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Unmet social care needs of people living with and beyond cancer: prevalence and predictors from an English longitudinal survey

Katerina Gousia[1,2] ⬤ | Ann-Marie Towers[1]

[1]Department of Social Policy, Sociology and Social Research, Centre for Health Services Studies, University of Kent, Canterbury, UK

[2]Department of Social Policy, Sociology and Social Research, Personal Social Services Research Unit, University of Kent, Canterbury, UK

Correspondence
Katerina Gousia, Centre for Health Services Studies, University of Kent, Canterbury, CT2 7NF, UK.
Email: a.gousia@kent.ac.uk

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Abstract

Objectives: This study estimates the prevalence of unmet social care needs of people over 50 living in England with cancer and the effect of cancer on unmet needs.

Methods: We used data from the English Longitudinal Study of Ageing. We estimated the mean, standard deviation and 95% CI of the prevalence of unmet social care needs among people with cancer. Logistic regression analysis with individual random effects was used to estimate the effect of cancer on unmet needs controlling for other determinants. Pain measures were included stepwise in the regression to estimate their mediating effect.

Results: The prevalence rate of unmet social care needs among people living with cancer is 9% (SD = 0.29; 95% CI: 8.3–10) compared to 6% (SD = 0.24; 95% CI: 6.1–6.5) among people without cancer. People with cancer have significantly higher odds of having unmet needs by a factor of 1.44 (95% CI: 1.20–1.72), after controlling for the effect of other characteristics. Adding pain measures reduces the effect of cancer to a factor of 1.36 (95% CI: 1.14–1.64) in the odds of unmet needs but still remains statistically significant.

Conclusions: A more integrated approach to cancer care is more likely to address the high level of unmet needs and consequent adverse implications.

KEYWORDS
cancer, integrated care, longitudinal, pain, person-centred care, Psycho-Oncology, social care needs

1 | BACKGROUND

There are currently 2.5 million people living with cancer in the UK and a predicted 4 million people will be living with and after cancer by 2030.[1] Due to advances in cancer therapies, the illness trajectory has changed and survival rates have increased.[2] As a result, people living with and beyond cancer (LWBC) are likely to develop a range of needs in their daily life, which go beyond their medical needs. Over two thirds of people with cancer have at least one or more practical, personal and emotional need,[3,4] which can be persistent over time.[5] At least one quarter of cancer survivors report long-term disability while both cancer patients and survivors experience levels of fatigue and pain that are higher than the general population average.[6,7]

As these difficulties develop people LWBC may receive help in a variety of ways, including help from family and friends or professional care at home. The extent to which informal carers can provide the care needed will vary enormously between individuals and is likely to have an impact on the physical, emotional and mental health of the carers themselves. Carer breakdown is a common precursor or trigger-point in people seeking help from formal care services. In the UK, the social care sector provides much needed support with activities of daily living, such as washing, dressing and meals, when people are unable to meet these needs themselves. However, unlike healthcare, which is provided by the NHS, social care is not free at the point of delivery. This means that anyone who is currently in need of help and support, due to the consequences of living with cancer, has to either fund this care themselves or be assessed for help through their Local Authority. Receipt of publicly funded social care will depend on a number of factors, including whether the individual meets the required 'eligibility criteria' (i.e., are their needs severe enough needs to warrant social care input) and means testing to establish whether they can afford to fund this care themselves.[8]

Often people will receive help for some but not all of their needs or even no help at all. Increasing needs among people LWBC and constraints in the supply of social care services and availability of informal carers mean that there is a growing risk that people's daily needs are not met. The implications of unmet needs for people with cancer are significant, both in terms of people's welfare and public spending. Unmet needs are linked to worse mental health, financial distress and increased use of health care services for both cancer patients and their carers.[3] Despite the important implications, the evidence on the prevalence and determinants of unmet needs of people LWBC in England is limited. One exception is a report by Macmillan Cancer Support,[3] which provides a first set of evidence on the social care needs of people with cancer. However, based on a small size online survey, this study is likely to suffer from representativeness issues and lacks richer data on other individual characteristics to allow a more detailed analysis of the determinants and distribution of these needs.

Our study aims to fill this evidence gap by: (i) providing nationally representative evidence on the prevalence of unmet social care needs of people LWBC in England and (ii) estimating the association of cancer with unmet needs, controlling for other determinants.

2 | MATERIALS AND METHODS

2.1 | Data and study population

We used observational data from the English Longitudinal Study of Ageing (ELSA) [14]. ELSA collects longitudinal multidisciplinary data from a nationally representative sample of the English population aged 50 and over.[1] The survey began in 2002/2003 and interviews of the original and refreshment samples, known as 'waves', take place every two years.[2] The available data consist of eight waves up to 2016/17. After a scoping review of other secondary data sources, the ELSA dataset was deemed the most suitable for this study because it uniquely combined rich data on cancer prevalence, social care needs and help received, as well as other individual characteristics. The UK Household Longitudinal Study (UKHLS) was another study with similar information, but due its very small sample size could not be used for statistical analysis. Comparisons of the socio-demographic characteristics of ELSA participants against estimates from the national census indicate that the initial sample was reassuringly representative of the English population.[9]

All ELSA waves were pooled together. The final sample size was 81,328. Of those, 4,767 observations reported LWBC ($M = 0.06$, $SD = 0.235$). A respondent was considered to have cancer at each wave if s/he was newly diagnosed with cancer or a malignant tumour at the time of the interview, or was previously diagnosed at the time of the previous wave and it was still ongoing or s/he had recovered from it. Of those, 55% were women ($N = 2,642$) and 45% were men ($N = 2,125$). Cancer affected about 34% ($N = 1,668$) of people aged below 64, 35% ($N = 1,663$) of people aged 65–74 and 32% ($N = 1,436$) of people aged 75 or more.

2.2 | Measurement of unmet social care needs

The definition of unmet social care needs has been a long-standing debate in the literature. Conceptual considerations pertain to issues around the type and severity of limitations, which can be classified as needs and the conditions under which they can be viewed as unmet.[10,11] Studies on unmet needs of people living with cancer usually involve self-assessed measures of unmet needs on a variety of items such as physical, psychological, financial or activities of daily living (ADL) needs and often use standardized assessment tools such as the Supportive Care Needs Survey or other interview formats.[5,12]

The operationalization of unmet social care needs in this study was shaped by three main considerations: (i) the literature on unmet social care needs in England, (ii) the data in hand and (iii) the policy background. To ensure policy relevance, our definition of social care needs was chosen to reflect, as closely as possible, that used by local authorities (LAs) under the Care Act 2014 when assessing whether someone has needs eligible for LA support in England. Thus, a person living with cancer was considered to have social care needs when s/he reported difficulties with: (i) 3 or more ADLs or (ii) 2 or more ADLs and poor wellbeing, measured by a score of over 3 in the 8-item Center for Epidemiologic Studies Depression Scale (CES-D 8). Our measure of unmet needs used in this study was an indicator variable taking the value 1 if a person had this level of needs and wellbeing and (i) received no care at all or (ii) received partial formal care but not for all of their ADL needs or (iii) received only unpaid informal intensive care of 20 h or more per week. This approach is consistent with the literature on unmet needs in England, which are measured based on the ADL count,[13] mirrors the eligibility criteria under the Care Act 2014 and is feasible to measure with the ELSA data.

Specifically, ELSA asks respondents whether they have a limitation with each of the following 6 ADLs: (1) dressing, including putting

TABLE 1 Unmet social care needs by cancer type and need severity: Mean (SD and 95% CI)

	Cancer	No Cancer
Total sample		
Unmet social care needs	0.09 (0.29; 95% CI: 8.3–10)	0.06 (0.24; 95% CI: 6.1–6.5)
3 or more activities of daily living (ADLs); 2 or more ADLs and poor wellbeing		
Unmet social care needs	0.815 (SD = 0.39; 95% CI: 7.8–8.4)	0.817 (0.81; 95% CI: 8.0–8.2)

on shoes and socks, (2) walking across a room, (3) bathing or showering, (4) eating, such as cutting up food, (5) getting in and out of bed and (6) using the toilet, including getting up or down. To each of these questions, respondents answer with a yes or no. If they answer yes, indicating need with a specific ADL, they are then asked whether they receive help or not for that need and from whom. If they receive help they then report whether they receive formal and/or informal help. Formal help includes help from social or health services such as home help and informal help includes help from family members, friends and neighbours. ELSA also records the intensity of informal care received and we could define intensive informal care as care provided over 20 h a week.[3]

2.3 | Other measures

We used self-reported measures from ELSA on gender, age, educational qualifications, family structure, employment status, ethnic origin, comorbidities, wealth and pain. Educational qualifications were grouped into three categories: below O-level, at O-level, or higher than A-level. Family structure included an indicator variable for whether people live in a couple and whether they have at least one child of any age living in the household. Employment status was derived from a self-reported ELSA question asking people to best describe whether their current situation is: employed, self-employed or out of the labour market (whether retired, unemployed or carer). An indicator variable was constructed for whether respondents are currently in paid employment or self-employment. A dummy variable for non-white was included to capture ethnicity. Comorbidities measures collected in ELSA with sufficient observations included indicators for arthritis, high blood pressure, asthma, diabetes, osteoporosis and dementia. Total net non-housing household wealth was split into quintiles. Measures for pain included indicator variables for whether respondents often experience no pain, mild, moderate or severe pain. We also included dummy variables for regions and interview waves to account for regional differences in the supply of formal care services and structural changes over time.

2.4 | Statistical analysis

We estimated the mean, standard deviation (SD) and 95% confidence interval (CI) of the prevalence of unmet social care needs among people LWBC. A logistic regression model with individual random

effects was used to estimate the degree of variance in unmet needs explained by cancer and the other predictors and odds ratios (OR) and 95% CIs were reported. People with cancer often experience pain which can contribute to higher needs (6). We added measures of pain severity stepwise in the regression model to explore whether pain explains any additional variance in unmet needs, acting as a possible mechanism of the effect of cancer. The analysis was run in Stata 15.1.

3 | RESULTS

3.1 | Prevalence of unmet social care needs

People with cancer have a higher rate of unmet social care needs. The prevalence rate is 9% (SD = 0.29; 95% CI: 8.3–10) among people LWBC compared to 6% (SD = 0.24; 95% CI: 6.1–6.5) among people without cancer (Table 1). Of those with eligible needs (3 or more ADLs or 2 or more ADLs and poor wellbeing), 81.5% (SD = 0.39; 95% CI: 7.8–8.4) of people with cancer and 81.7% (SD = 0.81; 95% CI: 8.0–8.2) of people without cancer have unmet needs (Table 1). The difference between the two groups is not statistically significant (t-test = 0.15; p-value = 0.88) suggesting that for severe needs, people with and without cancer have the same likelihood of having them met.

3.2 | Predictors of unmet social care needs

Table 2 presents the summary statistics for the predictors of unmet social care needs for the full sample and the subsample of people LWBC. The two samples have differences in terms of characteristics such as gender, age, family structure, employment status, ethnicity and comorbidities. To understand whether the higher prevalence of unmet needs is associated with cancer we need to control for the other confounding factors in a regression framework.

The estimated odds ratios and 95% CIs from the random effects logistic model are presented in Table 3. Cancer has a positive and statistically significant association with unmet needs above and beyond the other predictors of the model. People LWBC have higher odds of having unmet needs by a factor of 1.44 (95% CI: 1.20–1.72) compared to people without cancer. Looking at the other predictors, men have higher odds of unmet needs than women and another year of age increases the odds of having unmet needs. Higher educational qualifications are associated with lower odds of unmet needs. Being in

TABLE 2 Summary statistics: Mean (SD)

	Full sample (n = 81,338)	Subsample of people living with and beyond cancer (LWBC) (n = 4,767)
Outcome		
Unmet social care needs[a]	0.07 (0.25)	0.09 (0.29)
Predictors		
Cancer[a]	0.06 (0.24)	1 (0.00)
Male	0.44 (0.49)	0.45 (0.50)
Age	65.8 (10.4)	69.0 (9.84)
Educational qualification		
Less than O-level/equivalent[a]	0.45 (0.49)	0.46 (0.49)
O-level/equivalent[a]	0.26 (0.44)	0.24 (0.43)
Higher than A-level[a]	0.29 (0.45)	0.29 (0.46)
Family structure		
In a couple[a]	0.71 (0.45)	0.69 (0.46)
Child in household[a]	0.43 (0.49)	0.38 (0.48)
Working status		
In work (paid employment/self-employed)[a]	0.36 (0.48)	0.24 (0.43)
Ethnicity		
Non-white[a]	0.03 (0.18)	0.02 (0.14)
Chronic conditions		
Arthritis[a]	0.35 (0.47)	0.39 (0.49)
High blood pressure[a]	0.35 (0.47)	0.38 (0.49)
Asthma[a]	0.11 (0.31)	0.11 (0.31)
Diabetes[a]	0.09 (0.29)	0.12 (0.32)
Osteoporosis[a]	0.06 (0.25)	0.09 (0.29)
Dementia[a]	0.01 (0.11)	0.02 (0.13)
Wealth quintiles		
1st[a]	0.18 (0.38)	0.17 (0.38)
2nd[a]	0.19 (0.39)	0.19 (0.39)
3rd[a]	0.21 (0.40)	0.20 (0.40)
4th[a]	0.21 (0.40)	0.22 (0.41)
5th[a]	0.21 (0.40)	0.22 (0.41)
Region		
East Midlands[a]	0.11 (0.31)	0.11 (0.31)
East of England[a]	0.12 (0.33)	0.12 (0.32)
London[a]	0.09 (0.28)	0.08 (0.28)
North East[a]	0.06 (0.24)	0.06 (0.24)
North West[a]	0.12 (0.33)	0.13 (0.33)
South East[a]	0.16 (0.37)	0.18 (0.38)
South West[a]	0.12 (0.32)	0.12 (0.33)
West Midlands[a]	0.11 (0.31)	0.10 (0.30)
Yorkshire and the Humber[a]	0.11 (0.31)	0.11 (0.31)

T A B L E 2 (Continued)

	Full sample (n = 81,338)	Subsample of people living with and beyond cancer (LWBC) (n = 4,767)
Pain		
No often pain[a]	0.61 (0.48)	0.55 (0.50)
Mild often pain[a]	0.12 (0.32)	0.11 (0.32)
Moderate often pain[a]	0.20 (0.39)	0.23 (0.42)
Severe often pain[a]	0.08 (0.27)	0.10 (0.30)

[a]predictor is a dummy variable. Mean values for dummy variables will be equal to proportions.

a couple has a negative and statistically significant association with unmet needs while having at least one child is not statistically significant. Non-whites have higher odds of unmet needs than whites do. Comorbidities have a positive and statistically significant association with unmet needs. The largest effect is observed for people with arthritis or dementia who have higher odds of unmet social care needs by a factor of 4.93 (95% CI: 4.32–5.61) and 2.84 (95% CI: 1.93–4.17) respectively. Belonging to a higher non-housing wealth quintile is associated with increasingly lower odds of unmet social care needs. There is also regional variation in the prevalence of unmet needs with London and regions in the Midlands and the North having higher odds of unmet needs compared to the South East, although only two of these regional effects were statistically significant.

Adding measures of pain severity in the model reduces the variance in unmet needs explained by cancer. Having cancer is associated with an increase in the odds of unmet needs of a factor of 1.36 (95% CI: 1.14–1.64) but still remains statistically significant. Pain itself is a statistically significant predictor of unmet social care needs. Compared to no pain at all, people who experience mild, moderate and severe pain often have higher odds of having unmet needs by a factor of 2.45 (95% CI: 2.06–2.91), 6.29 (95% CI: 5.47–7.24) and 18.58 (95% CI: 15.87–21.76) respectively.

4 | DISCUSSION

We found that 9% of people LWBC have unmet social care needs. While this is lower than evidence found in other studies[4,5] this can be attributed to the strict definition of unmet needs used in this study, since the Care Act 2014 only considers severe needs as eligible for social support. Thus our evidence can be interpreted as a lower bound of the extent of unmet needs among people LWBC. Even after controlling for other factors, people with cancer still had higher odds of having unmet needs in a statistically significant way. With an estimated marginal effect of cancer of 0.014 (95% CI: 0.007–0.021, p-value < 0.01)[4] and a sample average of unmet needs of 0.07, this finding suggests that people LWBC are 2% more likely to have unmet needs above other characteristics.

We explored pain as a possible mechanism of this effect and found that measures of different pain severity explained part of the variation in unmet needs related to cancer. One possibility is that when people suffer with chronic pain, due to cancer or treatment for cancer, they are assessed under a medical model focussing only on the treatment of the pain itself. Whilst this is arguably the right strategy in acute cases, once pain management becomes an ongoing challenge and impacts on the person's everyday life and ability to self-care, it needs to be assessed under an integrated health and social care model. Without the social care element, the person's needs (regardless of what might be causing them) will be unmet, with consequences for the person's wellbeing and daily life.

After controlling for pain, cancer still had a positive and statistically significant relationship with unmet social care needs that was not explained by other predictors. Further research is required to explore what other factors explain the higher prevalence of unmet needs among people with cancer. Our analysis has shown that this is due to more severe ADL limitations among people LWBC (Table 1). We explored pain as one possible mediating mechanism for worse ADL limitations, but there could be others such as fatigue, which is particularly high among people with cancer.[7] Due to limited data on fatigue, we left this for future research. One cannot also exclude a priori possible supply side constraints in accessing care. We found that a large proportion (81%) of people with needs severe enough to receive social care support, still do not get the support they need, regardless however of cancer diagnosis (Table 1). The estimated regional effects were statistically significant for certain regions, but not others, suggesting that differences in unmet needs may sometimes but not always be due to structural regional supply differences. Given that the provision of social care services takes place at the LA level, future research should consider more localized evidence to understand possible limitations in the supply of appropriate services and information to cancer patients.

4.1 | Study limitations

First, this study relied on survey data. As with any self-reported data, it is possible that there is a degree of over-/under-reporting bias, which could also differ by gender. Although we controlled for a number of confounding factors and individual random effects that could be correlated with possible reporting bias, we acknowledge that this may still be a limitation. Second, our analysis did not account for differences in the type or stage of cancer due to lack of detailed

TABLE 3 Logistic random effects regression models predicting the probability of having unmet social care needs

	(1) OR (95% CI)	(2) OR (95% CI)
Cancer[a]	1.44 (1.20–1.72)***	1.36 (1.14–1.64)***
Male[a]	1.52 (1.32–1.74)***	1.64 (1.44–1.87)***
Age	1.01 (1.00–1.02)***	1.01 (1.00–1.02)***
Education (Ref: Less than O-level)		
O-level/equivalent[a]	0.72 (0.61–0.84)***	0.77 (0.66–0.91)***
Higher than A-level[a]	0.49 (0.41–0.58)***	0.58 (0.49–0.69)***
Family structure		
In a couple[a]	0.76 (0.66–0.87)***	0.69 (0.60–0.78)***
Child in household[a]	0.93 (0.84–1.01)	0.91 (0.83–1.01)
Working status		
In work[a]	0.28 (0.24–0.34)***	0.33 (0.28–0.39)***
Ethnicity (Ref: white)		
Non-white	1.4 (1.00–1.95)**	1.15 (0.83–1.59)
Chronic conditions		
Arthritis[a]	4.93 (4.32–5.61)***	2.69 (2.37–3.07)***
High blood pressure[a]	1.27 (1.14–1.42)***	1.20 (1.07–1.34)***
Asthma[a]	1.84 (1.55–2.18)***	1.61 (1.36–1.89)***
Diabetes[a]	1.59 (1.35–1.88)***	1.52 (1.29–1.80)***
Osteoporosis[a]	2.18 (1.82–2.63)***	1.73 (1.45–2.08)***
Dementia[a]	2.84 (1.93–4.17)***	2.79 (1.59–4.54)***
Wealth quintiles (Ref: 1st)		
2nd[a]	0.65 (0.57–0.74)***	0.74 (0.65–0.85)***
3rd[a]	0.47 (0.41–0.55)***	0.57 (0.49–0.66)***
4th[a]	0.35 (0.29–0.41)***	0.43 (0.37–0.51)***
5th[a]	0.31 (0.26–0.38)***	0.41 (0.34–0.50)***
Region (Ref: South West)		
London[a]	1.32 (1.17–2.01)	1.20 (0.91–1.57)
East Midlands[a]	1.54 (1.18–2.02)***	1.32 (1.02–1.71)**
West Midlands[a]	1.22 (0.93–1.60)	1.08 (0.83–1.40)
North East[a]	1.07 (0.78–1.46)	1.01 (0.75–1.35)
North West[a]	1.35 (1.05–1.75)**	1.09 (0.86–1.41)
Yorkshire and the Humber[a]	1.14 (0.87–1.51)	0.97 (0.74–1.27)
South East[a]	0.86 (0.66–1.11)	0.80 (0.63–1.04)
East of England[a]	0.86 (0.66–1.13)	0.82 (0.64–1.06)
Pain (Ref: no often pain)		
Mild often pain[a]		2.45 (2.06–2.91)***
Moderate often pain[a]		6.29 (5.47–7.24)***
Severe often pain[a]		18.58 (15.87–21.76)***

Abbreviations: CI, confidence interval; OR, odds ratio.

[a]Predictor is a dummy variable.

***$p < 0.01$, **$p < 0.05$.

data found in a multi-disciplinary survey, as is ELSA. It is thus possible that there are prevalence differences by cancer subgroup, which we have not explored. Third, this study used a narrow definition of unmet social care needs. Although reflecting the English policy background, this definition may underestimate wider needs of people with cancer, which can still be debilitating as has been documented in other studies.[4,5] Despite these limitations, this study is to the best of our knowledge the first to provide nationally representative evidence on the prevalence of unmet needs among people LWBC over 50 and an estimate of the association of cancer with unmet social care needs.

4.2 | Clinical implications

We provided evidence that people with cancer have a high prevalence of unmet needs that go beyond their purely medical needs. This highlights the importance of assessing people LWBC for both their ongoing medical and social care needs through integrated care policy and practice. Such an approach is more likely to address people's needs and mitigate knock-on effects on individual and carer wellbeing and pressures on other parts of the health system. It can also recognise the interdependencies between health and social care needs and provide as a result a more efficient model of care such as for example through the integrated management of pain.

5 | CONCLUSIONS

People LWBC have a higher than average rate of unmet social care needs. This is because they have more severe limitations with ADLs and the help they receive does not meet these needs adequately. The pain associated with treatment and the long-term implications of cancer is also related to more severe social care needs. A more integrated and person-centred approach to cancer care, that takes into account the interdependencies between health and social care needs is thus more likely to address unmet needs and consequent adverse implications for people with cancer as well as the wider health and social care system.

CONFLICT OF INTEREST
Authors declare no conflict of interests.

AUTHORS CONTRIBUTION
Dr Katerina Gousia led on the research design, data cleaning, data analysis, draughting and interpretation of the results. Ann-Marie Towers contributed to the research design, draughting and interpretation of the results.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are openly available from the UK Data Service (UKDS) at https://beta.ukdataservice.ac.uk/datacatalogue/series/series?id=200011, reference number GN 33368.

ORCID
Katerina Gousia https://orcid.org/0000-0002-2494-786X

ENDNOTES
[1] English Longitudinal Study of Ageing (ELSA) also interviews their spouses independent of age. The proportion of people in the sample below 50 years old is 2.75%.

[2] As ELSA is a study of people aged 50 and over, a refreshment sample of 50–51 year olds is needed as the study progresses in order to fully represent those aged 50+. The ELSA sample has been refreshed at waves 3, 4, 6 and 7.

[3] Waves 1 to 5 do not record intensity of informal care received in hours. An assumption was made to consider as intensive care when informal care was received for 3 or more activities of daily living.

[4] Regression coefficients and marginal effects from the logistic regression are available upon request.

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