). Informal primary carers of
453 stroke survivors living at home-challenges, satisfactions and coping: A systematic review of
454 qualitative studies. *Disability & Rehabilitation*, 31(5), 337-351.

455

456 Grover, S., Chakrabarti, S., Aggarwal, M., et al. (2012). Comparative study of the experience
457 of caregiving in bipolar affective disorder and schizophrenia. *International Journal of Social*
458 *Psychiatry*, 58(6), 614-622.

459

460 Hill, K., Smith, R., Fearn, M., Rydberg, M. & Oliphant, R. (2007). Physical and psychological
461 outcomes of a supported physical activity program for older carers. *Journal of Aging &*
462 *Physical Activity*, 15(3), 257-271.

463

464 Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science and*
465 *Medicine*, 61(3), 697-708.

466

467 Holmes, A.M. & Deb, P. (2003). The effect of chronic illness on the psychological health of
468 family members. *Journal of Mental Health Policy & Economics*, 6(1), 13-22.

469

470 Janney, C.A., Fagiolini, A., Swartz, H.A., et al. (2014). Are adults with bipolar disorder active?
471 Objectively measured physical activity and sedentary behavior using accelerometry. *Journal*
472 *of Affective Disorders*, 152, 498-504.

473

474 Jardim, C. & Pakenham, K. (2010). Carers of adults with mental illness: Comparison of
475 respite care users and non-users. *Australian Psychologist*, 45(1), 50-58.

476

477 Johnson, E.D. (2000). Differences among families coping with serious mental illness: A
478 qualitative analysis. *American Journal of Orthopsychiatry*, 70(1), 126-134.

479
480 Kartalova-O'Doherty, Y. & Doherty, D.T. (2008). Coping strategies and styles of family carers
481 of persons with enduring mental illness: A mixed methods analysis. *Scandinavian Journal of*
482 *Caring Sciences*, 22(1), 19-28.
483
484 Lawn, S. & McMahon, J. (2014). The importance of relationship in understanding the
485 experiences of spouse mental health carers. *Qualitative Health Research*, 24(2), 254-266.
486
487 Lazarus, R.S. (1999). *Stress and emotion: A new synthesis*. London: Springer.
488
489 Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
490
491 Mackay, C. & Pakenham, K.I. (2011). Identification of stress and coping risk and protective
492 factors associated with changes in adjustment to caring for an adult with mental illness.
493 *Journal of Clinical Psychology*, 67(10), 1064-1079.
494
495 Mannion, E., Meisel, M., Solomon, P., & Draine, J. (1996). A comparative analysis of families
496 with mentally ill adult relatives: Support group members versus non-members. *Psychiatric*
497 *Rehabilitation Journal*, 20(1), 43-50.
498
499 McCrone, P., Dhanasiri, S., Patel, A., Knapp, M. & Lawton-Smith, S. (2008). *Paying the*
500 *price: The cost of mental health care in England to 2026*. London: King's Fund.
501
502 McGurk, R., Kneebone, I.I. & Pitten-Cate, I.M. (2011). 'Sometimes we get it wrong but we
503 keep on trying': A cross-sectional study of coping with communication problems by informal
504 carers of stroke survivors with aphasia. *Aphasiology*, 25(12), 1507-1522.
505
506 McLaughlin, D., Hasson, F., Kernohan, W.G., et al. (2011). Living and coping with
507 Parkinson's disease: Perceptions of informal carers. *Palliative Medicine*, 25(2), 177-182.
508
509 Mental Health Foundation (MHF). (2016). Fundamental Facts About Mental Health
510 <https://www.mentalhealth.org.uk/publications/fundamental-facts-about-mental-health-2015>
511 [Accessed 20 July 2016].
512

513 Mey, A., Fowler, J.L., Knox, K., et al. (2014). Review of community pharmacy staff
514 educational needs for supporting mental health consumers and carers. *Community Mental*
515 *Health Journal*, 50(1), 59-67.

516

517 Molyneaux, V., Butchard, S., Simpson, J. & Murray, C. (2011). Reconsidering the term
518 'carer': A critique of the universal adoption of the term 'carer'. *Ageing and Society*, 31(3),
519 422-437.

520

521 Moore, B.C., Biegel, D.E. & McMahon, T.J. (2011). Maladaptive coping as a mediator of
522 family stress. *Journal of Social Work Practice in the Addictions*, 11(1), 17-39.

523

524 Nunnally, J. (1978). *Psychometric theory*. (2nd ed.). New York: McGraw.

525

526 Ogilvie, A.D., Morant, N. & Goodwin, G.M. (2005). The burden on informal caregivers of
527 people with bipolar disorder. *Bipolar Disorders*, 7(s1), 25-32.

528

529 Östman, M. & Hansson, L. (2004). Appraisal of caregiving, burden and psychological distress
530 in relatives of psychiatric inpatients. *European Psychiatry*, 19(7), 402-407.

531

532 Östman, M., Wallsten, T. & Kjellin, L. (2005). Family burden and relatives' participation in
533 psychiatric care: Are the patient's diagnosis and the relation to the patient of importance?
534 *International Journal of Social Psychiatry*, 51(4), 291-301.

535

536 Pakenham, K.I., Chiu, J., Bursnall, S. & Cannon, T. (2007). Relations between social
537 support, appraisal and coping and both positive and negative outcomes in young carers.
538 *Journal of Health Psychology*, 12(1), 89-102.

539

540 Pallant, J. (2008). *SPSS Survival Manual: a step-by-step guide to data analysis using SPSS*
541 *for Windows (Version 15) Guide to Data Analysis Using SPSS (3rd ed.)*. Milton Keynes:
542 Open University Press.

543

544 Peterson, S.E. (2009). *Mental illness*. In: S. J. Lopez (Ed.) *The encyclopedia of positive*
545 *psychology*. West Sussex: Blackwell.

546

547 Raenker, S., Hibbs, R., Goddard, E., et al. (2013). Caregiving and coping in carers of people
548 with anorexia nervosa admitted for intensive hospital care. *The International Journal of*
549 *Eating Disorders*, 46(4), 346-354.

550

551 Rastelli, C.P.B., Cheng, Y., Weingarden, J., Frank, E. & Swartz, H.A. (2013). Differences
552 between unipolar depression and bipolar II depression in women. *Journal of Affective*
553 *Disorders*, 150(3), 1120-1124.

554

555 Rees, T. (2007). Influences of social support on athletes. In: S. Jowett & D. Lavallee. *Social*
556 *psychology in sport*. Champaign, IL: Human Kinetics.

557

558 Rees, T. & Hardy, L. (2000). An investigation of the social support experiences of high-level
559 sports performers. *The Sport Psychologist*, 14(4), 327-347.

560

561 Rogers, J. & Agius, M. (2012). Bipolar and unipolar depression. *Psychiatria Danubina*, 24(1),
562 100-105.

563

564 Rosenwax, L., Malajczuk, S., & Ciccarelli, M. (2014). Change in carers' activities after the
565 death of their partners. *Supportive Care in Cancer*, 22(3), 619-626.

566

567 Sarason, I.G., Sarason, B.R., Shearin, E.N. & Pierce, G.R. (1987). A brief measure of social
568 support: Practical and theoretical implications. *Journal of Social & Personal Relationships*,
569 4(4), 497-510.

570

571 Saunders, J.C. (2003). Families living with severe mental illness: A literature review. *Issues*
572 *in Mental Health Nursing*, 24(2), 175-198.

573

574 Schulze, B. & Rössler, W. (2005). Caregiver burden in mental illness: Review of
575 measurement, findings and interventions in 2004-2005. *Current Opinion in Psychiatry*, 18(6),
576 684-691.

577

578 Shah, A.J., Wadoo, O. & Latoo, J. (2010). Psychological distress in carers of people with
579 mental disorders. *British Journal of Medical Practitioners*, 3(3), 327-334.

580

581 Simon, G.E. (2003). Social and economic burden of mood disorders. *Biological Psychiatry*,
582 54(3), 208-215.
583

584 Song, L. & Singer, M. (2006). Life stress, social support, coping and depressive symptoms: A
585 comparison between the general population and family caregivers. *International Journal of*
586 *Social Welfare*, 15(2), 172-180.
587

588 Spangenberg, J.J. & Theron, J.C. (1999). Stress and coping strategies in spouses of
589 depressed patients. *The Journal of Psychology*, 133(3), 253-262.
590

591 Stanton, R., Happell, B. & Reaburn, P. (2014). The mental health benefits of regular physical
592 activity, and its role in preventing future depressive illness. *Nursing: Research & Reviews*, 4,
593 45-53.
594

595 Stjernswärd, S. & Östman, M. (2008). Whose life am I living? Relatives living in the shadow
596 of depression. *International Journal of Social Psychiatry*, 54(4), 358-369.
597

598 Tabachnick, B.G. & Fidell, L.S. (2013). *Using multivariate statistics (6th ed.)*. Boston:
599 Pearson.
600

601 Tennakoon, L., Fannon, D., Doku, V., et al. (2000). Experience of caregiving: relatives of
602 people experiencing a first episode of psychosis. *The British Journal of Psychiatry*, 177(6),
603 529-533.
604

605 Thoits, P.A. (1986). Social support as coping assistance. *Journal of Consulting & Clinical*
606 *Psychology*, 54(4), 416-423.
607

608 Thomas, C., Morris, S.M. & Harman, J.C. (2002). Companions through cancer: The care
609 given by informal carers in cancer contexts. *Social Science & Medicine*, 54(4), 529-544.
610

611 Thompson, R.J., Mata, J., Jaeggi, S.M., et al. (2010). Maladaptive coping, adaptive coping,
612 and depressive symptoms: Variations across age and depressive state. *Behaviour Research*
613 *& Therapy*, 48(6), 459-466.
614

615 Trouillet, R., Doan-Van-Hay, L.M., Launay, M. & Martin, S. (2011). Impact of age, and
616 cognitive and coping resources on coping. *Canadian Journal on Aging*, 30(04), 541-550.
617

618 Van Exel, J.V., Graaf, G.D. & Brouwer, W. (2007). Care for a break? An investigation of
619 informal caregivers' attitudes toward respite care using Q-methodology. *Health Policy*, 83(2),
620 332-342.
621

622 Vasudeva, S., Sekhar, C.K., & Rao, P.G. (2013). Caregivers burden of patients with
623 schizophrenia and bipolar disorder: A sectional study. *Indian Journal of Psychological*
624 *Medicine*, 35(4), 352-357.
625

626 Weimand, B.M., Hall-Lord, M.L., Sällström, C. & Hedelin, B. (2013). Life-sharing experiences
627 of relatives of persons with severe mental illness—a phenomenographic study. *Scandinavian*
628 *Journal of Caring Sciences*, 27(1), 99-107.
629

630 Wijndaele, K., Matton, L., Duvigneaud, N., et al. (2007). Association between leisure time
631 physical activity and stress, social support and coping: A cluster-analytical approach.
632 *Psychology of Sport & Exercise*, 8(4), 425-440.
633

634 Winefield, H.R. (2000). Stress reduction for family caregivers in chronic mental illness:
635 Implications of a work stress management perspective. *International Journal of Stress*
636 *Management*, 7(3), 193-207.
637

638 Wittmund, B., Wilms, H.U., Mory, C. & Angermeyer, M.C. (2002). Depressive disorders in
639 spouses of mentally ill patients. *Social Psychiatry & Psychiatric Epidemiology*, 37(4), 177-
640 182.
641

642 World Health Organization (WHO). (2016). *Depression fact sheet* [Online]. Available from:
643 <http://www.who.int/mediacentre/factsheets/fs369/en/>
644 [Accessed 1 May 2016].
645

646 Zeidner, M. & Endler, N.S. (1996). *Handbook of coping: Theory, research, applications* (Vol.
647 195). New York: John Wiley & Sons.
648

649 **TABLE 1:** *Descriptive statistics of carer measures, results are shown as mean (SD) and*
 650 *ranges*

651

| Variable | Mean (SD) | Range |
|-------------------------------------|-------------|-------|
| Age (years) | 43 (17.4) | 18–80 |
| Cohabitation duration (years) | 18.9 (13.9) | 1–53 |
| Support duration (years) | 7.5 (7.9) | 1–36 |
| Psychological distress (GHQ-12) | 16.4 (7.2) | 0–33 |
| Adaptive coping (Brief COPE) | 40.1 (8.1) | 24–62 |
| Maladaptive coping (Brief COPE) | 24.8 (7.4) | 13–44 |
| Quantity of social support (SSQ-6) | 2.4 (1.5) | 0–6 |
| Social support satisfaction (SSQ-6) | 4.5 (1.5) | 1–6 |

652 GHQ-12, General Health Questionnaire; SD, standard deviation; SSQ-6, Social Support
 653 Questionnaire-6.

654

655 **TABLE 2:** *Standard multiple regression analysis for predictor variables on psychological*
 656 *distress*

657

| Model | Unstandardized | | Standardised | <i>t</i> | <i>P</i> -value |
|-----------------------------|----------------|-------|--------------|----------|-----------------|
| | Coefficients | | Coefficients | | |
| | B | SE | β | | |
| (Constant) | 20.167 | 3.716 | | 5.43 | <0.001 |
| Adaptive coping | −0.033 | 0.079 | −0.037 | −0.415 | 0.679 |
| Maladaptive coping | 0.358 | 0.081 | 0.369 | 4.423 | <0.001 |
| Quantity of social support | −0.301 | 0.521 | −0.057 | −0.578 | 0.565 |
| Social support satisfaction | −2.381 | 0.558 | −0.508 | −4.266 | <0.001 |

658 $F(4,67) = 30.87, P < 0.001$. SE, standard error of mean.

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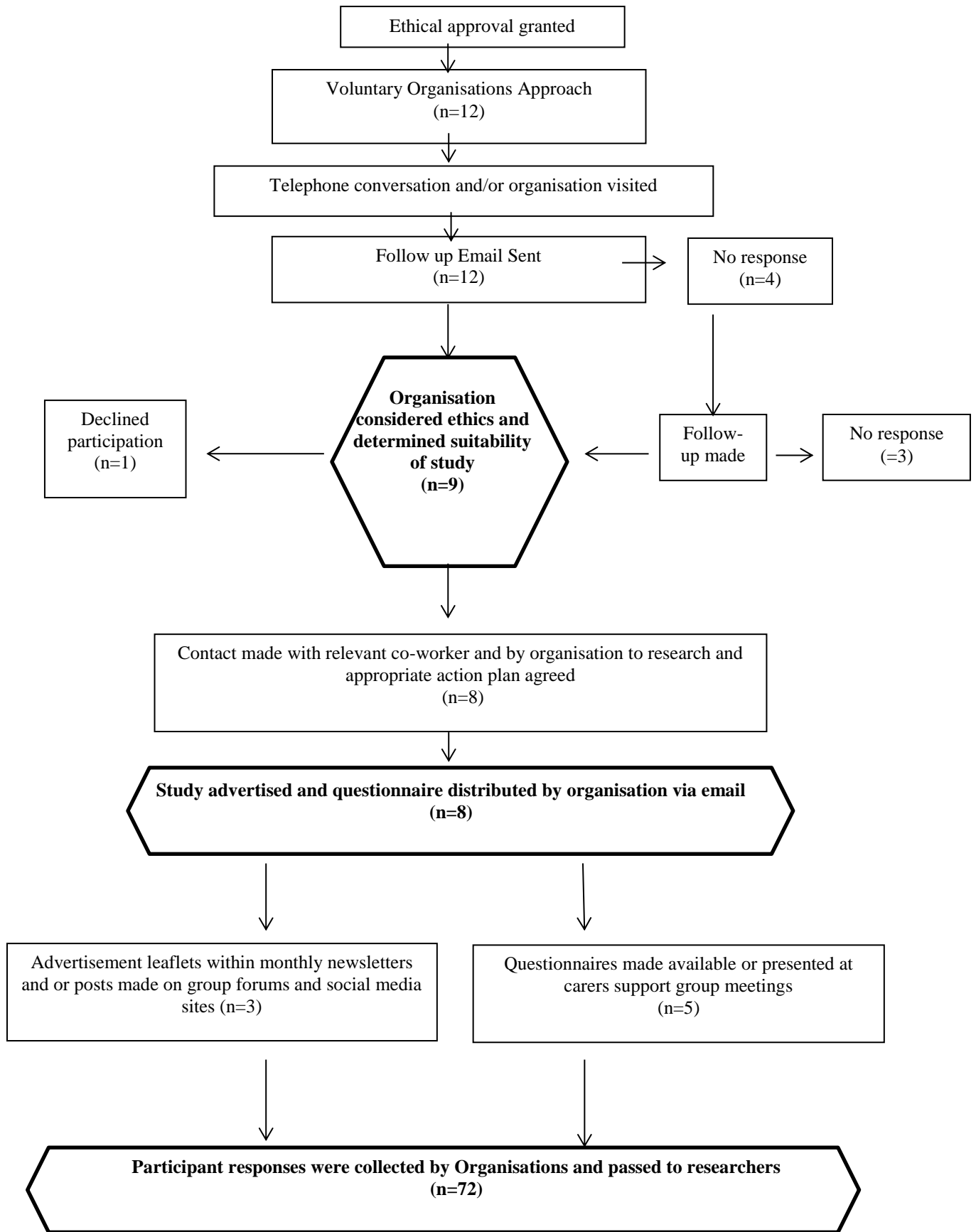


FIG. 1: Process of recruitment of non-for-profit organisations and participants