Title: **Informal caregivers of people with an intellectual disability in England: health, quality of life, and impact of caring.**

Authors:

Vasiliki Totsika (corresponding author): Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick, Coventry, CV4 7AL, UK

Email: V.Totsika@warwick.ac.uk ; Telephone: 0044 (0)24 765 22185

Richard Hastings: CEDAR, University of Warwick, Coventry, CV4 7AL, UK

Dimitrios Vagenas: Institute of Health and Biomedical Innovation, Queensland Institute of Technology, Australia

Acknowledgements: The authors would like to thank Dr Leen Vereenooghe for her kind assistance in accessing research publications in Dutch. No external funding was associated with this study.

Conflict of interest: No conflict of interest to declare

Abstract

There is wide variation in reported impact of caring on caregiver well-being, and often a negative appraisal of caregiving. Researchers are beginning to question the robustness of the evidence base on which negative appraisals are based. The present study aimed to draw on data from a population-representative sample to describe the health, quality of life, and impact of caring of informal caregivers of people with an intellectual disability (ID). Informal carers of people with ID (N=260) were identified among 2,199 carers in the English Survey of Carers in Households 2009/10. Generalised estimating equations explored the association between socio-demographic and caring profile with quality of life, physical health status, and impact on psychological health and personal life. Compared to other caregivers, providing care to a person with ID was not associated with reduced quality of life. There was a 82% increased risk of reporting poorer health status, even though poorer health was not likely to be attributed to caregiving. A higher risk of negative impact on personal life was seen in comparison with the wider group of caregivers, but not in comparison with more similar-sized caregiver groups (mental health or dementia). Carers of people with ID were more likely to be struggling financially and have a high caring load. These factors were systematically related to lower well-being. A uniformly negative appraisal of caring for people with ID was not supported by these English population-representative data. Poverty and long caregiving hours may make caregivers more susceptible to negative well-being. Support for caregivers of people with ID should focus on alleviating those two factors.

Keywords: informal carers; intellectual disability; impact of caregiving; health; quality of life

What is known about this topic

- The provision of informal care is considered to have a negative impact on carers. However, data from population-representative studies do not always support a negative appraisal of caregiving.
- There is no large-scale population-level evidence on the well-being of informal caregivers of people with intellectual disability (ID)

What this paper adds

- After controlling for demographic and caring profile, carers of people with ID reported similar quality of life to all other caregivers but worse physical health status, without attributing their poorer health to caregiving.
- There was a small negative impact on personal life, comparable to the impact experienced by carers of people with mental health problems or dementia.

Introduction

In the UK, over 35% of adults with an intellectual disability (ID) live with family or friends who care for them (Hatton *et al.* 2014). Shortages in residential accommodation for people with ID are currently experienced by many countries (Colombo *et al.* 2011), and social care provision will increasingly rely on informal caregivers to care for people with ID.

Informal caregivers are people who provide unpaid care to relatives, friends or partners who are disabled or have a long-standing illness or condition. Care can be provided for any number of hours, in one's own home or outside. Informal caregivers currently make up about 10% of the UK population (White 2013) and the economic value of their contribution exceeds the overall annual budget of the entire UK health system (Buckner & Yeandle 2011). Despite the sizeable economic and societal gains derived from informal caregivers' contribution, much of the research and media portrayal of informal caregiving highlights singularly the negative impact on carers' health and lives (Roth *et al.* 2015). The negative appraisal of caregiving has important implications for policy (e.g., carer assessment of needs leading to financial support). However, the dominance of a negative view does not offer a balanced perspective on the experience of caregiving, which might be especially important for new caregivers, and does not allow for understanding how to develop intervention models building on strengths.

In a recent review, Brown & Brown (2014) concluded that: (a) there are serious methodological limitations in existing studies that prevent us from concluding that negative outcomes are necessarily due to caregiving, and (b) that effects can also be positive, if researchers are not examining evidence through a negative-impact lens only. With respect to methodological limitations, Brown & Brown (2014) highlighted the need for a clear understanding of what is meant by impact in relation to its operational definition in each study (for example, a self-report measure of physical health status is not the same as a self-report measure asking about the perceived *impact* of caregiving on health), and a clearer understanding of the comparison group used for benchmarking the outcomes.

Caregivers differ in their caring role, activities, and caring demands. Referring generically to informal caregivers for public health and policy purposes is helpful, but the lack of specificity complicates research evidence interpretation. In research, the label often refers to all caregivers without reference for whom they care (e.g., (Legg *et al.* 2012) (Smith *et al.* 2014) (Trivedi *et al.* 2014)). ID research typically adopts the opposite approach: studies examine the well-being of specific groups of caregivers: mostly mothers, sometimes fathers, and lately siblings.

Focusing on evidence emerging from population-based studies, caregivers, compared to non-caregivers, report poorer mental health (Hirst 2005, Smith *et al.* 2014, Trivedi *et al.* 2014) - although not always (see (Robison *et al.* 2009, Tuithof *et al.* 2015). The evidence on physical health is even less consistent. In addition to recent findings of a small mortality advantage for caregivers (Ramsay *et al.* 2013), Robison *et al.*(2009) found significantly better self-reported health status and health-promoting behaviours, while Smith *et al.* (2012) found no significant differences in either self-reported physical health status or number of illnesses, after accounting for potential confounders. Poorer self-reported physical health status has been found in UK census data from 2001 (Legg *et al.* 2012). Quality of life has not been compared in large population groups of caregivers with non-caregivers, except within specific caregiving groups (e.g., cancer (Goren *et al.* 2014)), and perceived *impact* is only meaningful within caregiving groups. Reviews of the overall evidence from population-based studies seem to support a less negative impact of caregiving compared to studies with convenience samples, and begin to identify benefits associated with caregiving, and in particular health benefits (Roth *et al.* 2015).

Factors implicated in poorer mental and physical health are socio-demographic characteristics of the carer (female gender, unemployment, poverty and age), characteristics of the care recipient (cognitive impairment, memory problems and behaviour problems) and care load: caring for more than 20 hours a week and being a carer for longer are two of the better studied caring profile characteristics associated with poorer health (Pinquart & Sörensen 2007, Smith *et al.* 2014, Trivedi *et al.* 2014).

However, as Brown & Brown (2014) point out, when we try to understand the effect of caregiving by comparing caregivers to non-caregivers we are confounding care provision with the relationship to another person. ID researchers largely deal successfully with this as most studies compare parents of offspring with ID to parents of offspring without ID, thus controlling for the presence of a parental relationship. Using this paradigm, overall findings demonstrate mostly poorer physical and mental health (Singer 2006, Bailey *et al.* 2007, Miodrag & Hodapp 2010, Lee 2013). In this field as well, recent reviews begin to question the wholly negative narrative (Hastings in press)and point to population-representative data that identified intact positive well-being and life satisfaction in mothers of children with developmental disabilities (Totsika *et al.* 2011a, Totsika *et al.* 2011b), as well as ID-specific evidence of experiencing positive gains from raising a child with ID (Hastings & Taunt 2002). Most of the evidence relates to parents of children with ID, while not much systematic evidence is available for parents of adults with ID, sibling carers, or any other specific caregiving group. For those less studied groups of ID carers, a view of negative well-being would be congruent with the dominant theoretical approach of viewing caregiving for someone with ID as a stressor (McConnell & Savage 2015), though it remains unclear whether the stressor is caregiving or caregiving for a person with ID.

In the present study, the aim is to examine the quality of life, health and impact of caring for a person with ID. We bring together the research paradigm of informal caregiving and that of research on caregiver well-being in ID, and aim to address some of the limitations identified by Brown & Brown (2014) by: (a) examining all available self-reported outcomes (including self-reported health *status*, and perceived *impact* of caregiving), (b) using data from a large population-representative sample of caregivers in England, and (c) benchmarking findings through comparison with different caregiver groups. This approach, thus, extends informal caregiver research to compare different groups of carers, and ID research by including non-parental caregivers.

Methods

We used data from the Survey of Carers in Households 2009/10 (NHS Information Centre 2010). This was commissioned by the UK Departments of Health, and Work and Pensions to estimate the prevalence of informal caregiving in England. Full description of methodology is available in the survey report (NHS Information Centre 2010) but important information is summarised here. A randomly selected sample of addresses (N=18,276) was screened for the presence of informal caregivers, and, where present (N=2,117 households), face to face interviews were conducted: 2,401 caregivers interviewed (75.8% response rate). Of those, 2,199 fitted the more stringent definition of caregiving used in UK: it excludes those caring as volunteers for organisations, those caring for someone in an institution, those providing financial support only, and those caring for someone with a temporary illness or disability (NHS Information Centre 2010).

Interviews were conducted with all eligible carers in the household (aged 16 years +): 81% of households included one caregiver, 19% of households included 2-4 carers. Data were collected on up to 7 care recipients per household: 83% of carers cared for one person, while the remaining cared for 2+ care recipients. Survey weights were developed to account for the probability of household selection (postcodes were randomly sampled but on a few occasions more than one households/dwellings fell under the same postcode; interviewers had to sample these) and to balance the profile of the sample to the English population in terms of key demographic characteristics: age, gender, ethnicity, working status, and region; NHS Information Centre 2010). Weights were used throughout the present study unless otherwise specified.

Participants

Identification of ID carers. For each person indicated as a care recipient (up to 7), carers were asked the reason the recipient needed care: dementia, physical disability, sight or hearing loss, a mental health problem, learning disability (i.e., ID in UK terminology), long-standing illness, terminal illness, alcohol or drug dependence, other. Carers could indicate as many impairments per person as applicable. Among the 2,199 informal carers, 11% (N=260 unweighted and N=258 weighted) cared for at least one person with ID (Table 1).

Comparison group. At the first step of the study, all ID carers were initially compared to the remaining 1,949 carers (weighted N; Table 1). At the second step of the study, we compared ID carers to carers of people with a mental health problem (MH carers) and dementia carers. These three caregiving groups had similar prevalence in the survey: 12% of were MH carers, 11% ID carers and 10% dementia carers (NHS Information Centre 2010). Some carers reported caring for people with either two of the three conditions (e.g., both ID and MH; N=117), or all three conditions (N=3). To avoid confounding the conclusions, we identified carers whose care recipients spanned across these conditions (N=120) and excluded them, leaving ID carers who did not care for anyone with MH or dementia (N=174), MH carers not caring for anyone with ID or dementia (N=198), and dementia carers not caring for anyone with ID or MH (N=188) (Table 2).

Measures

Caregiver well-being. Carers rated their quality of life on a single 5-point item: ‘If we were to define “quality of life” as how you feel overall about your life, including your standard of living, your surroundings, friendships and how you feel day-to-day, how would you rate your quality of life? Very good, fairly good, neither good nor bad, fairly bad, very bad’. A single 5-point item was used to rate health status: ‘How is your health in general? Very good, good, fair, bad, very bad’. To measure impact of caregiving on health participants were asked: ‘Has your own health been affected by the care you provided in any of these ways: Feeling tired, feeling depressed, loss of appetite, disturbed sleep, general feeling of stress, physical strain, short tempered/irritable; had to see own doctor, developed my own health condition, made an existing condition worse’. Carers selected any impact that applied to them. Carers also rated the impact on their personal relationships and leisure (termed personal life impact hereafter): ‘Has your ability to spend time doing leisure or social activities been affected by the assistance you give to X in any of these ways? Unable to socialise or take part in social or leisure activities at all (due to caring responsibilities); reduced time with spouse or partner; reduced time with other family members; reduced time with friends; difficulties making new friends; reduced time spent doing sport or physical activity; reduced time spent doing pastime or hobby’.

Demographic and caring profile. Information was obtained on carer gender, age (in 10-year bands), ethnic group, educational qualifications, employment status and marital status. Information on income was captured by asking for the total household income and subjective poverty (‘How is your household are getting along financially nowadays? We manage very well; quite well; we get by alright; we have some financial difficulties; severe financial difficulties). However, the income variable had about 40% missing data, suggesting non-random non-response, so it was not used. Instead, subjective poverty was used (with just

1.1% missing) to indicate the presence of financial difficulties (none vs. some/severe financial difficulties).

Carers were asked the total number of hours they spent caring each week across all care recipients (more or less than 20 hours a week); and the number of years (in bands) they had been a carer for each care recipient. The latter was used to create an overall number of years caring variable that was used to offset the outcomes (see *Analysis*). Finally, carers indicated the type and frequency of care to each care recipient. We selected personal and physical care as the most physically demanding for the carer. Personal care included dressing bathing, washing, shaving, cutting nails, feeding, using the toilet, and physical help entailed assistance with walking, climbing stairs, and getting into/out of bed. Carers who provided frequent (once a day or more) personal care *and* frequent physical care were identified as providing intensive-level care (Table 1).

Analysis

Generalised estimating equations (GEE) examined the association between caregiving for someone with ID and reported quality of life, health and impact of caring, after adjusting for a number of potentially confounding variables. GEEs are an extension of generalised linear models and are appropriate for clustered data. Similar to ordinary regression, GEEs provide an estimate of the association between an outcome and a coefficient. In GEEs, these associations are mathematically transformed (in exponential format) and become equivalent to Relative Risk (RR) (Knol *et al.* 2012), thus easing interpretation.

Quality of life and health status were modelled as 3-level ordinal outcomes (i.e., collapsing very good/fairly good, and fairly bad/very bad). Impact on health (0-10 range) and impact on personal life (0-7) were modelled as count outcomes. Overall years caring was used as an offset variable: this essentially adjusts the outcome to the exposure rate. For example, reporting an impact of 1 when caring for 1 year is likely different to reporting an impact of 1 when caring for 10 years, and the offset takes this into account.

Potential confounders were carer gender, carer age (grand-median centred), marital status (living with a partner – not living with a partner), ethnic group (White British vs. all other ethnic groups), subjective poverty (struggling financially – coping), educational qualifications (no educational qualifications - any educational qualifications), employment status (in paid employment- not in paid employment), and number of people living in household (grand-median centred). The caring load was accounted for by three variables: caring for longer hours (>20 hrs a week), intensive-level care (i.e., at least daily provision of personal and physical care), and caring for more than one care recipient. Care recipient characteristics (such as age and relationship to caregiver) could not be used because there were more than one care recipients per caregiver. By adjusting, instead, for the number of years caring, we are accounting to some extent for the fact that ID carers were more likely to care for offspring.

Overall missing data were very few. Among the four outcomes, three had zero missing data, and quality of life had 0.1% missing data. Among covariates, missing data ranged from 0% to 1.1%. The two variables with the highest levels of missing data were subjective poverty (1.1%) and hours caregiving per week (0.6%). Six of the 11 covariates had zero missing data. Given the extremely low levels of missing data, fitting of the GEEs, which assume missing completely at random (MCAR), was deemed appropriate. GEEs use quasi-likelihood estimation methods, and therefore overall model fit indices are not provided.

Procedure and ethical considerations

Data for this study were obtained through the UK Data Service which stores the Survey of Caregivers in Households 2009-10 (http://dx.doi.org/10.5255/UKDA-SN-6768-1.) and makes data accessible for research use. Data are provided anonymised and researchers need to preserve the conditions of use which specify protecting the anonymity of study participants. No further ethical approval was sought as the study was based exclusively on analysis of secondary anonymous data.

Results

The demographic and caring profile of ID carers

Compared to all other caregivers (Table 1), ID carers were more likely to be women (67%), younger, be living in a house with more people, and to struggle financially (37%), even though fewer of them had no educational qualifications (24%), and they were no more likely to be unemployed, single, or from an ethnic minority background. ID carers were more likely to be caring for 2+ care recipients (24%), to care for longer hours (i.e., more than 20 hours a week) (73%), and to have been a carer for 5 years or longer (74%). These differences in caring profile relate probably to the fact that most care recipients with ID were offspring (66%). More ID carers also provided frequent (daily) personal care (45%) than comparison carers (21%), and more ID carers provided frequent physical care (27%) than comparison carers (20%).

--Insert Table 1---

Compared to MH carers (Table 2), ID carers were more likely to be women, to live in households with more people, to care for longer hours every week, to have been a carer for more than 5 years, and to provide intensive-level care. No differences were present for age, partner status, unemployment, ethnicity, subjective poverty, educational qualifications, or number of care recipients. Therefore, ID carers and MH carers were fairly similar with respect to their socio-demographic profile, but ID carers had a significantly higher caring load.

Compared to dementia carers (Table 2), ID carers were more likely to be younger, to struggle financially, live in a house with more people, care for longer hours, more years, and provide intensive-level care. Dementia carers were more likely to be White British. Therefore, ID carers differed from dementia carers in their higher caring load, but also across four socio-demographic characteristics.

--Insert Table 2 here--

Quality of life, health and impact of caring

Across all 2,199 carers, 48% reported no impact on health (a score of 0) while 56% reported no personal life impact (a score of 0). Poor health status was reported by 8% of carers, while 7% reported poor quality of life.

Comparing outcomes between ID carers and all other carers

Table 3 presents the first analysis where ID carers (N=260) were compared against all other carers (N=1939). After adjusting for potential confounder effects of demographic characteristics and caring load, caring for someone with ID was associated with significantly worse health status (by 82% as RR=1.82, 95% CI: 1.30, 2.53), but not with higher impact on health (RR=1.10, 95% CI: 0.94, 1.29), suggesting carers of people with ID were likely to report worse health, but were no more likely to think their worse health was due to caregiving. Caring for someone with ID was not associated with poorer quality of life (RR = 1.15, 95% CI: 0.80, 1.75), but was associated with a slightly elevated risk (27%) of higher impact on personal life (RR = 1.27, 95% CI: 1.06, 1.52).

Carer age was associated with a 15% higher risk for reporting poorer health (RR=1.15, 95% CI: 1.07, 1.24). Being female was associated with a 40% increase in the risk of reporting a more negative impact of caregiving on health (RR=1.41, 95% CI: 1.24, 1.60), but was not related to reported quality of life. Socio-economic indicators had strong associations with outcomes. Subjective poverty was associated with a higher risk of reporting poorer quality of life (about 300%: RR = 3.98), poorer health status (150%), and greater impact of caregiving on health (53%) and personal life (35%). Unemployment and having no educational qualifications were not related to perceived impact of caregiving on health, but significantly increased the risk for poorer quality of life (RRs 1.74 and 1.46 for unemployment and no educational qualifications, respectively) and poorer health (RRs 1.92 and 1.82 for unemployment and no educational qualifications, respectively). Unemployment was associated with 73% lower risk of perceived negative impact of caregiving on personal life, while having no educational qualifications was associated with 64% lower risk.

We explored these unemployment/educational qualifications relationships further: chi-square associations suggested that those having educational qualifications were more likely to be employed, and also more likely to report struggling financially. We hypothesised a 3-way interaction between unemployment, lack of educational qualifications and subjective poverty on perceived impact of caregiving on personal life, and fitted this in a GEE but the results did not confirm this. Exploring then 2-way interactions, findings suggested that the positive effect of unemployment on perceived impact of caregiving on personal life was direct, but that the effect of educational qualifications was moderated by subjective poverty: the perceived impact of caregiving on personal life was more negative among caregivers with educational qualifications who were struggling financially (RR= 1.23, 95% CI: 1.02, 1.48).

Ethnicity and not living with a partner had no associations with outcomes (Table 3). Long caregiving hours (>20 hrs a week) were associated with a 100% increase in the risk of poorer quality of life, 74% increase in the risk of poorer health, and 82% increase in the risk of perceived negative impact of caregiving on health and personal life. Providing intensive-level care was associated with 65% increased risk of poorer quality of life, 32% increased risk for perceived negative impact of caregiving on health, and 67% increased risk for perceived negative impact of caregiving on personal life. Being a caregiver to 2+ people (as opposed to just 1 care recipient) was associated with an increase in the risk for poorer quality of life (115%) and poorer health (62%), but a decrease in the risk for perceived negative impact of caregiving on health or personal life (54%). The latter association was explored further. Chi-square tests showed that long caregiving hours were more likely among those caring for one person only. Indeed, an interaction term (number of people caring for * caring for >20 hrs a week) in the GEEs (instead of the two variables' main effects) suggested that caring for >20hrs for 1 person was associated with a significant increased risk for perceived negative impact of caregiving on health (RR=1.74, 95% CI: 1.50 to 2.03) and personal life (RR= 1.73; 1.48 to 2.03).

--Table 3---

Considering Tables 1 and 3 together, we conclude that caring for at least one person with ID was significantly associated with an increase in the risk of reporting poorer health and perceived impact of caregiving on personal life, but not poorer quality of life or perceived negative impact of caregiving on health. Negative outcomes were associated mainly with socio-economic indicators, particularly subjective poverty, and a high caring load, particularly long hours (>20 hrs per week) and intensive-level care. Carers of people with ID were more likely to be experiencing poverty and a high caring load when compared to all other carers (Table 1).

Comparing outcomes between ID carers and MH and dementia carers

We examined whether findings might change if we refined the comparison group. We accounted again for all potential confounders, though we removed ethnicity and single status from these models, as they had not been associated with outcomes in the previous GEEs. Compared to MH carers, caring for someone with ID was not associated with poorer quality of life, health, or perceived impact of caregiving on outcomes (Table 4 first row). It should be noted that the model for health status converged when the correlation matrix was independent, not exchangeable as in all other models (i.e., when it was assumed that health status was not correlated among carers within the same household).

Compared to carers of people with dementia, Table 5 suggested that carers of people with ID perceive their health status as significantly poorer (RR=3.21, 95% CI: 1.73, 5.95), but were significantly less likely to perceive a negative impact on their health due to their caregiving (RR=0.57, 95% CI: 0.44, 0.74). There was again no significant difference in quality of life or perceived impact of caregiving on personal life (Table 5 first row). Subjective poverty and caregiving for more than 20 hours each week were two systematic predictors of poorer outcomes in these analyses (Tables 4 and 5).

Discussion

We used data from a population-representative sample of caregivers in England to examine well-being among carers of people with ID. Compared to all other caregivers, after accounting for demographic and caring profile, caring for a person with ID was not associated with poorer quality of life but was associated with 82% higher risk of reporting poor health status. Interestingly, carers of people with ID did not seem to think that their poorer health was the result of caregiving. This perception is consistent with an hypothesis that caregiving does not lead to poorer health, but health differences may predate caregiving (Brown & Brown 2014). Recent longitudinal population data suggested that people who went on to become caregivers reported poorer physical health before caregiving commenced (Ramsay *et al.* 2013). In our cross-sectional study, we cannot tell if differences in health preexisted, but this important distinction between self-perceived *health status* and self-perceived *impact on health* allowed interesting insight into the conceptualisation of ‘impact’, a term that is prone to misuse in research evidence.

Caregiving for someone with ID was associated with a 27% higher risk of reporting negative impact on personal life (relationships with other people, spare time and hobbies). This risk was not present when we restricted the comparison to caregivers of people with mental health problems and those caring for someone with dementia. This difference in results highlights two points: (1) that interpretation of findings should always consider the context of the comparison (i.e., who is the comparison group); and (2) that the perception of impact seems to be relative to the clinical condition of the care recipient. Therefore, carers of people with ID experience a more negative impact on their personal lives compared to other caregivers, but this is not different to the impact experienced by those who care for people with mental health problems or dementia, after controlling for caregiving load. One possibility is that across all three conditions there are commonalities in care recipients’ characteristics, for example, challenging behaviour which relate to factors affecting personal life, such as time to socialise or access to respite (McGill *et al.* 2006).

When considering carers’ socio-demographic profile, ID carers reported experiencing significantly more financial difficulties than other carers (except MH carers). Subjective poverty was the single socio-demographic characteristic systematically associated with poorer well-being across analyses. It appears that the experience of economic vulnerability is strongly associated with caregiver well-being. The high, likely non-systematic, missingness of income data unfortunately prevented us from examining whether the finding would be present for income poverty. Economists suggest little overlap between subjective poverty and income poverty (Bradshaw & Finch 2003), so people who report being poor might not actually be poor by income standards. Families of children with ID are more likely to experience income poverty and hardship compared to families whose children have other or no disability (Emerson *et al.* 2010).

We considered several caring load indicators and, across each, carers of people with ID were experiencing higher caring load. Compared to MH and dementia carers, ID carers were still more likely to have been caring for more years, to provide longer care (>20 hrs a week), and more intensive care (frequent physical assistance and frequent personal care). This profile is similar to recent Dutch population data on ID caregivers (Wittenberg *et al.* 2012). Accounting for the number of years people had been caregivers, long caregiving hours were still associated with significantly poorer quality of life, health status, impact on health and impact on personal life. Caregiving to more than 2+ people was associated with poorer quality of life and poorer health, but its negative association with perceived impact on health and personal life was moderated by long caregiving hours, which were more likely among carers caregiving for 1 person only.

While one of the strengths of the present study is the use of population-representative data, an important limitation is the lack of care recipient characteristics from the analyses, either because there were several care recipients per caregiver (e.g., with respect to gender or age of care recipient) or because data were not available (e.g., for challenging behaviour). Challenging behaviour has been associated with caregiver health and well-being in several studies across different conditions (Pinquart & Sörensen 2007, Totsika *et al.* 2011a, Fauth *et al.* 2015). Further, the clinical condition of care recipients relied on carer report which is a typical limitation in population surveys. On balance, the use of a more stringent caregiver definition makes the present findings relevant to those defined as informal carers by UK services. Because the data were cross-sectional, there is no assumption of causative risk but any referral to risk is restricted to associations expressed as relative risk indicators (i.e., effect sizes).

It is important to highlight that both the cross-sectional nature of the data and the consideration of carers as a group without differentiating whether they care for children, young adults or older adults may be masking important variation in their well-being that is related to significant life stages, as evidence has shown that, for example, psychological well-being in parents of people with ID fluctuates around significant transitions, e.g., diagnosis (Glidden & Jobe 2009). In addition, the use of single-item measures to measure quality of life and health status may have resulted in reduced sensitivity to capturing variation among groups. However, the single health status item used here is one of the most frequently used health measures in national surveys around the world and has demonstrated good discriminant validity (Bowling 2005). On the contrary, the single item of quality of life has not been as extensively tested, and although as a single measure it has good face validity with regard the construct of quality of life, it prevents us from examining in depth specific domains of quality of life.

Caregiving follows complex patterns and the English survey tried to capture this by measuring information on up to seven care recipients for each carer. A number of ID carers also cared for people with other conditions or for people who combined ID with other conditions. All these were included in the first part of the analysis where we compared ID carers to all other carers, and therefore any conclusions are also relevant to ID carers who also care for people with mental health problems or dementia, or indeed other conditions. In the second part of the study, we excluded these carers because we wanted to compare for potential differences in well-being among carers of people with LD and mental health problems and dementia. We thus removed 120 carers who either cared for people who combined ID with mental health problems and/or dementia or who cared for several people with either of these three conditions of interest. Therefore, the resulting groups included carers who only cared for people with one of the conditions of interest (ID, MH or dementia), but they could have also included other conditions that were not focal to the research question (e.g., terminal illness). Therefore, it is important to note that the findings from this second part of the study do not generalise to carers of people with ID, MH or dementia who are experiencing parallel caregiving across these three conditions.

The paradigm of the current study extended the current evidence base by examining well-being among different group of carers. Findings supported recent calls for rejecting a negative-impact lens of caregiving (Brown & Brown 2014, Roth *et al.* 2015, Hastings in press) in favour of a more nuanced one: quality of life and perceived impact on health in this English population sample were experienced as similar to other caregiving groups.

Our findings can support information needs of new caregivers of people with ID, by highlighting that, on average, their quality of life and the impact on their health will not be any different to that of other caregivers. Furthermore, the impact on their health may be better compared to caregiving for someone with dementia. Caregivers of people with ID are likely to have poorer health, but possibly not due to the care they provide to their relative or friend with ID. A small, negative impact on their personal life will also be evident, on a par with carers of people with mental health problems and dementia. However, it is important to emphasise that caregiver well-being will mostly relate to how much carers feel they struggle financially and the long hours of care they provide. Present findings highlight that support for caregivers of people with ID should focus on alleviating poverty (or the perception thereof), and long hours of intensive caregiving. The latter further supports the need for continued and systematic access to short breaks (respite care), which have been shown to improve the well-being of carers of people with ID and importantly the well-being of families as a whole (Robertson *et al.* 2011).

References

Bailey, D. B., Golden, R. N., Roberts, J. & Ford, A. (2007) Maternal depression and developmental disability: Research critique. *Mental Retardation and Developmental Disabilities Research Reviews,* **13,** 321-329.

Bowling, A. (2005) Just one question: If one question works, why ask several? *Journal of Epidemiology and Community Health,* **59,** 342-346.

Bradshaw, J. & Finch, N. (2003) Overlaps in dimensions of poverty. *Journal of Social Policy,* **32,** 513-525.

Brown, R. M. & Brown, S. L. (2014) Informal caregiving: A reappraisal of effects on caregivers. *Social Issues and Policy Review,* **8,** 74-102.

Buckner, L. & Yeandle, S. (2011) *Valuing Carers 2011: Calculating the value of carers' support.,* Carers, UK. Available at:http://circle.leeds.ac.uk/files/2012/08/110512-circle-carers-uk-valuing-carers.pdf (21 Dec 2015).

Colombo, F., Llena-Nozal, A., Mercier, J. & Tjadens, F. (2011) *Help wanted? Providing and paying for long-term care,* OECD Publishing.

Emerson, E., Shahtahmasebi, S., Lancaster, G. & Berridge, D. (2010) Poverty transitions among families supporting a child with intellectual disability. *Journal of Intellectual and Developmental Disability,* **35,** 224-234.

Fauth, E. B., Femia, E. E. & Zarit, S. H. (2015) Resistiveness to care during assistance with activities of daily living in non-institutionalised persons with dementia: associations with informal caregivers' stress and well-being. *Aging & Mental Health,* **11,** 1-11.

Glidden, L. M. & Jobe, B. M. (2009) By choice or by chance: longitudinal perspectives on resilience and vulnerability in adoptive and birth parents of children with developmental disabilities. *International Review of Research in Mental Retardation,* **37,** 69-93.

Goren, A., Gilloteau, I., Lees, M. & DiBonaventura, M. (2014) Quantifying the burden of informal caregiving for patients with cancer in Europe. *Supportive Care in Cancer,* **22,** 1637-1646.

Hastings, R. P. (in press) Do children with intellectual and developmental disabilities have a negative impact on other family members? The case for rejecting a negative narrative. *International Review of Research in Developmental Disabilities,* **50**.

Hastings, R. P. & Taunt, H. M. (2002) Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation,* **107,** 116-127.

Hatton, C., Emerson, E., Glover, G., Robertson, J., Baines, S. & Christie, A. (2014) *People with learning disabilities in England 2013,* Public Health England. Available at:https://www.improvinghealthandlives.org.uk/publications/1241/People_with_Learning_Disabilities_in_England_2013 (21 Dec 2015).

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

Knol, M. J., Le Cessie, S., Algra, A., Vandenbroucke, J. P. & Groenwold, R. H. H. (2012) Overestimation of risk ratios by odds ratios in trials and cohort studies: alternatives to logistic regression. *Canadian Medical Association Journal,* **184**.

Lee, J. (2013) Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review. *Research in Developmental Disabilities,* **34,** 4255-4273.

Legg, L., Weir, C., Langhorne, P., Smith, L. N. & Stott, D. J. (2012) Is informal caregiving independently associated with poor health? A population-based study. *Journal of Epidemiology and Community Health,* **67,** 95-97.

McConnell, D. & Savage, A. (2015) Stress and resilience among families caring for children with intellectual disabilities: Expanding the research agenda. *Current Developmental Disorders Report,* **2,** 100-109.

McGill, P., Papachristoforou, E. & Cooper, V. (2006) Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health and Development,* **32,** 159-165.

Miodrag, N. & Hodapp, R. M. (2010) Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry,* **23,** 407-411.

NHS Information Centre (2010) *Survey of Carers in Households 2009/10. The Health and Social Care Information Centre,* The Health and Social Care Information Centre. Available at:http://www.hscic.gov.uk/catalogue/PUB02200/surv-care-hous-eng-2009-2010-rep1.pdf (21 Dec 2015).

Pinquart, M. & Sörensen, S. (2007) Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological Sciences,* **62B,** P126-P137.

Ramsay, S., Grundy, E. & O'Reilly, D. (2013) The relationship between informal caregiving and mortality: an analysis using the ONS Longitudinal Study of England and Wales. *Journal of Epidemiology and Community Health,* **67,** 655-660.

Robertson, J., Hatton, C., Emerson, E. & Welch, V. (2011) The impacts of short break provision on families with a disabled child: an international literature review. *Health and Social Care in the Community,* **19,** 337-371.

Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N. & Porter, M. (2009) A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *Journal of Gerontology: Social Sciences,* **64,** 788-798.

Roth, D. L., Fredman, L. & Haley, W. E. (2015) Informal caregiving and its implications for health: A reappraisal from population-based studies. *Gerontologist,* **55,** 309-319.

Singer, G. H. S. (2006) Meta-Analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation,* **111,** 155-169.

Smith, L., Onwumere, J., Craig, T., McManus, S., Bebbington, P. & Kuipers, E. (2014) Mental health and physical illness in caregivers: results from an English national survey sample. *British Journal of Psychiatry,* **205,** 197-203.

Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. & Lancaster, G. (2011b) Behavior problems at 5 years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology,* **39,** 1137-1147.

Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. & Berridge, D. (2011a) A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorders and intellectual disability. *Journal of Child Psychology and Psychiatry and Allied Disciplines,* **52,** 91-99.

Trivedi, E., Beaver, K., Bouldin, E. D.*, et al.* (2014) Characteristics and well-being of informal caregivers: Results from a nationally representative US survey. *Chronic Illness,* **10,** 167-179.

Tuithof, M., ten Have, M., van Dorsselaer, S. & de Graaf, R. (2015) Emotional disorders among informal caregivers in the general population: target groups for prevention. *BMC Psychiatry,* **15**.

White, C. (2013) *2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001,* Office of National Statistics. Available at:http://www.ons.gov.uk/ons/dcp171766_300039.pdf (21 Dec 2015).

Wittenberg, Y., Kwekkeboom, M. H. & de Boer, A. H. (2012) *Bijzondere mantelzorg. Ervaringen van mantelzorgers van mensen met een verstandelijke beperking of psychiatrische problematiek,* The Hague / Amsterdam: The Netherlands Institute for Social Research / Amsterdam University of Applied Sciences. Available

Table 1. Comparison of the demographic and caring profile of ID carer with all other carers

	ID carers	Comparison carers	*p* value of difference
Unweighted N	260	1939	n/a
Weighted N	258	1945	n/a
% Female carer	67	59	0.021
% Aged 35-44 yrs	28	14	<0.001
% Living with a partner	66	71	0.098
% White British	85	88	0.136
% Struggling financially	37	21	<0.001
% No educational qualifications	24	30	0.059
% Not in paid employment	56	51	0.103
Median number of people in HHD[1]	3	2	<0.001
% Caring for 2+ care recipients	24	16	0.001
% Care >20 hours a week	73	45	<0.001
% Caring for 5+ years	74	50	<0.001
% Frequent personal care provision	45	21	<0.001
% Frequent physical care provision	27	20	0.013
% Intensive-level care[2]	24	12	<0.001

[1] HHD: household; [2]combined frequent physical and frequent personal care ;

Table 2. Comparing of the profile of ID carers with carers of people with mental health problems and carers of people with dementia

	ID carers (1)	MH carers (2)	Dementia carers (3)	(1) vs (2) *p* value	(1) vs (3) *p* value
Weighted N	174	198	188	n/a	n/a
% Female carer	70	59	64	0.024	0.181
Median age	35-44	45-54	55-64	0.488	<0.001
% Living with a partner	71	67	77	0.467	0.190
% White British	86	84	95	0.511	0.003
% Struggling financially	34	37	11	0.546	<0.001
% No educational qualifications	23	29	21	0.159	0.695
% Not in paid employment	54	61	43	0.183	0.050
Median number of people in HHD[1]	3	2	2	<0.001	<0.001
% Caring for 2+ care recipients	21	22	25	0.803	0.469
% Care >20 hours a week	77	55	38	<0.001	<0.001
% Caring for 5+ years	78	54	37	<0.001	<0.001
% Intensive-level care[2]	24	14	10	0.013	<0.001

[1] HHD: household; [2] combined frequent physical and frequent personal care

Table 3. Comparing ID carers to all other caregivers (reference category). Adjusted Relative Risk (RR) and 95% Confidence Intervals from generalised estimating equations.

	Quality of life (poor)	**Health status (poor)**	**Impact on health (negative)**	**Impact on personal life (negative)**
Caring for a person with ID	1.15 (0.80, 1.75)	**1.82 (1.30, 2.53)**	1.10 (0.94, 1.29)	**1.27 (1.06, 1.52)**
Demographic profile				
Carer female	1.22 (0.96, 1.54)	1.17 (0.95, 1.43)	**1.41 (1.24, 1.60)**	1.08 (0.96, 1.22)
Carer age	1.05 (0.96, 1.15)	**1.15 (1.07, 1.24)**	0.97 (0.92, 1.01)	1.00 (0.95, 1.04)
White British	0.68 (0.45, 1.02)	0.77 (0.52, 1.13)	.921 (0.80, 1.07)	.90 (0.72, 1.13)
Not living with a partner	0.75 (0.54, 1.03)	1.27 (0.96, 1.67)	1.14 (0.97, 1.33)	1.09 (0.91, 1.31)
Not in paid employment	**1.74 (1.30, 2.32)**	**1.92 (1.51, 2.45)**	0.92 (0.80, 1.07)	**0.73 (0.63, 0.86)**
No educational qualifications	**1.46 (1.10, 1.94)**	**1.82 (1.46, 2.28)**	0.86 (0.75, 1.00)	**0.64 (0.55, 0.76)**
Struggling financially	**3.98 (2.93, 5.41)**	**2.56 (1.94, 3.37)**	**1.53 (1.33, 1.77)**	**1.35 (1.15, 1.58)**
Number of people in household	1.02 (0.89, 1.17)	0.92 (0.82, 1.02)	**0.93 (0.87, 0.99)**	0.97 (0.91, 1.04)

	Quality of life (poor)	**Health status (poor)**	**Impact on health (negative)**	**Impact on personal life (negative)**
Caregiving load				
Caregiving for 2+ people	**2.15 (1.53, 3.02)**	**1.62 (1.16, 2.25)**	**0.54 (0.46, 0.64)**	**0.54 (0.45, 0.63)**
Caregiving >20 hours a week	**1.98 (1.48, 2.64)**	**1.74 (1.38, 2.18)**	**1.82 (1.58, 2.09)**	**1.68 (1.46, 1.94)**
Intensive-level care	**1.65 (1.18, 2.30)**	1.06 (0.78, 1.46)	**1.32 (1.14, 1.54)**	**1.67 (1.43, 1.96)**

Footnote: Outcomes were offset by number of years caregiving. Where cells are in bold font, the Wald chi-square test was significant at p<.05.

Table 4. Comparing ID carers to carers of people with mental health problems: adjusted Relative Risk (RR) and 95% confidence intervals.

	Quality of life (poor)	**Health status (poor)**	**Impact on health (negative)**	**Impact on personal life (negative)**
Caring for a person with ID	0.56 (0.29, 1.05)	1.11 (0.64, 1.90)	0.71 (0.57, 0.89)	1.08 (0.81, 1.44)
Demographic profile				
Carer female	1.31 (0.76, 2.25)	1.07 (0.68, 1.69)	**1.55 (1.22, 1.97)**	1.06 (0.82, 1.37)
Carer age	1.14 (0.96, 1.34)	**1.26 (1.08, 1.46)**	.96 (0.88, 1.03)	.93 (0.86, 1.01)
Not in paid employment	**2.35 (1.27, 4.37)**	**1.85 (1.09, 3.14)**	1.05 (0.83, 1.33)	1.01 (0.78, 1.32)
No educational qualifications	1.17 (0.64, 2.19)	1.20 (0.70, 2.04)	.93 (0.71, 1.22)	**0.65 (0.48, 0.89)**
Struggling financially	**4.60 (2.47, 8.56)**	**2.41 (1.39, 4.18)**	**1.57 (1.24, 1.99)**	**1.35 (1.02, 1.80)**
Number of people in household	0.98 (0.79, 1.20)	0.99 (0.82, 1.22)	1.05 (0.97, 1.13)	0.99 (0.89, 1.00)
Caregiving load				
Caregiving for 2+ people	**3.60 (1.89, 6.87)**	1.54 (.82, 2.92)	**0.64 (0.49, 0.82)**	**0.73 (0.56, 0.97)**
Caregiving >20 hours a week	**2.27 (1.17, 4.40)**	1.50 (0.84, 2.69)	**1.65 (1.25, 2.16)**	**1.43 (1.05, 1.95)**
Intensive-level care	1.11 (0.55, 2.24)	1.20 (0.65, 2.22)	1.13 (0.91, 1.42)	**1.60 (1.20, 2.13)**

Footnote: Outcomes were offset by number of years caregiving. Where cells are in bold font, the Wald chi-square test was significant at $p<.05$.

Table 5. Comparing ID carers to carers of people with dementia: adjusted Relative Risk (RR) and 95% confidence intervals.

	Quality of life (poor)	**Health status (poor)**	**Impact on health (negative)**	**Impact on personal life (negative)**
Caring for a person with ID	1.24 (0.64, 2.39)	**3.21 (1.73, 5.95)**	**.57 (0.44, 0.74)**	1.08 (0.81, 1.44)
Demographic profile				
Carer female	**2.25 (1.19, 4.25)**	1.52 (0.91, 2.55)	**1.32 (0.99, 1.75)**	1.06 (0.82, 1.37)
Carer age	1.19 (0.92, 1.53)	1.20 (1.00, 1.44)	0.96 (0.87, 1.06)	.93 (0.86, 1.01)
Not in paid employment	**2.02 (1.12, 3.66)**	1.69 (0.98, 2.90)	1.05 (0.80, 1.38)	1.01 (0.78, 1.32)
No educational qualifications	**2.07 (1.13, 3.79)**	1.56 (0.87, 2.79)	.93 (0.71, 1.22)	.86 (0.64, 1.15)
Struggling financially	**2.45 (1.08, 5.55)**	**2.41 (1.39, 4.18)**	**1.57 (1.24, 1.99)**	**1.43 (1.10, 1.85)**
Number of people in household	0.95 (0.75, 1.19)	**2.12 (1.12, 4.00)**	1.05 (0.97, 1.13)	0.99 (0.91, 1.08)
Caregiving load				
Caregiving for 2+ people	**1.96 (1.04, 3.70)**	**1.81 (1.03, 3.21)**	**0.64 (0.49, 0.82)**	**0.65 (0.48, 0.87)**
Caregiving >20 hours a week	**3.94 (1.64, 9.50)**	**2.18 (1.17, 4.03)**	**1.65 (1.25, 2.16)**	**2.03 (1.54, 2.66)**
Intensive-level care	**2.20 (1.13, 4.31)**	1.13 (0.58, 2.17)	1.13 (0.91, 1.42)	1.07 (0.85, 1.36)

Footnote: Outcomes were offset by number of years caregiving. Where cells are in bold font, the Wald chi-square test was significant at $p<.05$.