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Title page

Title: Perceptions of Unmet Needs for Community Social Care Services in England. A Comparison of Working Carers and the People they Care for.

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Conflict of interest

There are no conflicts of interest.

Abstract

Previous UK research has found expressed unmet need for services by unpaid working carers and among disabled and older people. There are, however, suggestions from research that views on unmet needs for services differ between carers and care-recipients. Working carers in the UK say that the care-recipient is sometimes reluctant to accept services and the few international comparative dyad studies that have been carried out find that carers perceive higher unmet need than care-recipients. Recent policy discussions in England have also recognised that there may be differences of opinion. We collected data in 2013 from working carer/care-recipient dyads in England about perceived need for services for the care-recipient, disability, unpaid care hour provision and individual and socio-demographic characteristics. We find that care-recipients as well as their carers perceive high unmet need for services, although carers perceive *higher* unmet need. For carers, unmet need is associated with the disability of the carer-recipient and being the daughter or son of the care-recipient; for care-recipients it is associated with unpaid care hours, carers' employment status and carers' health. The majority of dyads agree on need for services, and agreement is higher when the working carer provides care for 10 hours or more hours a week. Services for care-recipients may enable working carers to remain in employment so agreement on needs for services supports the implementation of legislation, policy and practice that has a duty to, or aims to, support carer's employment.

Keywords: Unpaid care, social care services, working carers, unmet needs, dual perspective

What is known about this topic:

- There is perceived unmet need for services by unpaid carers in England.
- Expressed needs for services may differ between working carers and the people they care for in the UK.
- Studies on dyads internationally find that perceived needs for services differ, with carers perceiving higher unmet need than care-recipients.

What this paper adds:

- Unmet need for services for the care-recipient in England is perceived as high by care-recipients, as well as by their working carers.
- The majority of dyads agree on whether or not more services are needed.
- Agreement on unmet need is higher when carers provide care for 10 or more hours a week compared to when carers provide fewer hours of care.

Introduction

Previous UK research on working carers - people in paid employment who provide unpaid care to family or friends because of long-term physical or mental ill-health or disability, or problems related to old age - has found expressed unmet need for services (Mooney *et al*. 2002, Phillips *et al*. 2002, Yeandle 2007, Milne *et al*. 2012). Population-based studies of disabled or older people in the UK have also found unmet need for services (Vlachantoni *et al*. 2011). The 2010 *Health Committee Report on Social Care* recognised unmet need for services as a shortcoming of the social care system (Commission for Social Care Inspection 2008, House of Commons 2010).

Unmet need for services is problematic for both carer and care-recipient. There are, however, suggestions in the literature that views on unmet needs for services differ. Research on working carers in the UK reports that, from the carer's perspective, care-recipients are sometimes reluctant to accept services (Twigg 1996, Seddon & Robinson 2001, Yeandle *et al*. 2007, Arksey & Glendinning 2008) and that this is a barrier to receipt of services (Yeandle *et al*. 2007), indicating possible disagreement on need for services. The *2009/10 Survey of Carers in Households in England* (HSCIC 2010a) found that 15% of those providing unpaid care say that they do so because the care-recipient would not want anyone else caring for them.

Although there are studies of need for services based on carers' perspectives and studies based on care-recipients' perspectives, there is little UK research drawing on *both* perspectives. There is some research comparing both perspectives on unmet need for *care* overall, but it does not specify needs for *services*. This comparative dyad research finds a difference in opinion on unmet needs, with carers perceiving higher unmet need, both in England (Walters *et al*. 2000, Hancock *et al*. 2006) and internationally (Cleary *et al*. 2006, Bakker *et al*. 2013).

A review of previous research was undertaken, drawing on our previous reviews in this area, updated by a search of relevant bibliographic databases, including Cochrane; EconLit; PsycINFO; PubMed; Scopus; Social Policy and Practice; Social Sciences Citation Index; Social Services Abstracts; Sociological Abstracts. We found only three studies that compared carer and care-recipient perspectives on need for services – dyad studies in the Netherlands (Van der Roest *et al*. 2009), U.S. (Zweibel & Lydens 1990) and Sweden (Foldemo *et al*. 2005) - with none in England. The Netherlands study focused on older people with dementia and used the Camberwell Assessment of Need for the Elderly (Reynolds *et al*. 2000) to elicit views of patients and carers. The Swedish study focused on people with schizophrenia and interviewed both carers and care-recipients. The U.S. study conducted interviews with carers of older care-recipients and care-recipients themselves. These studies all found that carers perceived higher unmet need for services than care-recipients.

Recent policy in England, in particular the 2014 *Care Act*, recognises that there may be differences of opinion between carer and care-recipient. The Act includes provision for both older or disabled people and carers, and recognises that carers' needs, as well as care-recipients' needs, might best be met by provision of services for the care-recipient 'whether or not there is a duty to meet that adult's needs in their own right' (House of Commons 2014: paragraph 152). It recognises that there may be disagreement, acknowledging 'the situation where a local authority might consider the best way of meeting a carer's needs for support is by providing care and support to the adult needing care but it is not possible to do so (for example, if that adult does not agree to such provision)' (House of Commons 2014: paragraph 156). Disagreement raises questions about whose decision is paramount (Twigg 1996, Pickard 2004), and may impact on the ability of Local Authorities to provide adequate services. It is certainly an important issue for working carers: recent research has shown that provision of services for the care-recipient is effective in supporting working carers to remain in employment (Pickard *et al.* 2015) and that this has both public expenditure (Pickard *et al.* 2012) and individual cost implications (Age UK 2012).

It has been theorised that carer 'burden' (as indicated by poor health, providing long care hours and/or subjectively-rated burden) affects carers' perceptions of care-recipients' needs, resulting in perceptions of higher needs than care-recipients (Lyons *et al*. 2002, Meiland *et al*. 2005, Cleary *et al*. 2006). In their comparison of carer and care-recipient's perspectives on unmet need for services in the U.S., Zweibel and Lydens (1990) found that carer 'burden' or difficulty, as measured by both health and subjectively-rated difficulty, was associated with disagreement on unmet needs. Van der Roest *et al* (2009), in the Netherlands, found that unpaid care hours and subjective carer 'burden' are associated with higher perceived unmet need by carers.

As Twigg and Atkin (1994) point out, needs-related characteristics for services exist within a context of how unpaid caring is constructed socially. Perceived need for services will thus be driven by care needs such as ill-health or disability and by normative factors structuring expectations of unpaid caring and service receipt, in particular expectations related to family relationship between carer and care-recipient (such as parent-son/daughter) but also expectations of caring related to ethnicity and gender. Minority ethnicity is a barrier to accessing health and social care services in the UK for both carers and care-recipients (Moriarty 2008, Greenwood *et al*. 2014) and may result in unmet need. In addition, cultural norms of duty and filial obligations related to ethnicity and caring may result in disagreement between carer and care-recipient on needs for services (Pinquart & Sörensen 2005, Ahmed & Rees Jones 2008, Williams & Johnson 2010, Parveen *et al*. 2011). Disagreement between daughter-carers and care-recipient parents has been found in international studies on perceived unmet need for services, with the daughter-carer perceiving more unmet need than their parent (Zweibel & Lydens 1990, Van der Roest *et al*. 2009), possibly reflecting changing gender expectations of caring (Doty *et al*. 1998).

There is a need to further investigate to what extent and in what ways care-recipients and carers converge or diverge in their perceptions of needs for services to plan services and policy, and because of the potential impact of unmet need for services on working carers' employment, the health and well-being of both carers and care-recipients, and the associated costs. We present evidence from a recent study in which we collected information from working carer/care-recipient dyads in England about perceived need for services, disability, hours of unpaid care provision, and individual and socio-demographic characteristics. This enabled a comparison between carer and care-recipient of the factors associated with perceived needs for services, an exploration of the extent of differences and similarities in perceived needs for services between working carers and care-recipients and the factors associated with these differences and similarities.

Methods

Survey

Our data were collected in 2012/13 to identify working carers' unmet needs for community social care services. Data collection began with an online screening survey of public sector employees in England to identify people in employment who provide unpaid care. This method was based on that used by Phillips and colleagues (2002). Potential participants were sent the survey link by either their trade union or employer, with responses being returned directly to us. The question used to identify carers was the 2011 Census question: 'Do you look after, or give any help or support to family members, friends, neighbours or others because of either long-term physical or mental ill-health/disability, problems related to old age?' (Office for National Statistics 2011). Carers identified in the initial survey who opted into the second stage of the study were sent a self-completion questionnaire for themselves; it included questions on socio-demographic characteristics, provision of care and perceived needs for services for the main person for whom they provide unpaid care. The main person cared-for is defined as the person who the carer spends most time helping and, if they spend an equal amount of time helping two or more people, is the care-recipient who lives with them. If more than one care-recipient lives with them, we asked them to define the main person they care for.

At the same time, carers were sent a questionnaire for the main person they care for to complete and return directly to us, a method used by Van den Berg *et al* (2005) in the Netherlands, but not used in England to date. Carer and care-recipient questionnaires had the same response number, allowing for later dyad identification. The care-recipient's questionnaire had questions about socio-demographic characteristics, disability including difficulties with Activities of Daily Living (ADLs), financial resources and similar questions to the carers’ questionnaire about perceived needs for services. Questionnaires were developed for adults, children aged 8-11 years and 12-15 years, and an easy-read version for adults with learning disabilities, enabling inclusion of a wide range of care-recipients. Children aged under 8 were not sent a care-recipient’s questionnaire, as self-completion questionnaires are inappropriate for young children (McCrystal 2004, Ravens-Sieberer *et al*. 2006). People who lack capacity were excluded, in line with our ethics approval guidelines.

We used validated questions from other surveys, including Phillips *et al*. (2002), the 2011 Census (Office for National Statistics 2011); 2009-10 Survey of Carers in Households (HSCIC 2010a); 2009-10 Personal Social Services Survey of Adult Carers in England (HSCIC 2010b); 2010-11 Social Care User Survey (HSISC 2011) and Health Survey for England (HSCIC 2012). Additional questions were piloted as part of the questionnaire piloting with carers and care-recipients who did not take part in the main study.

Ethics approval was obtained from the Social Care Research Ethics Committee (Reference: 12/IEC08/0029). Consent for both screening survey and questionnaire was assumed from their voluntary self-completion. All participants were sent Participant Information Sheets explaining the study, confidentiality and that participation was voluntary. For those aged under 16, written consent was also obtained from their parent or guardian.

Analysis: comparison of factors associated with needs for services

There are two main strands to the analysis. The first compares, for carers and care-recipients, factors potentially associated with need for services, using bivariate chi-squared tests of association and then multivariate logistic regression. These analyses were conducted for carers and care-recipients separately. Carers were asked whether or not the person they care for has the right amount of support or services and, if not, what services they need from a list: home care, personal assistant, cleaner, daycare, lunch club, meals on wheels, supported employment, special school or college, after school club or holiday club, community transport services, equipment, short break, residential home and other services not already specified. Care-recipients were asked the same question about services for themselves. In the carer bivariate analyses, a variable indicating whether or not a need for services for the care-recipient was reported was tested for association with a number of factors. The variable was also the dependent variable in the multivariate logistic regression. A value of '0' was assigned to this variable if there was no perceived need for services; and the value '1' when a need for *any* of the services was reported. In the care-recipient analyses the corresponding variable is need for services for themselves.

Factors tested against perceived need for services in the bivariate analysis, and that are independent variables in the logistic regression, were identified from previous UK and international research as potentially relevant to differences in perceived need for services. These are disability, hours of unpaid care per week, carer’s gender, ethnicity, health, employment status, care-recipient’s ethnicity and gender, and relationship of carer to care-recipient (Zweibel & Lydens 1990, Twigg & Atkin 1994, Doty *et al* 1998, Pinquart & Sörensen 2005, Ahmed & Rees Jones 2008, Van der Roest *et al*. 2009, Williams & Johnson

2010, Parveen *et al*. 2011). We excluded carer's and care-recipient's age from the analysis because significant associations between those variables and the family relationship of care-recipient to carer meant we were unable to use both. We used the family relationship variable in the analyses because of the potential role of family relationships in differences in perceived unmet need (e.g. Twigg & Atkin 1994).

We created binary variables for all potential factors used in the analyses. The disability variable is personal care disability, defined as difficulty with, or an inability to perform, one or more ADLs, where '0' is no difficulties and '1' is one or more difficulties. The variable is derived from questions asked of care-recipients about difficulty with or inability to do one or more of the following: getting in and out of bed on their own; washing face and hands; having a bath or shower; dressing or undressing; using the toilet; eating, including cutting up food. Hours of unpaid care is the hours a week carers say that they look after the main person they care for and has two categories: less than ten hours a week ('0') and ten hours or more a week ('1'), derived from seven possible 'hours per week' response categories. Ten hours or more a week unpaid caring is the threshold at which working carers' employment is at risk (King and Pickard, 2013).

Ethnicity is own ethnicity. Respondents identified their ethnic group from a list; the categories were then collapsed into two: White ('0') or Black and Minority Ethnic (BME) ('1') background. Carer's health is derived from a question in which carers self-rated their health in one of five categories and this was recoded into 'very good or good' with a value of '0', or 'fair, bad or very bad', with a value of '1'. The variable for relationship of care-recipient to carer is in two categories: parent ('1') and relationship other than parent (spouse/partner, son or daughter, other relative or friend) (‘0’). Employment status is either full-time, coded ‘0’, or part-time, coded ‘1’, where part-time is 30 hours a week or less (Evandrou and Glaser 2002) and is derived from a continuous variable of hours per week usually worked by the carer. Gender is either male (‘0’) or female (‘1’).

Many of these factors are associated with each other. However, collinearity diagnostics using the method advocated by Field (2013) showed that the Variance Inflation Factors for all variables are below 2.5; levels above that are considered potentially problematic for regression analyses. We therefore did not exclude any variables on that basis.

Analysis: factors associated with agreement and disagreement on needs for services

The second strand of the analysis investigates factors associated with agreement or disagreement between carers and care-recipients in perceived needs for services, using multivariate logistic regression. The dependent variable in this analysis is agreement or disagreement on need for services for the care-recipient. Using carer and care-recipient responses to perceived needs for *any* service for the care-recipients as detailed above, within each carer/care-recipient dyad the value ‘0’ was allocated when the dyad agree whether more services are needed; and the value ‘1’ was allocated when the carer in the dyad perceives that more services are needed but the care-recipient does not. The sub-group of 11 dyads where care-recipients perceive that more services are needed but carers do not is excluded because the sub-sample sizes are too small for regression analyses. The covariates, identified from previous UK and international research as potentially relevant to differences in perceived need for services, are the same as in the first phase of analyses detailed above.

In all the logistic regression analyses, the odds ratio (the odds of an outcome compared with the reference category) for each variable is estimated, along with the 95% confidence interval and significance level. A level of 0.05 is used as the criterion to determine statistical significance. Diagnostic tests for goodness-of-fit (Hosmer-Lemeshow test statistics) are reported for the logistic regression models. Analysis was completed using IBM SPSS 21 (IBM Corp 2012).

Results

Sample

In total 2,891 employees completed the screening survey, of whom 1,645 provide unpaid care. Questionnaires were completed by 384 working carers and, within that, by 165 care-recipient/carer dyads. For this analysis we used data from 150 of those dyads, excluding dyads where there was no information on need for services from *both* carer and care-recipient or if the care-recipient was living in a care home; the latter because the focus is on unmet need for services for those being cared for in the community (figure 1). Within the 150 dyads, 92% of carers worked in local government and were recruited through their trade union, while 8% worked in national government and were recruited through their employer.

[Figure 1 about here]

The response rate for the questionnaire for carers was 51%, similar to the 56% response rate achieved by Phillips *et al* (2002) on which the primary data collection methods were based.

For people receiving care, the response rate (22%) was similar to that of Van den Berg *et al* (2005) (21%). Our sample is in many ways comparable to national data on working carers and the people they provide care for (table 1). There are, however, higher proportions of working carers who are women and who are aged 45-54 and lower proportions aged under 35 in our survey than nationally; this is reflective of the underlying public sector population from which our sample was drawn (Damant & Jenkins 2011). There is also a higher proportion of carers in fair, bad or poor health which may reflect their older age-profile. Provision of unpaid care hours by working carers in our sample is higher than for working carers nationally.

[Table 1 about here]

Factors associated with perceived need for services: comparison of carer and care-recipient

For both carers and care-recipients, perceived unmet need for services is high. Nearly half of care-recipients (47%) and two thirds of carers (66%) perceive a need for more services (table 2). In the bivariate analyses (table 2), for both carers and care-recipients, perceived need for services for the care-recipient is significantly associated with ADL-disability. A higher proportion of those with at least one difficulty with ADLs have unmet needs compared to those with no difficulties with ADLs. Hours of provision of unpaid care are not significant for carers in assessing need for services, whereas for care-recipients they are, with a higher proportion of those receiving 10 hours or more a week unpaid care from the working carer having unmet need. A significantly higher proportion of those caring for parent or parents-in-law have unmet needs, compared to those caring for someone else. For care-recipients, a significantly higher proportion have unmet need for services when the carer works part-time compared to when they work full-time. For carers, working hours are not significant.

[Table 2 about here]

Results from multivariate logistic regression in Table 3 show that both care-recipient's disability and their family relationship with the care-recipient are significantly associated with whether the carer perceives unmet need for services. Odds of perceived unmet need for services are 2.6 times higher when the care-recipient has an ADL-disability compared to not having an ADL-disability, and 3.3 times higher when the carer is the son or daughter of the care-recipient compared to any other relationship. For care-recipients, care hours and carer's health and employment status are significantly associated with whether they perceive unmet need for services (table 4). Odds of perceived unmet need for services are four times higher when carers provide care for 10 or more hours a week compared to less than 10 hours a week, twice as high if the carer is in fair, bad or very bad health compared to good or very good health, and four times higher if the carer works part-time compared to full-time. Hosmer-Lemeshow goodness-of-fit tests show that both the carer model (table 3) and the care-recipient model (table 4) predict values not significantly different from observed values, indicating good fit.

[Tables 3 and 4 about here]

Difference and similarity in perceived need for services

Two thirds of carer/care-recipient dyads agree on perceived need for services. A third disagree. The majority of disagreement is that the carer perceives a higher need for services than the care-recipient, however for 7% of dyads it is the other way round (table 5).

[Table 5 about here]

Multivariate logistic regression looking at factors associated with within-dyad differences in perceived need for any service finds that the only factor significantly associated with agreement or disagreement on unmet need for services is unpaid care hours (although this is borderline). Odds of disagreement – when the carer perceives a need for services but the care-recipient does not - is approximately a third lower when carers provide care for 10 or more hours a week compared to less than 10 hours a week. The Hosmer-Lemeshow goodness-of-fit test shows that the model predicts values not significantly different from observed values, indicating good fit.

[Table 6 about here]

Discussion

Looking at both perspectives, we find that unmet need for services for the care-recipient is perceived as high by care-recipients, as well as by their working carers. The level of unmet need among care-recipients in our study is consistent with other research on unmet need for services among disabled and older people in the UK (Vlachantoni *et al*. 2011, Burchardt *et al*. 2015) and with research on the impact of cuts under the Coalition government to local authority budgets and services (Forder & Fernández 2010, Fitzgerald *et al*. 2014). Whilst our finding tallies with government reports on unmet needs for social care, it is contrary to the assumption in such reports that those receiving help from an unpaid carer do not have unmet needs (Commission for Social Care Inspection 2008, House of Commons 2010).

In our study, the majority of dyads agree on unmet need for services; a third disagree. Where disagreement exists, in the overwhelming majority of cases carers perceive more unmet need for services than care-recipients. The limited previous research comparing perspectives on unmet needs for services also found that carers perceived more unmet need than care-recipients, although this research was not carried out in the UK (Zweibel & Lydens 1990, Foldemo *et al*. 2005, Van der Roest *et al*. 2009). One reason may be reluctance by care-recipients to accept services. In previous research on working carers in England, some carers expressed the opinion that this was a barrier to receipt of services (Twigg 1996, Seddon & Robinson 2001, Yeandle 2007, Arksey & Glendinning 2008). This is potentially an issue for working carers as services for the care-recipient are associated with higher employment rates among carers (Pickard *et al*. 2015).

Personal care, or ADL, disability of the care-recipient is significantly associated for carers with perceived unmet need for services for the care-recipient in our study. This is consistent with previous research (Van der Roest *et al*. 2009) which found that perceived unmet needs for services were higher for those providing unpaid care for someone with higher level of disability, although that study used different measures of disability - severity of dementia -

and was carried out in the Netherlands. Research using data from a large-scale survey conducted on the disabled population in Spain in 2008 found unmet need for long-term care is higher for those with both higher subjective and ADL-based measures of need (García-Gómez *et al*. 2014).

Higher intensity of unpaid care provision by working carers in our study is significantly associated with expressed unmet need for services by care-recipients but not carers. This suggests that unpaid care, even at high hours, is not (completely) meeting the care needs of care-recipients. This seems plausible, given that all of the carers are in employment, which may impact on ability to provide unpaid care (Doty *et al*. 1998). Alternatively, or additionally, unpaid carers may be providing higher hours of care when there is unmet need for services to try to make up the shortfall. Our results concur with the finding by Van der Roest *et al* (2009) that higher unpaid care hours were associated for care-recipients with lower subjective met needs for care. Again, this is contrary to assumptions on provision of unpaid care and lack of need for services (Commission for Social Care Inspection 2008, House of Commons 2010).

Ten or more hours a week care, the level at which this relationship is significant, is the threshold at which carer's employment is at risk (King & Pickard 2013) meaning that carers may be struggling to 'juggle' work and care, with a potential impact on both. In our study, care-recipients perceive higher unmet need for services when carers work part-time compared to full-time. It may be that carers are working part-time because of unmet service needs for the person they care for. Yeandle *et al* (2007) found that almost half of those working part-time said they were only in work of this type because of their caring responsibilities. Around half the sample of carers said they only worked part-time because the services available to them were inadequate to enable them to work full-time. Furthermore, Yeandle *et al* found that many carers working part-time struggled financially. This may mean that part-time working carers are less able to pay for shortfalls in services.

It has been suggested that carer 'burden' affects carers' perceptions of care-recipients' needs, explaining higher perceptions of needs than the care-recipient and thus explaining disagreement (Lyons *et al*. 2002, Meiland *et al*. 2005, Cleary *et al*. 2006). Unpaid care hours are sometimes used as an indicator of carer 'burden', as is health of the carer and subjective difficulty. Zweibel and Lydens (1990), comparing carer's and care-recipient's perspectives on unmet need for services in the US, found that carer's poorer health or subjectively-rated difficulty was associated with disagreement on unmet needs. In our study, neither care hours nor carer's health are significantly associated with carers' perceptions of need for services for the care-recipient. Odds of agreement on need for services for the care-recipient are, however, significantly higher when care hours are higher, indicating that for a subset of carers greater care hours are associated with perceived need for more services.

Whilst for parents who are care-recipients there is no significant association of relationship with perceived need for services, for their daughter or son carer there is, with higher odds of perceiving unmet needs than other caring relationships. This has been found in studies on perceived unmet need for services in the Netherlands and US (Zweibel & Lydens 1990, Van der Roest *et al*. 2009) and is consistent with literature on gender roles and gender and familial expectations of caring, whereby there is an expectation that daughters provide unpaid care (Finch 1989, Qureshi & Walker 1989, Twigg & Atkin 1994, Doty *et al*. 1998). In our study the expectation appears to come from the parent who is the care-recipient. This generational disagreement may reflect that, as increasing proportions of women enter the workforce, they move from an ‘ethic of care’ (Stohs 1994) to an ‘ethic of equity’ (Doty *et al*. 1998), which challenges traditional socially constructed gender roles around caring.

Generational differences may also be partly based on age. In general, older people perceive themselves as less dependent than their unpaid carers do (Zweibel & Lydens 1990). Age has been linked to differing expectations of care, with older people having lower expectations, and higher expressed satisfaction, with their existing care than younger people (Bleich *et al*. 2009, Sizmur 2011).

This study is based on carers working in the public sector and survey participation was voluntary. Most of the respondents were recruited to the study through a trade union, and it is possible that union members, particularly those working in local government, may have a different view on need for services than other working carers. This may potentially affect the generalisability of the results. However, working carers and care-recipients in this study are in many ways comparable to carers nationally and many of our findings are similar to previous research, including the finding on carers’ higher level of perceived unmet needs for services compared to care-recipients (Zweibel & Lydens 1990, Foldemo *et al*. 2005, Van der Roest *et al*. 2009).

Our study sample includes care-recipients with learning disabilities and a range of levels of other disabilities. However, comparing perceptions of carers and care-recipients when the care-recipient lacked the capacity to complete the self-report questionnaire was outside the scope of this study, both methodologically and ethically. It is possible that perceptions of needs for service of these dyads differ from those of our sample. Our findings are therefore not generalisable to this group.

A strength of this study is the methodology, whereby we explore the dual perspective on unmet need for services in England. Internationally, most studies on unmet needs for services do not obtain information from both carer and care-recipient, and none that we can find does so in England. Our study has data from 150 dyads in England on need for services for care-recipients, together with a wealth of data on care needs and socio-demographic characteristics.

By exploring this dual perspective, the study has contributed to knowledge of differences and similarities in perceptions of needs for services by working carers and care-recipients in England. Perceived unmet need for services is high for care-recipients as well as their carers. The majority (two-thirds) of dyads agree on whether or not more services are needed, which was not necessarily expected on the basis of previous research. Where there is disagreement, this is less marked when care for 10 hours or more hours a week is provided, the threshold at which working carers are at increased risk of leaving employment. Agreement on needs for services, where both the working carer and the care-recipient perceive a need, supports the implementation of legislation, policy and practice that has a duty to, or aims to, support carer’s employment, because services for care-recipients may enable working carers to remain in employment. When views on need for services are the same, providing those services for the care-recipient can support both care-recipients and working carers. The majority agreement seen in this study, and its relationship with the higher care hours that are associated with increased risk to carer’s employment, therefore has positive implications for such policy and practice.

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Tables

Table 1: Comparison of characteristics of dyad sample of working carers and care recipients to national surveys, England

Percentages and 95% confidence intervals (in brackets)

		Personal Social Services Research Unit (PSSRU) Survey	**National Surveys**
Working carers			*Understanding Society*
Gender	% female	84.7 (78.9, 90.5) (N=150)	62.6 (60.6, 64.5) (N=2,450)
Age	% <35	2.7 (0.1, 5.3)	19.7 (18.2, 21.4)
	% 35- 44 years	19.6 (13.2, 26.0)	21.4 (19.8, 23.0)
	% 45-54 years	46.6 (38.6, 54.6)	34.7 (32.8, 36.6)
	% 55-64 years	33.8 (26.2, 41.4)	21.1 (19.5, 22.8)
	% 65 years and over	0 (N=147)	3.1 (2.5, 3.9) (N=2,450)
Ethnicity	% Black and Minority Ethnic	11.6 (6.4, 16.8) (N=147)	8.4 (7.4, 9.6) (N=2,449)
Health	% in fair, bad or poor health	40.7 (32.8, 48.6) (N=150)	11.9 (10.6, 13.4) (N=2,221)
Unpaid care hours	% 10 or more a week	73.5 (66.4, 80.6) (N=147)	27.3 (25.5, 29.1) (N=2,351)
	% 20 or more a week	51.0 (42.9, 59.1) (N=147)	14.7 (13.3, 16.2) (N=2,421)
Care-recipient			*Survey of Carers in Households*)
Gender	% female	67.8 (60.3, 75.3) (N=148)	64.1 (61.3, 66.9) (N = 1,123)
Age	% under 16 years	8.1 (3.7, 12.5)	7.2 (5.7 , 8.7)
	% 16-64 years	31.8 (24.3, 39.3)	27.8 (25.2 , 30.4)
	% 65 years and over	60.1 (52.3, 67.9) (N=150)	65.0 (62.3 , 67.7) (N=1,162)
Relationship to carer	% parents/in-law	56.7 (48.8, 64.6)	54.7 (51.8 , 57.6)
	% spouse/partner	14.0 (8.4, 19.6)	12.9 (11.0 , 14.8)
	% son/daughter	20.0 (13.6, 26.4)	12.7 (10.8 , 14.6)
	% other	9.3 (4.7, 13.9) (N=150)	19.7 (17.4 , 22.0) (N=1,168)
Ethnicity	% Black and Minority Ethnic	13.3 (7.9, 18.7) (N=150)	-
Disability	% ADL-disabled	74.0 (66.9, 81.1) (N=146)	-

Sources: *Understanding Society, (University of Essex, 2012); Survey of Carers in Households (HSCIC, 2010a); Personal Social Services Research Unit (PSSRU) Survey 2013.*

In the *PSSRU Survey* 'fair, bad or poor health' is defined in terms of 'fair, bad or very bad health', whereas in *Understanding Society*, it is defined in terms of 'fair or poor health'. 'ADL-disability' refers to people who have difficulty with, or inability to perform, one or more Activities of Daily Living (ADLs) or personal care tasks.

Table 2: Factors potentially associated with perceived unmet need for services: comparison of carers and care recipients

		% of carers who say that the person they care for needs more services	**% of care-recipients who say they need more services**
ADL disability of care recipient	No ADL disability	47.4	28.9
	ADL disability	73.1	54.6
	N (significance)	146 (*)	146 (*)
Unpaid care	Less than 10 hours a week	61.5	25.6
	10 or more hours a week	68.5	55.6
	N (significance)	147 (ns)	147 (*)
Carer's gender	Male	56.5	34.8
	Female	67.7	49.6
	N (significance)	150 (ns)	150 (ns)
Carer's health	Very good or good	65.2	41.6
	Fair, bad or very bad	67.2	55.6
	N (significance)	150 (ns)	150 (ns)
Carer's employment status	Full-time (30 or more hours a week)	65.9	39.6
	Part-time (less than 30 hours a week)	66.7	59.6
	N (significance)	148 (ns)	148 (*)
Ethnicity (own)	White	66.9	44.6
	BME	67.2	65.0
	N (significance)	147 (ns)	150 (ns)
Care-recipient's gender	Male	64.6	50.0
	Female	66.7	46.1
	N (significance)	150 (ns)	150 (ns)
Relationship of care recipient to carer	Care-recipient is other than parent/in-law	55.7	52.5
	Care-recipient is parent/in-law	73.0	43.8
	N (significance)	150 (*)	150 (ns)
Total perceived need for more services for care-recipient		66.0%	47.3%
N		150	150

Source: Personal Social Services Research Unit (PSSRU) Survey 2013

* Significant at 95% confidence level or higher, ns: not significant

ADL-disability refers to difficulty with, or inability to perform, one or more Activities of Daily Living (ADLs) or personal care tasks

Note: The figures presented here compare the results from the Chi-squared tables of association carried out for carers and care-recipients separately. So for example 73.0% of carers who care for a parent/parent-in-law expressed unmet need for services, whereas only 43.8% of care-recipients who are parents/parents-in-law of the carer expressed unmet need. 73.0% of carers who care for a parent/parent-in-law expressed unmet need for services compared to 55.7% of those caring for someone other than their parent/parent-in-law expressed unmet need. This difference is significant.

Table 3: Factors potentially associated with carer's perceived unmet need for services for care-recipient.

		Odds ratio (95% Confidence Interval)	**Significance (p value)**
ADL-Disability of care recipient	No ADL-disability	**1.0**	
	ADL-disability	**2.617 (1.123, 6.098)**	**0.026**
Unpaid care	Less than 10 hours a week	1.0	
	10 or more hours a week	1.446 (0.564, 3.71)	0.443
Relationship care-recipient to carer	Care-recipient is other than parent/in-law	**1.0**	
	Care-recipient is parent/in-law	**3.289 (1.335, 8.105)**	**0.01**
Carer's health	Very good or good	1.0	
	Fair, bad or very bad	1.217 (0.561, 2.641)	0.62
Carer's gender	Male	1.0	
	Female	1.172 (0.42, 3.268)	0.762
Carer's employment status	Full time	1.0	
	Part time	1.458 (0.655, 3.268)	0.355
Care-recipient's gender	Male	1.0	
	Female	0.766 (0.304, 1.928)	0.571
Constant		0.636	0.681

Source: Personal Social Services Research Unit (PSSRU) Survey 2013

ADL-disability refers to difficulty with, or inability to perform, one or more Activities of Daily Living (ADLs) or personal care tasks

N=150

Hosmer-Lemeshow Test: Chi-square: 4.025, p= 0.855

Significant results in bold.

Table 4: Factors potentially associated with care-recipient's perceived unmet need for services for self

		Odds ratio (95% Confidence Interval)	**Significance (p value)**
ADL-Disability of care recipient	No ADL-disability	1.0	
	ADL-disability	1.843 (0.761, 4.463)	0.175
Unpaid care	Less than 10 hours a week	**1.0**	
	10 or more hours a week	**4.035** **(1.5, 10.855)**	**0.006**
Relationship care-recipient to carer	Care-recipient is other than parent/in-law	1.0	
	Care-recipient is parent/in-law	1.294 (0.542, 3.094)	0.562
Carer's health	Very good or good	**1.0**	
	Fair, bad or very bad	**2.166** **(1.001, 4.687)**	**0.05**
Carer's gender	Male	1.0	
	Female	1.36 (0.476, 3.888)	0.566
Carer's employment status	Full time	1.0	
	Part time	**4.153** **(1.813, 9.509)**	**0.001**
Care-recipient's gender	Male	1.0	
	Female	1.027 (0.424, 2.489)	0.953
Constant		0.233	0.181

Source: Personal Social Services Research Unit (PSSRU) Survey 2013

ADL-disability refers to difficulty with, or inability to perform, one or more Activities of Daily Living (ADLs) or personal care tasks

N=150

Hosmer-Lemeshow Test: Chi-square: 8.342, p= 0.401

Significant results in bold.

Table 5: Agreement and disagreement between carer and care recipient on perceived unmet need for services for care-recipient

	% (N)
Both carer and care-recipient agree do not need more services	26.7 (40)
Both carer and care-recipient agree do need more services	40.0 (60)
Total agreement	**66.7 (100)**
Carer perceives more need for services, care recipient does not	26.0 (39)
Care recipient perceives more need for services, carer does not	7.3 (11)
Total disagreement	**33.3 (50)**
Total	**100 (150)**

Source: Personal Social Services Research Unit (PSSRU) Survey 2013

Table 6: Factors potentially associated with disagreement between carer and care-recipient in perceived unmet need for services

		Odds ratio (95% Confidence Interval)	**Significance (p value)**
ADL-Disability of care recipient	No ADL-disability	1.0	
	ADL-disability	1.046 (0.41, 2.668)	0.926
Unpaid care	Less than 10 hours a week	**1.0**	
	10 or more hours a week	**0.389** **(0.151, 1.001)**	**0.05**
Relationship care-recipient to carer	Care-recipient is other than parent/in-law	1.0	
	Care-recipient is parent/in-law	1.747 (0.626, 4.874)	0.287
Carer’s health	Very good or good	1.0	
	Fair, bad or very bad	0.424 (0.175, 1.032)	0.059
Carer’s gender	Male	1.0	
	Female	0.461 (0.154, 1.382)	0.167
Carer’s employment status	Full time	1.0	
	Part time	0.542 (0.218, 1.347)	0.187
Care-recipient’s gender	Male	1.0	
	Female	0.57 (0.201, 1.619)	0.291
Constant		2.313	0.489

Source: Personal Social Services Research Unit (PSSRU) Survey 2013

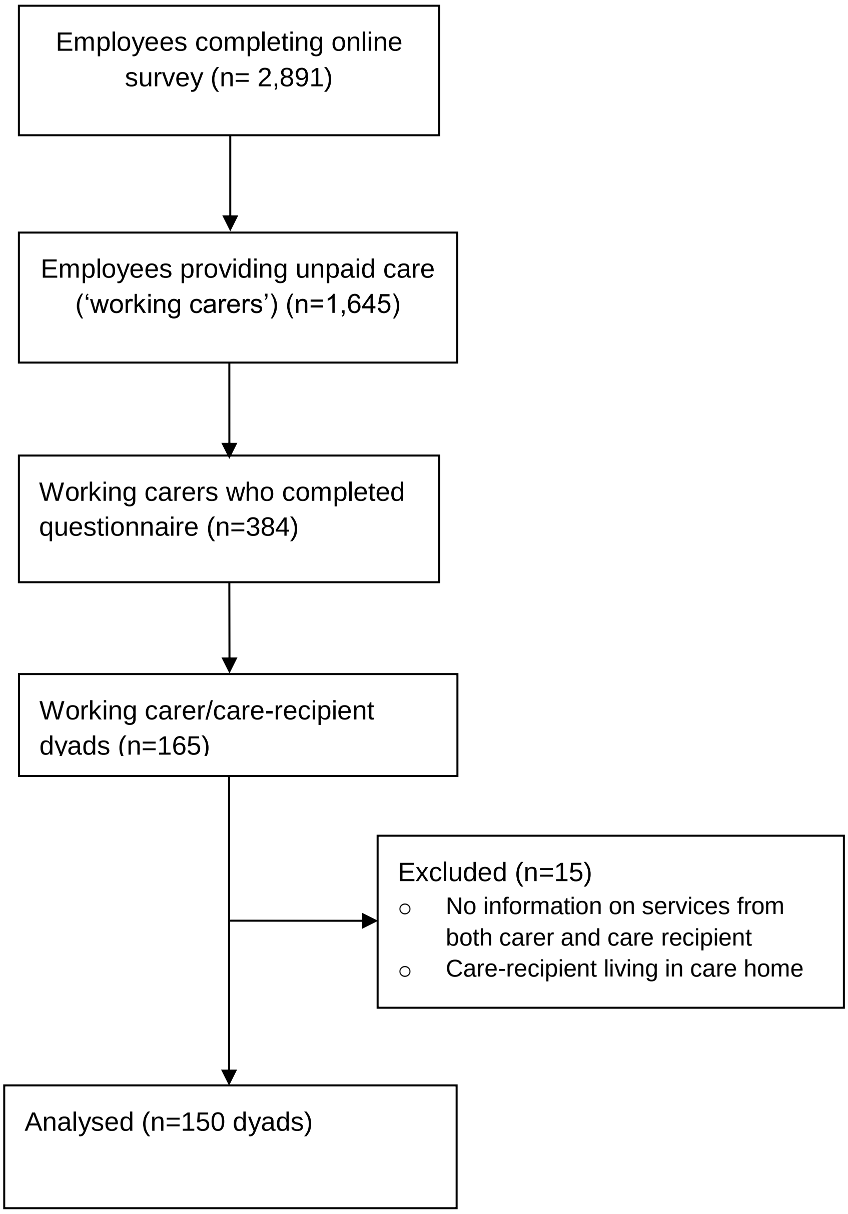
ADL-disability refers to difficulty with, or inability to perform, one or more Activities of Daily Living (ADLs) or personal care tasks

N=150

Hosmer-Lemeshow Test: Chi-square: 8.924, p= 0.258

Significant results in bold.

Figure 1: Flow chart of participants through Personal Social Service Research Unit (PSSRU) study of unpaid care and employment, 2012/13: final dyad sample selection



Tables and Figures