# Physical and psychological health of family carers co-residing with an adult relative with an intellectual disability

Jillian M. Grey, PhD*, Vasiliki Totsika, PhD+, Richard P. Hastings, PhD+

* DECIPHer, School of Social Sciences, Cardiff University, 1-3 Museum Place, Cardiff CF10 3BD

+Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick, Coventry, CV4 7AL

Address for correspondence:

Jillian M. Grey
DECIPHer
School of Social Sciences
Cardiff University
1-3 Museum Place
Cardiff
CF10 3BD

Tel: +44 (0)29 20 875360; email: Greyj2@cardiff.ac.uk

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## Conflicts of interest

The authors' declare that there is no conflict of interest.

# Abstract

*Background:* Providing long term care to an adult relative with ID can impact negatively on caregivers' health and well-being.

*Methods:* Data were collected via on-line and postal questionnaires on 110 family carers' physical and psychological health, family stress and perceived positive gains from caring. Psychological adaptation and carers' satisfaction with available support were also examined.

*Results:* Study participants reported more health problems than general populations. Higher support needs of care recipients were associated with increased family stress. Carers being female was associated with lower family stress. Older age and better socio-economic position were associated with better psychological outcomes. Other associations were consistent with psychological adaption and perceived helpfulness of support buffering negative outcomes and facilitating positive gains from caring.

*Conclusion:* Family carers of adults with ID appear to experience poorer health outcome than population norms. Adaption to the caregiving role may buffer negative outcomes. Further large scale, population-based, longitudinal research is needed.

A body of evidence exists internationally to suggest that providing care to an adult family member with ID within the family home can have an adverse effect upon carers’ physical and psychological health (Chou, Chiao, & Fu, 2011a; Chou et al., 2011b; Rowbotham et al., 2011; Seltzer et al., 2011; Yamaki et al., 2009). The literature suggests that these carers have a greater propensity to stress, anxiety, depressive symptoms (Burton-Smith et al., 2009; Seltzer et al., 2011) and physical health problems (Seltzer et al., 2011; Yamaki et al., 2009) than non-caregivers. A large-scale study comparing health outcomes of carers of adults with ID with age matched non-caregiving peers (Yamaki et al., 2009), showed that carers were significantly more likely to report experiencing higher rates of arthritis, diabetes, high blood pressure, osteoporosis, cardiovascular diseases, obesity and activity limitation than their non-caregiving peers.

Differing theoretical approaches to family stress and caregiving have been applied in the field of ID research. For example, the ‘wear and tear’ approach (Johnson & Catalano, 1983) suggests that caregiving for an extended period has a detrimental and eroding impact upon health outcomes. More recently, adaptive theories of family stress (McCubbin & Patterson, 1983; Townsend et al., 1989) have been adopted. These theories propose that carers exposed to long-term challenges develop strategies which, combined with available resources, act as potential buffers against the negative impact of providing care. McCubbin and Patterson’s (1983) Double ABCX model of family stress characterises the family as a dynamic and changing system. Families who face a pile-up of stressors which challenge available resources (e.g. support, finances and health) may find their ability to manage an ongoing stressful situation reduced. An ongoing imbalance between stressors and available resources poses a threat to carers’ well-being.

Factors associated with negative outcomes for carer well-being include care recipient having more profound or severe ID and poorer adaptive behaviours (Chou et al., 2010a; Llewellyn et al., 2010), challenging behaviours (Minnes et al., 2007; Walden et al., 2000), the presence of epilepsy (Esbensen et al., 2007; Kerr et al., 2009), socio-economic hardship (Chou et al., 2010b; Eisenhower & Blacher, 2006) and co-residency (Seltzer et al., 2011). Seltzer et al. (2011) compared outcomes for parents with a son or daughter with ID (1) who co-resides with family (2) a non-co-resident group of parents; and (3) a group of age matched non-caregiving peers. They found co-residency to be associated with lower levels of income, less frequent social contact with family and friends, and more physical and psychological problems for carers by mid and later life. Another study exploring health status, social support and quality of life among family carers of adults with profound and multiple disabilities in Taiwan, (Chou et al., 2011a) found positive health outcomes to be associated with a higher education level, being in employment, and higher levels of social support.

Although caregiving is multi-faceted and studies have shown heterogeneity in carers' responses to the demands of providing care (Kim et al., 2003; Minnes et al., 2007), much of the literature has focused on the negative impact of caring (Burton-Smith et al., 2009; Chou et al., 2011a, 2011b; Chou et at., 2010a; Minnes et al., 2007; Yamaki et al., 2009). However, the caregiving environment may also afford families the opportunity for growth and development of skills (Ha et al., 2008; Rowbotham et al., 2011). Evidence suggests that coping strategies adopted by carers (Hayden & Heller, 1997; Kim et al., 2003; Seltzer et al., 2004), and cognitive appraisals of the caregiving situation (Rowbothom et al., 2011) are important factors in moderating the impact of caregiving demands.

Much of what is known about positive gains of caregiving within a UK context is currently derived from studies conducted with parents of children with ID or developmental disorders such as autism (Hastings et al., 2002; Hastings et al., 2005a; Hastings & Taunt, 2002; Jones et al., 2014). To date, there remains a paucity of evidence on the multi-dimensional aspects of providing care to an adult with ID within family homes in the UK.

Whilst evidence suggests support and resources moderate the negative effects of caregiving (Chou et al., 2010a, 2010b; Walden et al., 2000), resources such as financial support, respite and day care services are finite. Therefore, resources are not always available to families, especially in difficult fiscal climates (Cummins, 2001). With recent reforms to the Welfare system within the UK, the rising cost of living and the extra costs associated with providing care, family carers are currently caught in what has been described as ‘the perfect storm’ (Carers UK, 2014). Many older carers continue to provide support, within a changing context. They may be faced with their own age-related decline in health (Bowey & McGlaughlin, 2007; McConkey et al., 2011; Seltzer et al., 2011; Shaw et al., 2011; Taggart et al., 2012), and changing household composition. Adult children without ID leave home and, as carers’ age, they are faced with the potential loss of a spouse (Seltzer et al., 2011; Kim et al., 2003) and decline in their family support network (Carter & McGoldrick, 1989). The aims of this study were, therefore, to 1) examine how the self-reported health of carers co-residing with an adult relative with ID in homes across the UK compares to UK national population norms; 2) examine correlates of carers’ physical and psychological health, taking account of positive and negative aspects of caregiving.

# Method

The study reported in this paper is a cross-sectional survey of family carers of adults with an ID. Potential participants were informed about the study through statutory or voluntary organisations for individuals with ID and/or their carers. Information was collected through either a postal or an online survey. For inclusion in this study, participants needed to be the main carer for an adult relative aged 18 years or over with ID who, at the time of the study, was living in the family home.

## Participants

**Carer characteristics.** Initially, 115 family carers agreed to take part in the study. Of those, 79 (69%) completed the internet version of the survey and 36 (31%) completed the postal survey. Five participants were excluded due to difficulties establishing whether they were caring for a relative in their own home or a large amount of missing data rendered the questionnaire unusable. The final number of participants was $N$ = 110, of whom 18 (16.4%) were male, and 92 (83.6%) were female. Family carers' ages ranged from 24 to 91 years ($M$ = 59.81 years; $SD$ = 12.00). The majority of carers were mothers/step-mothers (73.0%), with other family carers being fathers/stepfathers, siblings, cousins, aunts, uncles, spouses and adult children (see Table 1). Of those who responded to the personal demographic questions, 53 (47.7%) had no to low levels of education and 51 (45.9%) were educated to advanced school level and above. The majority of family carers did not have paid work ($N$ = 73, 65.8%). Over half ($N$ = 60, 54.1%) were married or living with a partner. With the inclusion of adult relatives with ID, the average number of people resident in each household was three (range 2-6 individuals, $SD$ = 0.91).

**Adult relative characteristics.** The age of adult relatives with ID ranged from 18-67 years ($M$ = 34.88, $SD$ = 11.57) with 65 (58.6%) being male and 43 (38.7%) being female. Five variables indicated whether adult relatives had additional support needs i.e. 1) 'is able to speak/sign 30 words or more’, 2) ‘has visual or hearing impairment’, 3) ‘is continent during the day time and/or night time’, 4) ‘currently has epileptic seizures’ and 5) ‘needs support at meal times’. Positively phrased variables (i.e. ‘speak/ sign 30 words’ and ‘continent during daytime/night time or both’) were reverse coded. A composite support needs variable was created with scores ranging from 0-5, with higher scores representing higher support needs (see Table 1).

## Measures

All measures were carefully chosen for their ease of completion and suitability for inclusion in an online or postal survey. Questionnaires were available in English and, where possible, Welsh languages. Participants completed a demographic questionnaire, specifically designed for the current study to collect data on carer, care recipient and family characteristics.

----------------------------------------Insert Table 1 here ----------------------------------

**Socio-economic position:** The household composition variable from the demographic questionnaire was weighted in accordance with the OECD-modified equivalence scale (Office for National Statistics (ONS), 2013a) to create a new single variable weighted to account for household composition. Equivalisation scales are used to adjust household income to account for household size, composition, and income (ONS, 2013a). Different weights are allocated to each member of a household depending on role (i.e. head of the household) and age (i.e. under or over 14 years of age). This variable was then summed to get a total value which represents ‘*equivalised household composition*’. A second single variable was calculated from the mean of the weekly household income for the year 2013 (when data were collected). Equivalised net or disposable household income for families ranged between £80 and £567 per week (mean £240.78, SD 126.04). Median weekly net UK household income for 2013 was £406 (ONS, 2013b). This new '*weekly income*' variable was then divided by the '*equivalised household composition'* variable to create a new single '*household income'* variable adjusted to take account of household size and composition. A dichotomous variable was subsequently derived using the '*equivalised household income'* variable, to represent families who would be considered as earning a weekly income which was above or below the poverty line. The poverty line was a weekly net household income of 60% below the median for 2013, which was £243.59 and below for the present sample.

Postal code information was linked to geographical lower layer super output areas (LSOAs) for each of the UK countries and used to estimate area deprivation using the Index of Multiple Deprivation. The Index of Multiple Deprivation (IMD) is an official, country specific measure which identifies relative deprivation for small areas. Each of the four UK constituent countries have unique indices comprising domains which target specific within country policies (Department of Communities and Local Government, 2011; Northern Ireland Statistics Research Agency, 2010; Scottish Government, 2012; Welsh Government, 2011). Common to all indices are the domains of income, education, employment, health, crime and living environment/housing. Quintile ranking is used to order scores for each of the indices. The IMD variables for Scotland (SIMD, 2012) and Northern Ireland (NIMDM, 2010) are both ranked 1 = most deprived and 5 = least deprived, whereas the indices for England (IMD, 2010) and Wales (WIMD, 2011) are ranked in the opposite order. Therefore the indices for Scotland and Northern Ireland were reverse ranked for conformity with the English and Welsh IMD variables. All IMD scores were then transformed into a single IMD variable for the UK. A dichotomous variable was created indicating whether carers were living in one of the 20% most deprived neighbourhoods in their UK country. This dichotomous variable was used as an indicator of deprivation likely to be experienced by each household only and not as a between country comparator.

**Family resources:** The Family Resources Scale (FRS, Dunst, & Leet, 1986, 1987) comprises 30 items rated on a six point Likert scale, measuring the extent to which resources for families are adequately met (e.g., basic necessities such as food and shelter, and less essential resources such as family holidays). Two of the subscales which indicated material hardship (‘necessities and health’ and ‘physical necessities and shelter’) were summed to create a single interval ‘*material resources’* variable with scores ranging from 0 to 60. These sub-scales demonstrated a high level of internal consistency with the current study sample (‘necessities and health’ Cronbach’s α = .87 and ‘physical necessities and shelter’ α = .89). The summed scores of the ‘*material resources’* variable were subsequently split at the median (i.e. 45), to form a single dichotomous ‘*hardship*’ variable indicating whether 0 = ‘resources were less adequately met’ or 1 = ‘resources were more adequately met’ for families.

Finally, a composite variable indicating families’ socio-economic position (SEP) was created using five indicators: small area deprivation (IMD), hardship, carers’ employment status, educational status (coded ‘0 = no/low education’ and ‘1 = advanced school level and above’) and income poverty. The SEP composite scores ranged from zero to five, with higher scores representing a higher socio-economic position (see Table 1).

**Carers’ health:** Health related quality of life of family carers was measured by the EQ-5D-3L (EuroQol Group, 1990). EQ-5D-3L is a generic measure of health-related quality of life which includes a descriptive system (EQ-5D) and a visual analogue scale (EQ-VAS). The descriptive scale which is measured at ordinal level (1 = no problems; 2 = some problems; 3 = extreme problems) enables participants to self-classify their health states along five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). Higher scores indicate a lower level of health in a particular dimension of health. The descriptive system has the potential of defining a total of 243 health states. The EQ-VAS is a 20 cm visual analogue scale on which respondents rate their subjective general health state on the date of completion. The scale ranges from 0 (worst imaginable health state) to 100 (best imaginable health state).

**Family stress:** The Questionnaire on Resources and Stress – short form (QRS-F: Friedrich, Greenburg, & Crnic, 1983), Parent and Family Problem Sub-scale-7 item version (Griffith et al., 2011) was used. The QRS-F is a self-report questionnaire which measures general stress related to caring for a family member with a disability or chronic illness. Respondents answer ‘true’ or ‘false’ to statements (e.g., ‘caring for my relative with ID puts a strain on me’). The original wording of item 3 (‘In future our family’s social life will suffer because of the increased responsibilities and financial stress’) was amended to reflect the situation for families with adult relatives with ID (i.e., ‘Our family’s social life has suffered because of caregiving responsibilities and financial stress’). The total score for this measure is 7, with lower scores reflecting lower levels of family stress. The composite measure showed a high level of internal consistency for the current study population (KR-20 coefficient = .81).

**Family support:** The Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984) is a self-report measure comprising 19 items designed to assess potential sources of support available to families and the degree of perceived helpfulness. Responses were coded on a 5 point Likert scale where 0 = not available, 1 = not at all helpful, 2 = sometimes helpful, 3 = generally helpful, 4 = very helpful and 5 = extremely helpful. The composite measure of all 19 items showed a good level of internal consistency for the current study participants (Cronbach’s $\alpha = .75$). A total score for ratings of helpfulness was calculated together with a count of the number of support services available to each family. The overall helpfulness scores were then divided by the count of the number of supports available to each family, to create a single weighted score of mean helpfulness of available supports.

**Coping strategies:** The Family Crisis Oriented Personal Scale (F-Copes; McCubbin, Olson & Larsen, 1981; McCubbin et al., 2000) consists of 30 statements designed to assess coping strategies and effective problem solving behaviour adopted by families in response to problems. The questions are presented on a 5-point Likert-scale, scored 1) strongly disagree, 2) moderately disagree, 3) neither agree nor disagree, 4) moderately agree and 5) strongly agree. The scale was designed to measure problem focused and passive coping strategies used by families in times of crisis. The subscales of acquiring social support (Cronbach's α = 87), reframing problems (Cronbach's α = .83) and seeking spiritual support (Cronbach's α = .83), all showed excellent levels of internal consistency for the study sample. These three sub-scales were summed to create a single variable for active coping strategies. Total active coping strategies scale had excellent internal consistency (Cronbach's α = .87), scores ranged from 23-115.

**Psychological distress:** The Kessler 6 (K6, Kessler et. al., 2002) is a six item scale measuring non-specific psychological distress over a past 30 day period. Respondents rate each of the 6 items a) so sad nothing could cheer you up, b) nervous, c) restless or fidgety, d) hopeless, e) everything was an effort, f) worthless) on a 5 point Likert scale scored to reflect how often carers experienced negative feelings: 1) none of the time, 2) a little of the time, 3) some of the time, 4) most of the time and 5) all of the time. The maximum score is 30, where higher scores indicate greater levels of distress. The K6 is not gender, age, nor education biased (Kessler et al., 2002). The measure showed excellent levels of internal consistency for the study sample (Cronbach's α = .90).

**Caregiver burden**: The Zarit Burden Index -12-items (ZBI; Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001). The abridged 12-item, self-report index has been developed from the original 29 item scale (Zarit, Reever, & Bach-Peterson, 1980) designed to measure subjective caregiving burden. Example questions are 'Do you feel stressed between caring for your relative and trying to meet other responsibilities to your family or work?' and 'Do you feel your health has suffered because of your involvement with your relative?' Each item is rated on a 5-point scale: 0) never, 1) rarely, 2) sometimes, 3) quite frequently, 4) nearly always. Question 9 ('Do you feel you have lost control of your life since x's condition?) was omitted from the current study, as this related to the onset of a condition in later life such as Alzheimer's disease. The maximum score of the 11 questions was therefore, 44 with higher scores indicating higher levels of burden. The total measure showed excellent internal consistency for the study population (Cronbach's α = .86).

**Positive gain:** The Positive Gain Scale (PGS: Pit-ten Cate, 2003) is a 7-item scale designed to assess perceived positive aspects of having a relative with a disability. Carers were asked to respond to statements along a 5-point Likert scale such as "having a relative with an intellectual disability has helped me grow as a person" or "having a relative with an intellectual disability has brought my family closer to one another". Responses were coded 1) strongly agree, 2) agree, 3) not sure, 4) disagree and 5) strongly disagree. Maximum score for the measure is 35, with higher scores indicating fewer perceived gains. The measure showed excellent internal consistency for the current study population (Cronbach's α = .91).

## Procedure

The study protocol was approved by the Research Ethics and Governance Committee at Bangor University in the UK. Study participants completed a battery of questionnaires either posted by mail or as an online survey. Recruitment of participants was facilitated through statutory and voluntary organisations that circulated a recruitment advertisement to their members and service users via email, websites and newsletters. Social media (e.g., Twitter and Facebook, on-line fora) were also used to distribute information about the study. The recruitment advertisement contained a brief description of the project, summary of eligibility criteria, what participation involved, together with a link to the on-line survey questionnaires. Contact details of the principal researcher were included for those requiring further information or those preferring to complete paper copies of questionnaires. The online link gave participants access to online versions of the participant information sheet, consent form and all project questionnaires. Participants opting to complete paper copies of questionnaires received the same information as those participating online. The first author also attended carers' group meetings and social groups for adults with ID, to promote the project and deliver paper questionnaires and address any queries or concerns of potential participants. Batches of questionnaires were sent to carers' and disability support organisations who had agreed to advertise the project to their members. A stamped addressed envelope was enclosed with the postal survey for return of the questionnaires. The number of postal questionnaires sent out via statutory or voluntary organisations or requested directly by family carers totalled 150 of which, 36 (24%) were returned completed. The overall response rate to online and postal routes is difficult to assess as it was not clear how many people would have been reached through online advertising methods.

## Results

The first aim of this study was to describe characteristics of family carers' physical and psychological health as compared to general population norms within the UK. To address this question, the percentage of problems (some or extreme problems combined) reported for each of the five domains of health on the EQ-5D descriptive system were plotted on a bar chart against national population data (Kind et al., 1998; Janssen, Cabases, & Ramos Goñi, 2014), (Fig. 4.1). Percentages are relative to study population sample ($N = 110$) and UK population sample ($N = 3,395$).

--------------------------------------Insert Figure 1 here --------------------------------------

Binomial tests indicated that the proportion of family carers from the study population experienced significantly higher problems ($p < .001$) across all five domains of physical and psychological health (EQ-5D) than UK norms (Kind, et al., 1998; Janssen, Cabases, & Ramos Goñi, 2014).

One sample *t*-tests were conducted to compare subjective general health scores (EQ-VAS) and psychological distress (K6) of study participants with population norms. The results of these comparisons suggested that family carers of adults with ID perceived their general health (EQ-VAS) and psychological distress (K6) as worse than those of general populations (see Table 2). Comparisons for the K6 data were obtained from the Centers of Disease Control and Prevention (CDC; 2013) which was designed to collect population data from non-institutionalised adults aged 18 and over across 50 states in the USA (available at: http://www.cdc.gov/brfss/annual_data/2012/pdf/Overview_2012.pdf). To our knowledge, general population datasets which have included a measure of psychological distress using the K6 for families with adult children are currently not available in the UK.

Using the suggested clinical cut off score of 13 or above to indicate risk of serious mental illness (SMI) (Kessler et al., 2003), binomial tests indicated that differences in the proportion of family carers from the study population reporting levels of distress above the clinical cut-off was significantly higher than that found in the US national population data (17.5% vs 3.6%, p <. 001). Effect sizes for the differences for each outcome measure were estimated as a standardised mean difference using pooled standard deviations (SDs). These were EQ-VAS ($SD_{pooled}$ = 17.04) 0.98 (95% CI: 0.78 to 1.18), and K6 ($SD_{pooled}$ = 3.81) 1.25 (95% CI: 1.05 to 1.45), indicating large effect size differences in the health of carers of adults with ID compared to normative populations.

--------------------------------------Insert Table 2 here --------------------------------------

To address the second research question of correlates of carers' health outcomes, bivariate associations between carers' socio-demographic characteristics and outcomes were initially explored. Where associations were significant, variables were entered in regression models. Whilst carers' age did not reach statistical significance with any of the outcome variables, it was included in the regression models due to previous research findings of associations with outcomes of carers' health (e.g., Seltzer et al., 2011). Hierarchical forced entry models were fitted for each of the outcomes (distress, burden, family stress, positive gains and general health status). At step 1, predictors entered were carer characteristics, adult relative characteristics and family SEP composite, to examine the relationships between the socio-demographic profile of carers and their well-being. At step 2, two further predictors were entered: active coping strategies and satisfaction with available support. The aim was to examine whether associations between socio-demographic characteristics and carer well-being changed after accounting for the effect of coping and support on well-being.

----------------------------------------Insert Table 3 here ----------------------------------

**Model 1: Carer psychological distress (K6).** Predictor variables entered at step 1 of the model accounted for a significant percentage of the variance in carers' psychological distress scores ($R^2 = .247$, $F_{(7,91)} = 4.27$, $p < .001$). Carers' age and SEP were both independently negatively associated with distress, suggesting that being older and of higher SEP are associated with reduced psychological distress. The addition of carers' satisfaction with available support and active coping strategies at step 2, accounted for additional score variance for psychological distress ($R^2$ change = .073, $F_{(9,89)} = 4.84$, $p = .01$). Carers' age and SEP both remained significantly negatively associated with distress. Active coping strategies were also independently negatively associated with carers' psychological distress, suggesting that the utilisation of more active coping strategies is associated with reduced psychological distress. Carers' gender, marital status, adult relative's age, gender and support needs, and satisfaction with available support were not independently associated with psychological distress.

**Model 2: Carer burden (ZBI).** At step 1, the model accounted for a significant percentage of variance in carer burden ($R^2 = .206$, $F_{(7,91)} = 3.38$, $p = .003$). Carer's age was the only variable significantly independently associated with carer burden, which was in a negative direction, suggesting older age was associated with lower levels of carer burden. The addition of satisfaction with available support and active coping strategies at step 2 accounted for additional significance in carer burden score variance ($R^2$ change = .138, $F_{(9,89)}$ = 9.33, $p <.001$). Carer's age, satisfaction with available help and active coping strategies were independently significantly negatively associated with carer burden. This suggests that older age, greater satisfaction with available support and the adoption of more active coping strategies was associated with lower levels of carer burden. None of the other variables were significantly associated with burden.

**Model 3: Positive gain from providing care (PGS).** At step 1, none of the variables were significantly associated with perceived positive gain from caring ($R^2$ = .028, $F_{(7,91)}$ = 0.37, p = .917). The addition of satisfaction with available support and active coping strategies accounted for a significant part of the variance in positive gain scores at step 2 ($R^2$ change = .165, $F_{(9,88)}$ = 9.11, $p < .001$). Satisfaction with available support and active coping were both independently significantly negatively associated with carers' perception of positive gain from providing care. This suggests that greater satisfaction with available support and adopting more active coping strategies were associated with more perceived positive gain from caring. None of the other variables were significantly associated with positive gain.

**Model 4: Family Stress (QRS-F).** Regression models at both step 1 ($R^2$ = .277, $F_{(7,91)}$ = 4.99, $p < .001$) and step 2 ($R^2$ change = .167, $F_{(9,89)}$ = 13.37, $p < .001$) were significant. Carers' age and gender were both negatively associated with family stress, whilst adult relatives' support needs were positively associated with family stress at both steps of the model. This suggests that being female and older were associated with lower levels of family stress. However, adult relatives having higher support needs were associated with higher levels of family stress. Active coping strategies were independently negatively associated with family stress at step 2, suggesting that carers' adoption of more active coping strategies was associated with reduced family stress. None of the other variables were independently significantly associated with family stress.

**Models 5 subjective general health (EQ-VAS).** At step 1, the model predicting general health was significant ($R^2$ = .149, $F_{(7,91)}$ = 2.25, $p$ = .04). Only SEP was independently positively associated with subjective health scores, suggesting higher SEP to be associated with better health status. At step 2, the model became non-significant ($R^2$ change = .027, $F_{(9, 89)} = 1.47$, $p = .236$). This suggests that when accounting for active coping strategies and satisfaction with available support, SEP was no longer independently associated with general health, neither were the remaining variables of carers' demographic profile and characteristics of care recipient.

## Discussion

The present study adopted a cross-sectional design to examine the well-being of family carers of co-residing adults with an ID. To address the first aim of the study, outcomes of self-reported physical and psychological health states were compared to population data. Comparative analysis indicated significant differences in health status across five domains of health (mobility, self-care, ability to carry out usual daily activities, pain/discomfort and anxiety/depression), with a greater percentage of study participants reporting poorer health outcomes compared to UK general population data (Kind et al., 1998). Further comparative analyses indicated carers in the study population were experiencing significantly poorer general health (EQ-VAS) and psychological distress (K6) (the latter when compared to US population data - The Behavioral Risk Factor Surveillance System, CDC, 2012).

To our knowledge, this is the first study to explore differences in the self-reported health status of UK family carers living with an adult relative with ID with general population data. The findings are consistent with previous research conducted outside of the UK (Burton-Smith et al., 2009; Seltzer et al., 2011; Walden et al., 2000; Yamaki et al., 2009), which also found carers to report poorer health than non-caregiving peers. Whilst the findings provide further evidence of health disparities between caregiving and non-caregiving families, caregivers of people with ID (both adults and children) also report worse physical health compared to other caregivers, even though they do not attribute their worse physical health to caregiving (Totsika, Hastings, & Vagenas, 2016).

The self-selection of study participants also cannot be ruled out as influencing the results of this study (Bethlehem, 2008a; Søgaard et al., 2004). The current study did, however, aim to address the problem of selection bias and under coverage of non-computer users by including the option of a paper copy questionnaire and adopting a mixed recruitment strategy. Language equity was also addressed by offering Welsh language questionnaires. However, the inclusion of other languages and easy read information may have increased participation by families from ethnic minority and marginalised communities. Using methods to address selection bias such as statistical modelling whereby weightings are applied to address potential differences between characteristics of participants and the target population may also help to address selection bias (Bethlehem, 2008b; Braver & Bay, 1992; Cuddeback et al., 2004).

The results of multiple regression analyses revealed mixed support for previous research. The association of older age and better psychological health has support from previous research which has shown family carers of adults with ID to self-report improvements in mental health status as they get older (Ben-Zur et al., 2005; Ha et al., 2008; Llewellyn et al., 2010; Minnes et al., 2007). A possible explanation to this age-related phenomenon may be found in Grant et al's, (2003) proposal that caregiving is a stage-based process involving key transitional stages of skills development. They suggest that, over time, carers develop an expertise of the "art and craft" of caregiving. Grant et al. (2003) further propose that long term caregiving relationships may evolve into increasingly reciprocal arrangements, leading to greater parity within these relationships. Further support for this finding is offered by Llewellyn et al. (2010) who found that younger carers were more likely to report experiencing stress related difficulties such as "feeling helpless" or "not able to relax” as a result of their caregiving role. Whilst older age is associated with a greater propensity to somatic health problems (Llewellyn et al., 2010; Seltzer et al., 2011; Yamaki et al., 2009), Minnes et al. (2007) propose that self-evaluative processes such as carers’ perception of aging, as opposed to chronological age, mediate the relationship between health and depression. The differences in reported health status between older and younger carers may, however, result from survivor effect (i.e. the greater propensity for healthier people to survive into older age). The tendency for cross-sectional studies to be susceptible to this effect (Zigman et al., 1994), supports the need for more longitudinal research.

Minnes et al’s (2007) mediation theory may also offer some explanation for further results of the current study such as the lack of association between personal characteristics of carers and general physical health outcomes. One possibility for this lack of association is that none of the socio-demographic characteristics we measured was related to the perceived physical health of participants in the current study, even though overall they reported worse physical health status than national norms. This could suggest that self-perceived general health in this population is related to the presence of other, unmeasured, characteristics of carers, for example the presence of physical health problems. Future studies would benefit from including objective evaluations of physical health (for example, the presence of specific diseases). Another possibility relates to the sampling method and suggests that the lack of associations may be specific to the present group of participants only. Finally a further possibility is that the measure used to evaluate general health status (EQ-5D) was not specific enough to capture any associations between carers and care recipients’ profiles with specific physical health conditions.

Consistent with a plethora of evidence and social role expectation (Burton-Smith et al., 2009; Chou et al., 2011b; Llewellyn et al., 2010; Minnes et al., 2007; Werner & Shulman, 2013), the majority of carers in the current study were female (83%). The mean age of study participants was just under 60 years of age. Inconsistent with the literature which suggests that mothers experience poorer health outcomes than fathers (Olsson & Hwang, 2001; Samadi et al., 2014), the current study found that being female was associated with more positive outcomes of family related stress. Much of the evidence which contradicts this finding is, however, derived from studies of families providing care to children and/or individuals with developmental disabilities such as autism (Jones et al., 2013; Olsson & Hwang, 2001; Samadi et al., 2014). Little is known about gender related difference in well-being when the care recipient is an adult. One US study comparing the impacts of lifelong caring found no differences in health outcomes for mothers and fathers providing care for a co-resident adult child with ID (Seltzer et al., 2011). A further study exploring outcomes for families providing care for co-resident adults with profound and multiple ID in Taiwan, also found no significant between gender differences in health status (Chou et al., 2011a). An explanation for the results found in the current study may relate to gender related differences in cognitive appraisal of stressful events. Theories propose that psychological outcomes occur as a processing response to stressful stimuli and not simply due to experiencing the stimuli alone (Grant & Whittell, 2000; Lazarus & Folkman, 1984; Folkman, Lazarus, Gruen., & DeLongis, 1986). Whilst relatively few studies have examined this phenomenon within ID populations, those which have, explored coping strategies in families of individuals with ID (Grant & Whittell, 2000) and children with autistic spectrum disorders (Hastings et al., 2005b). These studies suggest that women have a greater propensity to adopt more positive coping strategies than their male counterparts. More research examining potential difference in caregiving outcomes and adaptive coping strategies of mothers and fathers of co-resident adults with ID is needed to gain a better understanding of potential gender related health outcomes. This would have practical implications for more informed and better targeted support services.

Psychological resources (i.e. active coping and satisfaction with available support) explained a significant amount of variance in the multiple regression analyses. Therefore the adoption of a greater number of active coping strategies was associated with lower psychological distress, caregiver burden, family stress and more positive gains. Satisfaction with support was associated with lower burden and more positive gains. Previous research provides support for these findings, which have demonstrated that the adoption of active or problem-focused coping and appropriate support can act to buffer the effects of daily stressors (Grant et al., 2003; Grant & Whittell, 2000; Llewellyn et al., 2010; Peer & Hillman, 2012). This finding may also provide further support for gender based difference in health outcomes of family carers.

Consistent with previous research, higher SEP was associated with lower psychological distress and better subjective general health (Chen et al., 2001; Chou, Lin, Chang, & Schalock, 2007; Chou et al., 2010b; Eisenhower & Blacher, 2006). However, when accounting for psychological resources (active coping and satisfaction with available support), SEP was no longer associated with physical health status. Although we should be cautious with this finding, it suggests that any adverse effects on physical health might be buffered by active coping mechanisms and the availability of helpful supports.

Consistent with previous research (Egan & Walsh, 2001; Walden et al., 2000), adult relatives having a greater number of support needs was associated with family related stress, even after accounting for factors relating to caregivers' psychological resources (coping and support). Overall, however the characteristics of the care recipient were not associated with carer outcomes. This was most puzzling in the case of support needs, as higher support needs would have been expected to be associated with more negative outcomes. One possibility is that our broad measure of support needs was not robust enough to capture care recipients' adaptive skill levels. Another possibility is that unlike childhood where children's adaptive skills are related to carer well-being (McCarthy et al., 2006; Plant & Sanders, 2007), in adulthood carers' well-being becomes less sensitive to the characteristics of the person with an ID, and more dependent on the quality and availability of supports, or potential changes in these supports. Future replications with care recipients of varying ages are needed to examine whether this is a phenomenon related to the life phase each family is going through or limited to our current sample only.

Throughout the discussion, we have mentioned that one potential limitation in the interpretation of the findings is the sampling method, as those who selected to take part might have been better or poorly adjusted. A further limitation was the reliance on carer informants for collecting data on care recipient characteristics. Current UK legislation (Department for Constitutional Affairs, 2007) indicates that care recipient information such as support or adaptive skills levels may be collected by direct data collection following assessments of capacity to participate in research and data collection. In our attempt to balance the need for such information with the need to capture information from as many UK families as possible, we opted for data collection methods that were only accessible to carers. Whilst aimed at reaching a wide population of family carers, this prevented us collecting in-depth data about care recipients' adaptive behaviours and additional support needs. The cross-sectional, correlational design can also only provide a 'snap-shot' of the health of family carers of adults with ID within the UK. Further, large scale, longitudinal, and population-based research is needed to gain a more long term view of carers' health and overcome some of the methodological problems of the current study.

The present study provides evidence that family carers co-residing with an adult relative with ID within the UK appear to experience poorer physical and psychological health outcomes than non-caregivers. The findings indicated that older carers tended to report less psychological distress, less perceived burden from caregiving, and less family stress. In contrast, psychological resources (coping and support) were systematically related to psychological health and positive gains, highlighting the importance of coping strategies that carers use, and the helpfulness of the available support. Finally, findings from the present study also highlighted the lack of associations between carer or care recipient characteristics and physical health. The relationship between physical health and caregiving is a complex one, where the relationship between poorer physical health and caregiving remains unclear (Pinquart & Sörensen, 2007). Findings from the present study seem to suggest that associates of physical health might be different to associates of psychological health. Further large scale, longitudinal research is needed which not only includes an examination of objective indicators of health but also biomarkers such as cortisol levels, to better our understanding of both associates of physical health and the long term impact of psychological stress upon carers' physical health.

## Implications for research, policy and practice

Despite the limitations outlined above, the present study does provide further support of the health disparities experienced by caregiving families when compared to non-caregiving peers. The findings suggest that older carers who continue providing long term care to their adult relative report experiencing fewer negative psychological outcomes. Also carers who adopt more active or problem-focused coping strategies and receive more helpful support appear less prone to negative health outcomes. Results from the present study build on previous evidence which suggests that family carers acquire a wealth of skills and expert knowledge through providing care to their family member. Policy makers and service practitioners may, therefore, wish to collaborate with family carers to instigate carer-led, peer support groups to utilise this expert knowledge and provide emotional focused support and teach active coping strategies. An exploration of service support which is of most help and value to carers is also needed to ensure services are better targeted and fit for purpose. This may also help local government and social care providers when evaluating which services to continue funding.

Overall, findings from the present study do not identify a particular socio-demographic group of carers as more susceptible to poorer well-being. Rather, they indicate that over time and with the appropriate support and coping, psychological well-being, at least, may benefit. Future research on other aspects of the caregiving experience may also help us understand what is important for good physical health status or why caregivers report lower well-being compared to the rest of the population.

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Table 1: Characteristics of participating family carers and their adult relatives with ID

| | | Number and percentage |
|---|---|---|
| Family carers' gender : | Male | 18 (16.4%) |
| | Female | 92 (83.6%) |
| Relationship to adult with ID: | | |
| - Mother/step-mother | | 81 (73.0%) |
| - Father/step-father | | 16 (14.4%) |
| - Sister/step-sister/sister-in-law | | 5 (4.5%) |
| - Brother/step-brother/brother-in-law | | 1 (0.9%) |
| - Spouse/partner | | 2 (1.8%) |
| - Other relatives (including aunt/uncle, cousin, daughter) | | 4 (3.6%) |
| Marital status: | Living with spouse/partner | 60 (54.1%) |
| | Not living with spouse/partner | 48 (43.2%) |
| Number of people living in family home: | | |
| - Two (carer and adult with ID) | | 34 (30.6%) |
| - Three | | 58 (52.3%) |
| - Four or more | | 18 (16.2%) |
| Family carers' highest level of educational attainment: | | |
| - No formal qualifications | | 14 (12.6%) |
| - O Level/GCSE | | 28 (25.2%) |
| - Vocational qualification/FE (Apprenticeship, NVQ) | | 11 (9.9%) |
| - A Level/BTECH | | 11 (9.9%) |
| - Professional qualifications (Engineering, Accountancy) | | 13 (11.7%) |
| - Higher education (BA/BSc) | | 18 (16.2%) |
| - Post-graduate education (Masters/Doctoral Degree) | | 9 (8.1%) |
| Has a job: | Yes (full or part time) | 36 (32.4%) |
| | No | 73 (65.8%) |
| Family Socio-Economic Position (ie. carers' level of education, availability of resources, area deprivation, household income and carers' employment status) with lowest to highest socio-economic position presented here in descending order | | 7 (6.4%) |
| | | 15 (13.6) |
| | | 39 (35.5%) |
| | | 24 (21.8%) |
| | | 19 (17.3%) |
| | | 6 (5.5%) |
| Income poverty | | |
| Weekly net income of below poverty line | | 51(46.4%) |
| Weekly net income of above poverty line | | 59 (53.6%) |
| Gender of adult relative with ID: | Male | 65 (58.6%) |
| | Female | 43 (38.7%) |
| Adult with ID able to speak/sign 30 words or more: | Yes | 79 (71.2%) |
| | No | 27 (24.3%) |
| Visual impairment | | 13 (11.7%) |
| Hearing impairment | | 17 (15.3%) |
| Needs support to eat | | 37 (33.3%) |
| Incontinent during the | Daytime | 25 (22.5%) |
| | Night time | 11 (9.9%) |
| Has epileptic seizures | | 19 (17.1%) |
| Adult relative with ID attends a day time activity (including paid work, workshop, voluntary work, day centre, respite) | | 83 (74.8%) |

Table 2: Mean, standard deviations and *t*-test results for health outcomes for study population and population normative data

| | Study population ($N$ = 110) | Normative data for adults | *t*-test results | Mean difference | 95% CI of the difference |
|---|---|---|---|---|---|
| EQ-VAS | 66<br>(18.4) | 82.8<br>(17.0) | -9.55* | -16.95 | -20.46 to -13.43 |
| Kessler 6 | 13.6<br>(5.6) | 8.89<br>(3.82) | 8.79* | 4.74 | 3.67 to 5.81 |

$^{*}p <. 001$ Higher scores on EQ-VAS indicate better health, higher scores on the K6 indicate poorer psychological health.

Table 3: Regression analysis of physical and psychological health of carers

| **Model** | **Predictor Variables** | **K6: Distress** | **ZBI: Burden** | **PGS: Positive gains** | **QRS-F: Family stress** | **EQ-VAS: Subjective health** |
|---|---|---|---|---|---|---|
| 1 | Carer gender (Female) | .019 | -.041 | -.073 | **-.204**[1] | -.058 |
| | Carer's age | **-.409**[3] | **-.332**[2] | .079 | **-.328**[2] | .160 |
| | Carer's marital status (Co-residing) | .051 | .156 | -.003 | .045 | .206 |
| | Adult relative's age | .016 | -.058 | .073 | -.115 | -.012 |
| | Adult relative's gender | -.049 | .106 | -.016 | .<br>.095 | .035 |
| | Adult relative's support needs | .138 | .146 | .016 | **.277**[2] | -.047 |
| | Family SEP | **-.250**[2] | -.031 | .005 | -.066 | **.222**[1] |
| 2 | Carer gender (Female) | .019 | -.046 | -080 | **-.205**[1] | -.053 |
| | Carer's age | **-.387**[3] | **-.303**[2] | .110 | **-.294**[2] | .153 |
| | Carer's marital status (Co-residing) | .029 | .128 | -.031 | .011 | .220 |
| | Adult relative's age | -.012 | -.089 | .041 | -.156 | -.002 |
| | Adult relative's gender (Male) | -.081 | .063 | -.064 | .046 | .056 |
| | Adult relative's support needs | .150 | .170 | .045 | **.295**[3] | -.064 |
| | Family SEP | **-.227**[2] | .001 | .042 | -.034 | .206 |
| | FSS: Satisfaction with support | -.093 | **-.202**[1] | **-.241**[1] | -.150 | .118 |
| | F-Copes: Active coping | **-.222**[1] | **-.243**[2] | **-.247**[1] | **-.328**[3] | .081 |

[1] p<.05, [2] p<.01, [3] p< .001

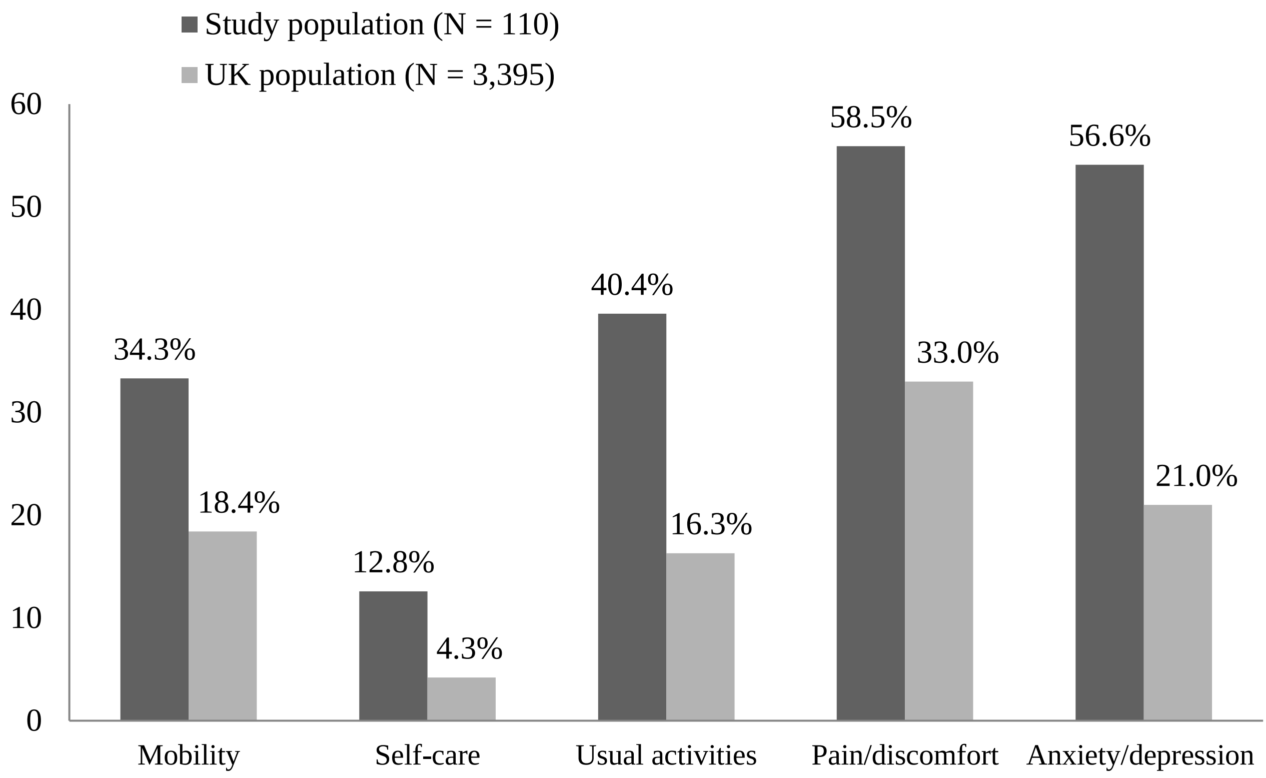

Fig 1: EQ-5D descriptive system: Percentage of carers reporting health problems in the study population and the general population across five domains of health