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Title: What is the Relationship between the Quality of Care Experience and Quality of Life Outcomes? Some Evidence from Long-Term Home Care in England

Juliette Malley [a*], Francesco D'Amico [a], Jose-Luis Fernandez [a]

[a] Quality and Outcomes of person-centred care policy Research Unit (QORU), Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science, London, UK

* Corresponding author

Email: j.n.malley@lse.ac.uk (JM)

Tel: 020 7955 6134

LSE, Houghton Street, London WC2A 2AE, UK

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Research highlights:

- Perceptions of home care experience are associated with quality of life outcomes.
- Interpersonal aspects are most strongly associated with quality of life outcomes.
- The association varies by need characteristics but not by age, gender or ethnicity.
- Interpersonal aspects may be useful indicators for monitoring home care quality.

Abstract

Quality of care has multiple dimensions, including safety, experience and effectiveness. Understanding the relationship between these dimensions is important for policy and practice, since there may be both synergies and trade-offs that occur when attempting to maximise them. For long-term care effectiveness is understood as care that promotes a good quality of life (QoL). Here we investigate the relationship between care experience and QoL in long-term home care. Data from a cross-sectional survey conducted in 2008/09 were analysed using fractional response regression models to explore the relationship between experience, measured through items capturing perceptions of the care delivery process, and patient-reported QoL-outcomes, measured using ASCOT, controlling for relevant individual characteristics. The analysis included 14,172 people aged 65 and over using home care services from across England. After controlling for the confounding effect of individual characteristics, a ten percentage point increase in overall process quality is found to be associated on average with a 2.13 percentage point increase in ASCOT. Interpersonal aspects of care, such as the responsiveness and caring behaviour of staff, have a stronger relationship with ASCOT than those related to the organisation of care by the provider, such as timekeeping and continuity of care, with a ten percentage point increase in the former associated on average with a 1.9 percentage point increase in ASCOT and a ten percentage point increase in the latter associated on average with a 0.3 percentage point increase in ASCOT. Perceptions of care experience, particularly those related to the interpersonal care aspects, have an important association with QoL-outcomes. Measures of the experience of interpersonal aspects of care may therefore be useful indicators of QoL-outcomes for the routine monitoring of long-term home care services. Although associated, the two dimensions are distinctive and for policymakers there is value in assessing both care experience and QoL-outcomes.

Keywords

England; Long-term care; Quality of Life; Quality of Care; ASCOT; home care; patient-reported outcome measure

Introduction

Providing high quality care is an important goal for all health systems. Government-sponsored quality measurement frameworks present a specific vision of quality and guide the development of measures, which are used to identify areas of good and poor practice, drive improvements and in many countries support patient choice. In England the government has recently adopted a framework for long-term care (LTC) that has parallels with the Organisation for Economic Co-operation and Development (OECD)/European Commission's (2013) framework. It identifies three dimensions of quality: (i) safety, (ii) a positive experience that is both caring and responsive, and (iii) effectiveness, which is understood as care that promotes a good quality of life (QoL) and is based on best practice (Department of Health, 2017, 2011; The National Quality Board, 2016). While for conceptual and measurement purposes it is useful to separate these dimensions, in practice they are related (Donabedian, 1980; Doyle et al., 2013; Manary et al., 2013). The relationship between experience and QoL-outcomes, which are the target of LTC services, is the focus of this study.

Understanding the relationship between experience and (what might be referred to as) care-related QoL-outcomes is important for policy and practice, since trade-offs may be needed to maximise each dimension. Conversely investing in improving the care experience may increase care effectiveness (Donabedian, 1980; Doyle et al., 2013; Manary et al., 2013). This latter argument underpins much government policy in England, which posits improvements in care experience as a mechanism for improving care outcomes. This is most visible in the policy of 'personalisation, which promotes a vision of care in which people have choice, control and flexibility over how care is delivered and consequently better care outcomes (Beresford, 2009; Manthorpe et al., 2011). It is also apparent in the sustained focus on delivering compassionate care (Bivins et al., 2017; Cavendish, 2013) -- a response to the series of scandals across the health and care system. Here greater compassion is seen as a mechanism for better patient outcomes (Cavendish, 2013).

Evidence about the strength of the relationship between aspects of the care experience related to the process of care delivery and care outcomes would help to support the work of organisations like the National Institute for Health and Care Excellence (NICE) in England that specify quality standards for care delivery. Such evidence is also valuable from a measurement perspective as it is generally considered to be easier for services to monitor and action feedback about the process of care delivery rather than feedback about care outcomes (Steel et al., 2004). Consequently, even if we accept that care outcomes should be the focus for improvement efforts, there might be an argument in favour of process indicators if there is a sizeable correlation with care outcomes.

A number of studies in primary, ambulatory care, and hospital settings have investigated the relationship between dimensions of patient-reported experience and outcomes (Anhang Price et al., 2014; Doyle et al., 2013), and these have tended to report weak relationships (Black et al., 2014; Llanwarne et al., 2013). It is not clear that findings from clinical settings, where care is more episodic and has a greater technical component, will apply to LTC settings (Malley and Fernández, 2010). We hypothesise that since LTC is delivered on a continuous basis and is generally very personal in nature, the relationship between experience and care outcomes is likely to be different and stronger. Only one study by Shippee et al. (2015), which explored the relationship between resident-reported QoL and various aspects of family-rated satisfaction with care, staff, environment and food in US nursing homes, has focused on an LTC setting. In line with our hypothesis, they found weak to moderate correlations (r=0.08-0.41) between elements of family satisfaction and resident-reported QoL. Due to data availability, however, relationships were explored at the facility level and the study does not provide insight into whether the strength of association varies across sub-groups of patients, whether there is variation in the aspects of care experience that are most closely related to outcomes, or whether the aspects that are important are the same as those found in primary, ambulatory and hospital settings.

In this study we use data from the patient survey programme to investigate whether there is an association between perceptions of the quality of care experience (process measures) and patient-reported QoL-outcomes for LTC services. We use an observational design and for reasons of data availability focus on publicly-funded home care services, which provide support with personal and instrumental activities of daily living such as eating, toileting and shopping. In England these fall within the social care system and are administered by local authorities (LAs). We investigate three questions. Is better reporting of experience associated with better QoL-outcomes? What aspects of experience are most important in determining QoL-outcomes? And how does the relationship between experience and QoL-outcomes vary according to user characteristics, such as their underlying health conditions, resources, immediate environment and indicators of diversity? This final question is important for understanding whether the relationship between the way care is delivered and care outcomes is more (or less) important for sub-groups of users, with equality implications.

Methods and data

To explore the relationship between user-reported quality of care experience and QoL-outcomes, we use data from an extension study to the 2008/09 national User Experience Survey (UES). The UES is a postal survey and was the precursor to the current Adult Social Care Survey. It covered different groups of users each year and in 2008/09 the survey population was home care users aged 65 and over receiving publicly-funded support. Each local administrative area (the LA) manages the survey for its area following national guidance (NHS Information Centre for health and social care, 2008). Since the methods used to collect the 2008/09 older people's UES dataset have been described in detail elsewhere (NHS Information Centre for health and social care, 2009, 2008), we concentrate here on the details of the extension study, which involved a sub-sample of LAs in England. The extension study received ethical approval from the University of Kent Research Ethics Committee.

All LAs were invited to participate in the extension study and forty-four out of 147 LAs (30 per cent) volunteered to take part. Participating LAs covered all nine geographical regions and were well-spread across constituency types (rural, metropolitan, large towns). These LAs used a standardised questionnaire, including questions on QoL-outcomes derived from the ASCOT measure (Netten et al., 2012a, 2011), the users' experience of care delivery, and user characteristics, e.g. self-perceived health (SPH), functional limitations in activities of daily living (ADLs), self-perceived limitations with the design of their home (DESIGN_HOME), whether they received regular practical help from someone living in their household (PRACTICAL_HELP_IN) or from someone living outside their household (PRACTICAL_HELP_OUT), and whether they had help to answer the questionnaire (HELP_ANSWER), and their home care provider.

Of the 42,541 questionnaires sent out, 21,688 were returned (51 per cent response rate). The analysis uses a sub-sample of these data that receive home care from a registered home care provider and receive home care from only one provider (20,353 cases), have complete information for the outcome variable (17,747 cases) and have responses to all the explanatory variables – a total of 14,172 observations. Although these data are now quite old this is a large, rich and unique dataset, without a more recent equivalent.

Characteristics of home care users

Table 1 compares the characteristics of the home care users in the extension study sub-sample to the national UES sample. As would be expected, the sample is predominately female, white and almost 50 per cent are aged 85 and over. The respondents to the extension study compare favourably to the national sample on responses to the quality of care items (Table 2 for description), key demographics and needs-related characteristics (NHS Information Centre for health and social care, 2009).

Tab 1. Quality of care and characteristics of home care user analysis sample

Quality of life outcomes

QoL-outcomes were measured using the ASCOT measure (Netten et al., 2012a, 2011), a multi-attribute utility index validated for home care users aged 65 and over (Malley et al., 2012; Netten et al., 2012a). ASCOT was designed to capture social care-related QoL and therefore can be considered to capture the aspects of QoL that are most likely to be impacted upon by LTC services. The extension study used a three-level developmental version of ASCOT and has items covering personal cleanliness and comfort, food and drink, control over daily life, social participation and involvement, occupation, accommodation cleanliness and comfort, and personal safety (see Table 2 for description of ASCOT attributes). An index can be calculated using valuations from a discrete choice experiment conducted with a sample of the English general population, where people were shown a series of scenarios involving two alternative profiles described in terms of the response options to ASCOT and were asked to choose one profile they preferred (Burge et al., 2006; Glendinning et al., 2008). The resultant index is rescaled to take values from zero (poor QoL) to one (good QoL) for ease of interpretation of the results. The ASCOT index is negatively skewed (Table 3).

Tab 2. ASCOT attribute descriptions [© PSSRU at the University of Kent]

Tab 3. Quality of life and quality of care scores for analysis sample

Quality of care experience

Studies exploring older people's conceptualisation of the quality of home care identify dimensions related both to the care worker-service user relationship and the organisation of care provision. The areas include: continuity of care workers; fluid communication of changes in care; flexibility of the service to meet needs and preferences; reliability of care workers; having a good relationship with care workers and feeling that they are caring, trustworthy, ensure privacy and dignity; responsiveness of care workers, and the skills and knowledge of staff (Francis and Netten, 2004; Harding and Beresford, 1996; Henwood et al., 1998; Qureshi et al., 1998; Qureshi and Henwood, 2000; Raynes et al., 2001; Sinclair et al., 2000). These dimensions are reflected in the range of quality of care questions (see Table 4).

We used polychoric correlations to explore the association between the quality of care items. Since we found they were moderately to strongly correlated (Cohen, 1969), we conducted an exploratory factor analysis to determine item dimensionality (see supplementary material A [INSERT LINK TO ONLINE FILE A]). This showed that all the variables bar satisfaction with the amount of visits (VISITAMT), which was dropped from the quality scales, loaded onto one dimension. The items were internally consistent, with Cronbach's alpha for the quality of care experience (QTOT) scale at 0.86. A solution involving two highly correlated factors (r=0.73), was also extracted. The two correlated scales broadly reflected interpersonal (WANTDONE, RUSH, SPENDLT, TREATED, RELSHIP, UNDSIT) and organisational (SUITTIME, INFORM, ARRIVET, SAMECW) aspects of care. Internal consistency was good for both scales, with a Cronbach's alpha of 0.79 for the interpersonal scale (QREL) and 0.74 for the organisational scale (QORG). The values are rescaled, so that the minimum is zero (poor experience) and the maximum is one (good experience), for ease of interpretation of the results. Apart from the organisational scale, the quality scales are negatively skewed for this sample (Table 3).

Tab 4. Description of quality of care items

Analysis

All analyses were conducted in Stata 14. We explore associations between QoL-outcomes, measured using the ASCOT index, and perceptions of the quality of care experience, using a quasi-likelihood estimator for a Beta distribution based mean-variance model that is similar to maximizing a Bernoulli likelihood function (Basu and Manca, 2012). This model is sometimes referred to in the econometric literature as a fractional response model (Papke and Wooldridge, 1996). It assumes the dependent variable is bounded between zero and one and allows for negatively-skewed distributions, so is more appropriate for use with the rescaled ASCOT index than a linear model.

We explore the following specifications for the relationship between experience, q, and QoL-outcomes, y:

- a model including the overall quality of care (QTOT) scale (MODEL 1)
- a model including the QREL and the QORG scales to explore whether there are differences in the relationship between QoL and the interpersonal and organisational dimensions of quality of care (MODEL 2).

The ASCOT index reflects the outcome state of individuals, which is influenced by a range of factors including: underlying health and disabling conditions (e.g. functional ability), additional resources used to support care provision (e.g. informal care), the immediate environment, socio-demographic variables and help to complete the postal questionnaire (Forder et al., 2016; Glendinning et al., 2008; van Leeuwen et al., 2014). These characteristics may also be associated with care experience and may therefore confound the relationship between care experience and outcomes. For example, service users with higher health and social care needs are likely to receive more care and could consequently rate their experience more positively, due to increased attentiveness and potentially greater flexibility to deliver a more personalised service. Conversely, there may be more potential for errors where the person is receiving many hours of care meaning they may rate their care experience more negatively (Care Quality Commission, 2013; Equality and Human Rights Commission, 2011). In both instances the observed relationship between care experience and outcomes may be due to service intensity rather than reflect a causal relationship s.

To control for the confounding influence of the characteristics, z, we include the user characteristics variables in Table 1 in each regression. For context, we also estimate a baseline model (MODEL 0) which includes only the effects of user characteristics, z, on QoL-outcomes. The general approach taken resembles a risk-adjustment model (Iezzoni, 2012), and can be written as:

$$y_i = \alpha + \sum_{k=1}^{K} \beta_k q_{ik} + \sum_{j=1}^{J} \gamma_j z_{ij} + e_i \qquad (1)$$

Where q_{ik} are K quality of care items or scales (as specified above), z_{ij} are the J user characteristics that affect QoL-outcomes, and y_i is the ASCOT index for user i. Since the data pertain to different LAs, we have used the clustered sandwich estimator for the variance. We also performed sensitivity checks, re-estimating the models firstly clustering on providers and then on both LAs and providers. Results were not substantially different from the main model, and there were no differences in the significance of the estimated coefficients. (Estimated model coefficients are shown in the supplementary material B [INSERT LINK TO ONLINE FILE B].)

We have only a binary indicator of service intensity, which limits the potential to explore the importance of service intensity in modifying the relationship between care experience and QoL-outcomes. Rather than include service intensity in the model, we estimate MODEL 1 on the sub-sample of low-intensity users (receiving less than 10 hours of home care per week, MODEL 3) and high-intensity users (receiving more than 10 hours per week of home care, MODEL 4), so allowing intensity to interact with all variables in the models.

Since model coefficients are not straightforward to interpret in generalised linear models, we estimate and present average marginal effects. (Estimated model coefficients are shown in the supplementary material B [INSERT LINK TO ONLINE FILE B].) For continuous variables, such as the quality of experience scales (QTOT, QREL, QORG) the average marginal effects can be interpreted as the average percentage point change in ASCOT that is associated with a one unit change in the independent variable. For discrete variables, including most of the user characteristics, the average marginal effects can be interpreted as the percentage point increase in ASCOT that is associated with a discrete change, i.e. from zero to one, in the independent variable.

Furthermore, since equity of provision is of interest to policymakers (The National Quality Board, 2016), we explore the effect of a selection of user characteristics on the relationship between the quality of care delivery and ASCOT. We do this by introducing an interaction term into the model (MODELS 5a-f) and focus on interactions with indicators of diversity, i.e. gender, age and ethnicity, and indicators of care need, i.e. number of ADL limitations (ADLS), self-perceived health (SPH) and self-perceived limitations with home design (DESIGNH). The model estimated is:

$$y_i = \alpha + \sum_{k=1}^{K} \beta_k q_{ik} + \sum_{j=1}^{J} \gamma_j z_{ij} + \sum_{k=1}^{K} \sum_{j=1}^{J} \delta_{jk} q_{ik} z_{ij} + e_i \qquad (2)$$

Since it is not straightforward to interpret the significance of interaction terms in non-linear models (Ai and Norton, 2003), we again derive average marginal effects for each of the interacted user characteristics variables. In this case the average marginal effects will include both the main and interaction effects for the user characteristic. To understand whether the interaction effect is significant, we therefore plot the average marginal effect of each of the interacted user characteristics on the predicted value of ASCOT at 0.1 intervals on the QTOT scale. If there is no interaction between the variable and quality of care then the lines for different levels of the interacted variable will be parallel; deviations from parallel lines imply an interaction effect (Greene, 2010). The significance of the average interaction effect can be understood by testing for the significance of the difference between the average marginal effect for each level of the user characteristic variable compared to the base level (the contrast margin) using Wald tests (Jann, 2013; Karaca-Mandic et al., 2012). We therefore also present contrast margins to supplement the output from the plots.

Results

Association between care experience and QoL-outcomes

Table 5 shows the polychoric correlation between the care experience items and ASCOT. Of the experience items, VISITAMT has the largest correlation followed by UNDSIT, WANTDONE and TREATED – all items from the interpersonal index. All of the items had moderate correlations with ASCOT, except four items that had weak correlations (Cohen, 1969). Except for RUSH (r=.29) the weakly correlated items were all from the organisational experience scale (SAMECW, ARRIVET and INFORMCH). This pattern of correlations suggests that interpersonal quality of care is more important than organisational quality of care in explaining QoL outcomes.

Tab 5. Polychoric correlations between ASCOT and the care experience items

After controlling for user characteristics, the perceived quality of care experience makes a significant and important contribution to ASCOT, with the model R^2 increasing by around 50 per cent between Model 0 (only user characteristics) and Model 1, which includes the overall quality indicator (QTOT) (Table 6). Reflecting the findings from correlations between the individual quality of care delivery items and ASCOT, Model 2 shows that the average marginal effect for interpersonal scale (QREL) is about six times as large as that for the organisational scale (QORG). Noting that all quality scales take values from zero to one, on average: a 0.1 unit increase in QTOT is associated with a 2.13 percentage point increase in ASCOT; a 0.1 unit increase in QREL is associated with a 1.86 percentage point increase in ASCOT; and a 0.1 unit increase in QORG is associated with a 0.29 percentage point increase in ASCOT. The association between QREL and ASCOT is significantly greater than that between QORG and ASCOT ($X^2(1)=104.42$, $p<.001$). To put the magnitude of the effects in perspective, the interquartile range for QTOT is .64 to .87, 0.67 to 0.94 for QREL and, 0.62 to 0.85 for QORG (see Table 3).

The effect of home care intensity on the relationship between quality of care and QoL-outcomes can be understood by comparing the estimated average marginal effect of QTOT across Models 1 (all observations), 3 (low intensity) and 4 (high intensity). The average marginal effect of QTOT on ASCOT in Model 3 is greater than the effect of QTOT in Model 4 by 8.5 ASCOT percentage points, which means that a 0.1 unit increase in QTOT is associated with on average a 0.85 percentage point larger increase in ASCOT for home care users with higher intensity services. The average marginal effect for user characteristics is relatively stable across Models 1, 3 and 4. The average marginal effects for older age groups become insignificant in the high intensity subsample (and the magnitudes are also reduced), but in other places where there are differences it is generally that the magnitude of the average marginal effects are greater in the high intensity subsample.

Tab 6. Average marginal effects (with standard errors) for the estimated relationship between the quality of care experience and ASCOT

Influence of user group characteristics on the relationship between care experience and QoL-outcomes

To explore the effect of user group characteristics on the relationship between care experience and ASCOT we developed a set of models (5a-5f) with interaction terms between QTOT and a range of user characteristics. The average marginal effects for each of the user characteristics from these models are shown in Table 7 (left column). The average marginal effects include both the main and interaction effects and show that a change in the level of each of the user characteristics is on average associated with a highly significant change in ASCOT. The graphs in Fig 1 show very little indication of any interaction effect for age and gender and relatively small main effects. There is a clear main effect for ethnicity, but the strength of the relationship between experience and ASCOT does not differ over the range of values of QTOT. Contrast tests of the average marginal effects were not significant (Table 5, right column).

The graphs in Fig 1 do indicate, however, that the effect of the perceived quality of care experience on ASCOT varies according to the needs profile of individuals. The effect of care experience on ASCOT is greater the more functionally disabled the respondent is, the worse their self-reported health and the more negative their perceptions are of the design of their home in relation to their needs. Contrast tests of the average marginal effects for all of these variables were significant, suggesting that on average the relationship between QTOT and ASCOT varies according to the different levels of home design, functional disability and self-reported health (Table 5, right column).

Tab 7. Average marginal effects and contrast margins for user characteristic variables from the interaction models (models 5a-5f)

Fig 1. Relationship between quality of care and quality of life for different user groups

Discussion

In this study we investigated the relationship between perceptions of care experience and user-reported QoL-outcomes of long-term home care for older people. After controlling for potentially confounding user characteristics, we find a significant association between perceptions of care experience and QoL-outcomes, with a ten percentage point change in perceptions of the care experience associated with on average a 2.13 percentage point increase in ASCOT. To put this effect into perspective is challenging as minimally important differences have not been estimated for ASCOT, but findings for the EQ-5D-3L which is a similarly broad multi-attribute utility index (although focused on health rather than broader QoL-outcomes) might be instructive in this regard. The estimated minimally important difference for the EQ-5D-3L ranges from 0.03 to 0.52 index points, depending on methods and health condition, which is equivalent to 1.9 to 32.6 percentage points (Coretti et al., 2014). Assuming a similar range might apply for ASCOT, a change of 0.1 in the perceptions of care experience index, which is roughly equivalent to a movement from the second to third and third to fourth quartile is associated with a meaningful change in QoL-outcomes.

We find that the interpersonal aspects of care (e.g. perceptions of the day-to-day responsiveness, the relationship with care staff, and aspects of reliability related to the behaviours of care staff), have a stronger relationship with ASCOT than the aspects more closely related to the organisation of care by the home care provider (e.g. whether care workers arrived on time, continuity of care, being informed about changes and whether care workers came at suitable times). These findings contrast with those from studies in primary care settings, which have found access and continuity of care to be most strongly associated with clinical outcomes (Llanwarne et al., 2013), but are closer to studies in acute care settings, which have found communication and trust in doctors to be most strongly associated with patient-reported outcomes (Black et al., 2014). These findings support our hypothesis that the relationship between the care experience and QoL-outcomes in the LTC setting will differ from that found in primary, ambulatory care, and hospital settings (where much of the research to date has been carried out), which we suggest is due to the continuous and personal nature of the care provided.

Importantly, in this study the association between perceived care experience and ASCOT does not vary by age, gender or ethnicity. This is consistent with research in an acute care setting (Black et al., 2014) and suggests there are no inequalities in this relationship by the socio-demographic variables examined in this paper. The association between perceived care experience and ASCOT did vary, however, for various needs-related variables with the average marginal effect being greater for individuals with poorer self-perceived health, more limitations with ADLs and a home that they perceived was not designed well to meet their needs. This might suggest that groups of users with higher needs have a greater capacity to benefit (in terms of QoL-outcomes) from their experience of care delivery than people with lower levels of need. An alternative explanation is that the relationship between care experience and QoL-outcomes is confounded by the intensity of services, with users receiving more intense services reporting a better experience. The models estimated on the high and low intensity sub-samples provide some insight into the relationship between intensity, care experience and QoL-outcomes, as the magnitude of the average marginal effect for the relationship between perceived care experience and ASCOT is greater for individuals receiving more intense care packages (greater than ten hours/week). The binary nature of the intensity variable means, however, that it is not possible to isolate the effect of service intensity from the effects of needs-related characteristics. The relationship between intensity of provision, care experience and QoL-outcomes for care users with different needs characteristics requires further investigation, particularly since publicly-funded home care provision has become increasingly concentrated on individuals with the greatest needs and services have experienced a step-change in the complexity of cases (Burchardt et al., 2016; Fernández et al., 2013).

As this discussion suggests a key limitation of the study (related to the cross-sectional survey data), is whether the observed relationship between care experience and QoL-outcomes can be explained causally and be interpreted as the impact of care experience on care effectiveness. We control here for a range of individual characteristics that capture baseline need and influence QoL-outcomes, but other potentially important confounders of the relationship between experience and outcomes remain unobserved. One such variable is the 'choice' behaviour of individuals vis-à-vis providers, since individuals are not randomly allocated to home care providers and providers vary in their quality, which is assumed to influence both the experience and the effectiveness of care (Care Quality Commission, 2018). Characteristics of individuals that are associated with 'choices' between providers are therefore likely to confound to some extent the relationship between experience and outcomes. Although, choice is fairly constrained in the publicly-funded market as LAs' commissioning practices mean that older people cannot choose any provider and providers operate with certain geographies (Fernandez et al., 2012), LAs do try to direct older people towards providers that meet their needs, e.g. specialist services for people with challenging behaviours related to dementia, or services that cater for people with particular religious beliefs. We have controlled as far as possible for characteristics likely to influence selection into providers, but there may be some residual selection bias. Reverse causality may also be an issue, if better outcomes lead people to reflect more positively on their experience. The ordering of the questions in the survey, with the experience items prior to the QoL items should guard against this to some extent, but without longitudinal data it is not possible to entirely separate out these effects.

More positively, since the dataset is large and representative this gives some confidence in the generalisability of these results. Although as the data are now quite old it is possible that the association between care experience and QoL-outcomes may have changed, e.g. due to the colder fiscal climate and developments in care practice, such as strengths-based approaches which emphasise the importance of building on the strengths that service users possess when assessing their need for care inputs (Saleebey, 1996). Our expectation would be that these changes would shift the average marginal effect of care experience on the ASCOT scale but would not change the underlying relationships as illustrated by the graphs in Fig 1. It should also be noted that we have used the QoL-outcome and experience measures available within the dataset. Alternative QoL and experience measures are available and whether these findings would be replicated with a different choice of QoL-outcome, perhaps one with a broader focus than ASCOT, or experience measures is an important question which should be addressed in future research.

Despite these limitations, and notwithstanding that the conclusions would be stronger if a causal interpretation of the relationship between care experience and QoL-outcomes can be supported, this analysis holds important lessons for LTC policy and practice. The strength of the association between interpersonal aspects of care delivery and QoL-outcomes supports the current policy focus on developing a caring and responsive service (Department of Health, 2017; The National Quality Board, 2016), and has importance in the context of the significant workforce issues facing the sector in the UK (Moriarty et al., 2018). Recruitment and retention are challenging, especially within the home care sector, with many providers facing high vacancy (10%) and turnover rates (32%) for staff. Although difficult to achieve given the context, in recent years there has been a focus on promoting values-based recruitment within the sector, whereby employers are encouraged to use recruitment procedures that identify people with the right skills and ethos to provide care (Manthorpe et al., 2017). This study lends support to this approach in two ways. First, the variability in care experience suggests that a caring and responsive service can be achieved through 'traditional' forms of service delivery and not only self-directed support. Given some of the challenges associated with implementing self-directed support among older people (Moran et al., 2013; Netten et al., 2012b; Slasberg et al., 2012), this should give some comfort to policymakers with regard to the capacity of traditional home care services to deliver the personalisation and compassion in care agendas. Second, the study tallies with work by Manthorpe et al (2017), which identified the importance of kindness and relationships between care workers and care recipients, as key aspects to consider for value-based recruitment in the sector.

These results are also useful for informing LTC quality monitoring frameworks, which have been employed in England since the early 2000s to monitor the quality and performance of a range of different public services (Martin et al., 2016). In more recent years, there has been a strong emphasis on measuring outcomes especially from the patients' perspective focus, with the intention that LAs will use the indicators to drive improvements in services (Department of Health, 2011). LAs (and providers) find it difficult, however, to interpret outcomes indicators and use them to improve services. They much prefer indicators of the experience of care delivery (Heath et al., 2015). Our results suggest that such experience measures are likely to be good, but only partial, indicators of QoL-outcomes in the home care context, given the amount of variation explained. There may, however, be a case for using care experience measures for routine monitoring purposes where simplicity is valued, but both experience and QoL-outcomes should be measured where a more detailed understanding is required. The outcomes framework could be developed to support these efforts through the inclusion of more indicators of care experience.

Relatedly, increasing numbers of LAs contractually require home care providers to use electronic monitoring technology to capture data about the start and end times of visits (UK Home Care Association, 2012). These systems allow LAs to pay providers for only the hours the care workers are with clients (Hayes and Moore, 2017), but they are also used by some LAs (for example LAs in the East of England region, (Chance, 2016)) to monitor and benchmark the quality of provision through indicators of punctuality, length of stay (compared to what was planned), planned visits delivered, and continuity of care. A valuable extension to the work here would be to investigate the relationship between these more objective indicators of care experience and QoL-outcomes. The findings reported here suggest that the aspects of quality captured by the electronic monitoring systems may not be good indicators of QoL-outcomes, which raises questions about their use for monitoring home care quality. Additionally, given that the English system is fairly unique in its focus on measuring user-reported rather than clinical outcomes when examining LTC (Bos et al., 2007; Hirdes et al., 2004, 1999; Kehyayan et al., 2015; Mor, 2005; OECD/European Commission, 2013), it would be useful to examine whether perceived care experience has similar relationships with clinical outcomes, such as pressure sores, in order to understand how the English system compares internationally.

Conclusion

This study has found a statistically significant and important association between experience and QoL-outcomes, as measured by the relationship between perceptions of care experience and ASCOT. It suggests that measures of the experience of care delivery, particularly the interpersonal aspects, may be useful indicators of QoL-outcomes for the routine monitoring of long-term home care services. On the other hand, measures related to the organisational aspects of care delivery are less useful indicators of QoL-outcomes and less valuable for routine monitoring of long-term home care services. It is important to recognise that experience and QoL-outcomes are distinctive dimensions and from the perspective of policymakers there is a value in measuring both. While this study has not demonstrated a causal relationship between experience and effectiveness, the relationships observed suggest that focusing on developing a caring and responsive service, potentially through focusing on value-based recruitment approaches, may be beneficial for QoL-outcomes. Further research exploring these relationships to determine causality is warranted.

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Tables and figures

Table 1: Quality of care and characteristics of home care user analysis sample

Variable	Obs.	Mean[a]	S.D.	Min	Median	Max	Nat. UES Mean
GENDER: male	14,172	0.27	0.44	0	0	1	0.29
AGE: 65-69	14,172	0.07	0.25	0	0	1	0.07
AGE: 70-74	14,172	0.09	0.29	0	0	1	0.1
AGE: 75-79	14,172	0.16	0.36	0	0	1	0.15
AGE: 80-84	14,172	0.23	0.42	0	0	1	0.23
AGE: 85-89	14,172	0.26	0.44	0	0	1	0.26
AGE: 90 and over	14,172	0.2	0.4	0	0	1	0.2
ETHNICITY: white	14,172	0.96	0.2	0	1	1	0.94
ADLS [b]	14,172	3.53	1.48	0	4	5	n.c.
SPH: very good	14,172	0.04	0.2	0	0	1	n.c.
SPH: good	14,172	0.23	0.42	0	0	1	n.c.
SPH: fair	14,172	0.54	0.5	0	1	1	n.c.
SPH: bad	14,172	0.14	0.35	0	0	1	n.c.
SPH: very bad	14,172	0.04	0.2	0	0	1	n.c.
DESIGN_HOME: meets needs very well	14,172	0.51	0.5	0	1	1	n.c.
DESIGN_HOME: meets most needs	14,172	0.37	0.48	0	0	1	n.c.
DESIGN_HOME: meets some needs	14,172	0.1	0.3	0	0	1	n.c.

DESIGN_HOME: totally inappropriate	14,172	0.02	0.13	0	0	1	n.c.
PRACTICAL_HELP_IN	14,172	0.32	0.47	0	0	1	0.3
PRACTICAL_HELP_OUT	14,172	0.61	0.49	0	1	1	0.59
HELP_ANSWER: not needed	14,172	0.32	0.47	0	0	1	0.39
HELP_ANSWER: from careworker	14,172	0.05	0.22	0	0	1	0.04
HELP_ANSWER: from someone else	14,172	0.62	0.48	0	1	1	0.57
INTENSITY: > 10 hours/week	14,172	0.29	0.45	0	0	1	0.31
SUITTIME [c]	14,172	0.71	0.24	0	0.67	1	0.72
INFORMCH [c]	14,172	0.63	0.32	0	0.67	1	0.63
WANTDONE [c]	14,172	0.84	0.22	0	1	1	0.84
RUSH [c]	14,172	0.69	0.29	0	0.67	1	0.7
ARRIVET [c]	14,172	0.73	0.25	0	0.75	1	0.73
SPENDLT [c]	14,172	0.81	0.25	0	1	1	0.81
SAMECW [c]	14,172	0.72	0.2	0	0.67	1	0.72
TREATED [c]	14,172	0.88	0.19	0	1	1	0.87
RELSHIP [c]	14,172	0.79	0.21	0	0.67	1	n.c.
VISITAMT [c]	14,071	0.96	0.15	0	1	1	n.c.
UNDSIT [c]	14,172	0.73	0.24	0	0.67	1	n.c.

Legend: [a] can be interpreted as a proportion for discrete variables; [b] ADLs included were problems cutting toenails by themselves, putting on shoes, having a bath or a shower, wash face and hands, and getting up from a chair. These were assessed on a three-point scale of no help, with difficulty, need help and the score was derived as the number of ADLs a given individual either carried out with difficulty or was unable to do; [c] rescaled on a 0-1 metric, for full question wording see Table 4; n.c. not collected in national UES

Table 2: ASCOT attribute descriptions [© PSSRU at the University of Kent]

Attribute	Description of attributes
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities.
Personal cleanliness and comfort	The service user feels that he/she is personally clean and comfortable and looks presentable or, at best, is dressed and groomed in a way that reflects his/her personal preferences
Food and drink	The service user feels that he/she has a nutritious, varied and culturally appropriate diet with enough food and drink that he/she enjoys at regular and timely intervals
Personal safety	The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm, and free from fear of being attacked or robbed.
Social participation and involvement	The service user is content with his/her social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends, family and feeling involved, or part of a community should this be important to the service user.
Occupation	The service user is sufficiently occupied in a range of meaningful activities, whether formal employment, unpaid work, caring for others or leisure activities

Accommodation cleanliness and comfort	The service user feels his/her home environment, including all the rooms, is clean and comfortable.

Table 3: Quality of life and quality of care scores for analysis sample

Variable	Obs.	Mean	S.D.	Min	Median	Max	IQR
ASCOT [a]	14,172	0.88	0.13	0	0.92	1	0.83, 0.97
QTOT [a]	14,172	0.75	0.16	0.06	0.77	1	0.65, 0.87
QREL [a]	14,172	0.79	0.17	0	0.83	1	0.67, 0.94
QORG [a]	14,172	0.70	0.19	0	0.69	1	0.62, 0.85

Legend: [a] rescaled on a 0-1 metric. IQR interquartile range; QTOT quality of care experience scale; QREL interpersonal quality scale; QORG organisational quality scale.

Table 4: Description of quality of care items

Dimensions of quality	Question and response options
Continuity of care workers	Do you always see the same care workers?[a] (SAMECW) always; nearly always; hardly ever; never
Fluid *communication* of changes in care	Are you kept informed, by your home care service, about changes in your care? (e.g. your visit will be late or you'll have a different carer)[a] (INFORM) always; usually; hardly ever; never
Flexibility of the service to meet needs and preferences	Do your care workers come at times that suit you?[a] (SUITTIMES) always; usually; sometimes; never
	Do you have as many visits from your care workers as you need?[b] (VISITAMT) yes, as many as need; no, need a few more; no, need a lot more
Reliability of care workers	Do your care workers arrive on time?[a] (ARRIVET) always; usually; sometimes; never; never know
	Are your care workers in a rush?[a] (RUSH) always; often; sometimes; never
	Do your care workers spend less time with you than they are supposed to?[a] (SPENDLT)

	never; sometimes; often; always
Good relationship with care workers and feeling that they are caring, trustworthy, ensure privacy and dignity	Overall, how do you feel about the way your care workers treat you? (e.g. whether they are understanding and treat you with respect for your dignity)?[a] (TREATED) always; usually; sometimes; never Would you describe your relationship with your care workers as…?[c] (RELSHIP) excellent; good; mixed; bad Do you feel that people from [Social Services] understand your situation?[c] (UNDSIT) everyone; most people; some people; no-one
Responsiveness of care workers	Do your care workers do the things that you want done?[a] (WANTDONE) always; nearly always; sometimes; never

Legend: [a] included in national UES, [b] drawn from longer version of home care UES (Qureshi and Rowlands, 2004), [c] drawn from home care survey for working age adults (Malley et al., 2006)

Table 5: Polychoric correlations between ASCOT and the care experience items

	ASCOT
SUITTIME	0.3048
INFORMCH	0.2508
ARRIVET	0.2386
SAMECW	0.1859
WANTDONE	0.3702
RUSH (reversed)	0.2947
SPENDLT	0.3070
TREATED	0.3627
RELSHIP	0.3377
UNDSIT	0.3770
VISITAMT	0.3833

Note: Correlations based on the sample of 14,172 observations. Full question wording shown in Table 4.

Table 6: Average marginal effects (with standard errors) for the estimated relationship between the quality of care experience and ASCOT

	MODEL 0	MODEL 1	MODEL 2	MODEL 3	MODEL 4
GENDER: male	0.006***	0.005**	0.006**	0.002	0.014**
	(0.002)	(0.002)	(0.002)	(0.002)	(0.005)
AGE: 70-74	0.012**	0.013**	0.012**	0.012*	0.015*
	(0.004)	(0.004)	(0.004)	(0.006)	(0.006)
AGE: 75-79	0.011**	0.013**	0.013**	0.015**	0.008
	(0.004)	(0.004)	(0.004)	(0.005)	(0.007)
AGE: 80-84	0.011*	0.014**	0.014**	0.018**	0.002
	(0.005)	(0.005)	(0.004)	(0.006)	(0.007)
AGE: 85-89	0.015***	0.020***	0.019***	0.022***	0.012
	(0.004)	(0.004)	(0.004)	(0.005)	(0.007)
AGE: 90 and over	0.012*	0.017***	0.017***	0.020***	0.007
	(0.005)	(0.005)	(0.005)	(0.006)	(0.008)
ETHNICITY: white	0.027***	0.023***	0.019***	0.022***	0.027***
	(0.005)	(0.005)	(0.005)	(0.007)	(0.007)
ADLS =3	-0.017***	-0.014***	-0.014***	-0.014***	-0.014*
	(0.002)	(0.002)	(0.002)	(0.003)	(0.006)
ADLS =4	-0.023***	-0.019***	-0.019***	-0.016***	-0.023***
	(0.003)	(0.003)	(0.003)	(0.003)	(0.007)
ADLS =5	-0.047***	-0.038***	-0.036***	-0.030***	-0.047***
	(0.003)	(0.003)	(0.003)	(0.003)	(0.007)
SPH: good	-0.011*	-0.011*	-0.011*	-0.007	-0.022*

	(0.005)	(0.005)	(0.005)	(0.004)	(0.011)
SPH: fair	-0.038***	-0.034***	-0.033***	-0.029***	-0.048***
	(0.005)	(0.005)	(0.005)	(0.004)	(0.012)
SPH: bad	-0.071***	-0.062***	-0.061***	-0.060***	-0.071***
	(0.007)	(0.007)	(0.007)	(0.006)	(0.013)
SPH: very bad	-0.109***	-0.102***	-0.101***	-0.091***	-0.126***
	(0.010)	(0.009)	(0.009)	(0.009)	(0.016)
DESIGN_HOME: meets most needs	-0.048***	-0.039***	-0.038***	-0.041***	-0.033***
	(0.003)	(0.002)	(0.002)	(0.002)	(0.004)
DESIGN_HOME: meets some needs	-0.098***	-0.075***	-0.072***	-0.077***	-0.071***
	(0.005)	(0.004)	(0.004)	(0.004)	(0.008)
DESIGN_HOME: totally inappropriate	-0.166***	-0.134***	-0.130***	-0.133***	-0.132***
	(0.015)	(0.011)	(0.011)	(0.014)	(0.018)
PRACTICAL_HELP_IN	0.036***	0.026***	0.024***	0.025***	0.024***
	(0.003)	(0.003)	(0.003)	(0.003)	(0.006)
PRACTICAL_HELP_OUT	0.011***	0.008**	0.007**	0.008**	0.007
	(0.003)	(0.003)	(0.003)	(0.003)	(0.006)
HELP_ANSWER: careworker	-0.0011**	-0.024***	-0.023***	-0.021***	-0.026**
	(0.004)	(0.004)	(0.004)	(0.004)	(0.009)
HELP_ANSWER: someone else	-0.029***	-0.025***	-0.024***	-0.025***	-0.019***
	(0.003)	(0.003)	(0.003)	(0.002)	(0.006)

QTOT	-	0.213*** (0.008)	-	0.187*** (0.009)	0.272*** (0.014)
QREL	-	-	0.186*** (0.01)	-	-
QORG	-	-	0.029*** (0.007)	-	-
N	14,172	14,172	14,172	10,108	4,064
R-squared	0.241	0.335	0.344	0.322	0.347

Legend: * p-value<0.05; ** p-value<0.01; *** p-value<0.001. Baseline categories: Female; Aged between 65 and 69; Non-white ethnicity; less than 3 limitations in ADLs; Very good SPH; Home design meeting needs very well; Not receiving practical help from within or from outside the household; Not having received help in answering the questionnaire. R-squared estimated by squaring the correlation of the observed and predicted values. QTOT quality of care experience scale; QREL interpersonal quality scale; QORG organisational quality scale.

Table 7: Average marginal effects and contrast margins for user characteristic variables from the interaction models (models 5a-5f)

	Average marginal effect	**Contrast Margin**
Model 5a		
DESIGN_HOME: home meets needs very well	0.170***	-
DESIGN_HOME: meets most needs	0.243***	0.073***
DESIGN_HOME: meets some needs	0.320***	0.150***
DESIGN_HOME: totally inappropriate	0.314***	0.144
Model 5b		
GENDER: female	0.216***	-
GENDER: male	0.204***	-0.012
Model 5c		
AGE: 65-69	0.190***	-
AGE: 70-74	0.199***	0.009
AGE: 75-79	0.213***	0.023
AGE: 80-84	0.206***	0.016
AGE: 85-89	0.224***	0.033
AGE: 90 and over	0.223***	0.032
Model 5d		
ETHNICITY: other ethnicity	0.265***	-
ETHNICITY: white	0.211***	-0.054
Model 5e		
ADLS = less than 3	0.160***	-

ADLS =3	0.192***	0.032*
ADLS =4	0.206***	0.047***
ADLS =5	0.265***	0.106***
Model 5f		
SPH: very good	0.156***	-
SPH: good	0.188***	0.032
SPH: fair	0.215***	0.059*
SPH: bad	0.259***	0.103***
SPH: very bad	0.293***	0.137***
N	14,172	14,172

Legend: * p-value<0.05; ** p-value<0.01; *** p-value<0.001

Figure 1: Relationship between quality of care and quality of life for different user groups