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Helping older people to use quality information to choose residential care

Stephanie Kumpunen¹, Lisa Trigg² and Jacquetta Holder

Abstract

Context: The availability of data about the quality of care homes has increased in England since the late 1990s, as in other countries, but it is widely underused by people choosing providers.

Objectives: To examine older people's understandings of a high-quality care home, their preferences for quality indicators, and how they would use comparative quality information about care homes to select one for themselves or a relative.

Method: Five group workshops were conducted with 27 older people with experience of social care services and relatives of care home residents in three local authority areas in England. Different methods were used to collect data: an open discussion, a card sorting exercise, and use of a score-card to compare fictitious homes.

Findings: The most popular indicators among participants in the workshops were linked to residents' quality of life. Indicators we may think of as being about clinical issues were valued the least. The value of some indicators was more widely recognised after discussion highlighted their relevance to choosing a care home for someone. Comparing quality information was said to be useful to shortlist homes to visit and inform visits, and many strategies were used to manage the data to select a home. Concerns were raised about the trustworthiness of some data and sources.

Limitations: The nature and scale of the work mean we cannot claim it to be a representative sample and this limits

the generalisability of the findings. The findings are, nevertheless, illuminating in terms of factors to consider when making available information to assist in choosing a care home. Recruitment challenges for the workshops and the implications of the difficulties participants had managing the data are discussed.

Implications: Quality indicators are likely to be ineffective at promoting comparison across care homes unless older people are supported to understand their significance. Policymakers and providers of quality indicators need to be aware of user preferences, build in decision-making support, find ways to better communicate complex measures and encourage people to identify their own views before reviewing published indicators. Methodological implications for further work in this area are also considered.

Keywords: Quality indicators, quality information, care home, older people, choice, group workshops, England

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Introduction

There has been an increase in the availability of care home quality data in England since the late 1990s, in the context of the marketisation of provision, and a related policy focus on promoting informed choice among consumers. Successive reviews have highlighted the need to improve the information on care quality to support older people choosing a care home provider (Office of Fair Trading, 2005, 2011; Competition and Markets Authority, 2017). Governments in England, Finland, the Netherlands, Sweden and the United States (US), have invested significantly in collecting and publishing data to help the public make decisions when choosing care providers (Rodrigues et al., 2014). Specialist, often private for-profit, organisations have also launched information services, using subscription and click-through charges to generate income.

Quality information can vary greatly by sector and country in terms of who collects the data, when and how. It can generally be divided into three types: input or structural indicators (e.g., attributes of the care setting, such as staffing levels); process indicators (e.g., how well care was provided and the customer experience) and outputs and outcomes (e.g. the impacts of care on quality of life) (Donabedian, 1966). Indicators may be drawn from routinely-collected data, such as that collected in Finland and Germany, or through the Minimum Data Set reported in the US (Rodrigues et al., 2014), or be summary metrics that communicate the overall quality of a care provider built from multiple sources of data, such as the ratings used by the Care Quality Commission (CQC), the quality regulator in England. They might relate to legal requirements or minimum standards, and can be used to support performance monitoring or quality improvement or to help the public choose a care provider.

Despite the growing breadth of indicators and the best intentions of information publishers, evidence suggests that quality information is underused and the public finds it confusing and believes some data sources lack trustworthiness (Damman et al., 2009; Fischer et al., 2015; Konezka & Perrailon, 2016). In both health and long-term care, patients, users of services and their families and carers are more likely to favour word of mouth recommendations and choose care providers based on non-quality related factors such as cost, location and availability of a place (Faber et al., 2009, Gadbois et al., 2017; Ketelaar et al., 2011; Pesis-Katz et al., 2013; Trigg et al., 2018).

Cultural and practical barriers may also underpin the underuse of quality information and choice. Older people often enter residential care as a 'last resort' and following hospitalisation or a crisis (Bebbington et al., 2001; Gadbois et al., 2017). Due to their often frail circumstances, their families frequently lead the decision on their behalf without prior discussion, therefore presenting less than optimal conditions for informed decision making (Castle, 2003; Davies

& Nolan, 2003). This is unlikely to change and, in most cases, relatives will probably remain key users of quality information about care homes. The pressure on the initial decision is also increased in England because, unlike in other countries such as Spain, residents rarely move if they do not like their first choice of home (Trigg et al., 2018).

The confusion surrounding quality information derives in part from the high prevalence of indicators in public reporting systems that focus on clinical quality (e.g. the percentage of pressure sores per home), which is common in long-term care systems that embed data collection in day-to-day practice (Rodrigues et al., 2014). Indicators reporting the quality of clinical care are often published alongside definitions and guidance for interpretation that are not easily understood unless information users have some medical knowledge or prior experience with conditions of older age (Gigerenzer et al., 2007).

Compounding the confusion surrounding public reporting, quality indicators across the many systems are presented in non-complementary forms that preclude easy comparison of providers. Understandability, and in turn, the ability to make comparisons across services can be affected by presentation design (including raw figures, plain text, star ratings, traffic light systems, ratios or mean values, percentages, bar charts, symbols, or a mixture of one or more of these methods) and by the overall number of indicators and complexity of information (Damman et al., 2016; Kurtzman & Greene, 2016). The expertise and numeracy and literacy skills of information users also play a role and are often over-estimated by those developing indicator information (Gigerenzer et al., 2007); and the research on presentation methods is largely overlooked in the design of new reporting websites (Hildon et al., 2012; Mukamel et al., 2016).

In England there is a range of information sources and quality indicators available. A number of organisations produce factsheets and checklists of questions to ask providers, while others offer personalised advice for the public. There are also specialist websites showing ratings and quality information, such as nhs.uk, carehome.co.uk and carehomeadviser.com, as well as patchy 'customer reviews' of care homes on general review websites such as Yelp. There is a range of national quality metrics collected, but none are specifically published for a lay public audience. For example, NICE indicators measure outcomes that reflect the quality of care;¹ CQC inspection reports and ratings that assess the quality of care from individual providers² and the Adult Social Care Outcomes Framework is used to set priorities, measure progress and improve transparency and accountability at local and regional levels.³ However, there are a few overlapping national-level conversations focused

1 <https://www.nice.org.uk/standards-and-indicators>

2 <https://www.cqc.org.uk/what-we-do/how-we-do-our-job/inspection-reports>

3 <https://digital.nhs.uk/data-and-information/publications/ci-hub/social-care>

on creating a simplified data set for care homes, perhaps resembling the national Minimum Data Set (for example Department of Health and Social Care and Care Quality Commission (2017) and Independent Age (2016)). A focus of these discussions has been identifying and developing measures that cover what matters most to people. As yet none of these publication efforts or indicators have been streamlined or brought together in a useful way for the public or professionals.

The purpose of our paper is to contribute to the academic literature on older peoples' understandings of and preferences for quality indicators, with a focus on England, and with the aim of providing useful evidence for guiding further research and the development of indicators. This research was part of a larger international study of information and choice of care homes for older people which included three countries: England, the Netherlands and Spain (Trigg et al., 2018). This included a review of national policies and provision of quality information in each country, and one-to-one interviews with professionals involved in care home selection, and residents and relatives, as well as workshops (Trigg et al., 2018). Here we focus specifically on England and describe and reflect in more detail on our data collection methods and report additional findings and implications for policy and practice in developing quality related information on care homes to inform public choice.

Methods

The research design and methods build on those developed for a study exploring the public's understanding of comparative hospital quality information (Fasolo et al., 2010). We adapted this study's activity-based focus group method to run what we called 'group workshops' in study information. Three activities were conducted and had the following aims:

1. **Open discussion about a good quality care home:** To understand participants' views of what makes a good quality care home, using their own words and frames of reference, while also encouraging consideration and discussion of the care home attributes that are important to them.
2. **Card sort exercise of 15 quality indicators:** To examine participants' perceptions of and preferences for quality indicators, and how discussion influences participants' understandings of quality and quality information.
3. **Choosing a care home from a scorecard comparing three fictional homes:** To examine how participants used quality information to select a provider.

We wanted to include older people using social/long-term care services but not resident in a care home, and relatives of care home residents who had chosen a home in the last 12 months. The first group was considered to represent 'potential' or 'prospective' users of care home quality information

because it is possible that their needs may change to require residential or nursing home care. Relatives, as aforementioned, are key players in care home selection and those with recent experience might be expected to be relatively 'expert', insofar as they may have already used quality information and considered what quality information is important to them.

Invitations and study information were forwarded to potential participants by managers of local carer support organisations and voluntary sector providers of community services identified by social services contacts and day centres run by care homes participating in the wider study. We aimed to conduct six workshops across three local authorities in London, the south-east and the north of England. All participants self-selected.

Support organisations reported difficulties recruiting relatives because they were not easily identifiable among their networks or had helped choose a care home place more than 12 months before recruitment began. Our study sample consisted mainly of older people who were service users (n=23) and very few relatives of care home residents (n=4). The majority of our sample was aged over 80 years, white, and had been married (table 1). Of the users of care services, 12 attended day care regularly and 11 were living in extra care housing (self-contained apartments for older people, who can be tenants, owners or leaseholders, with features such as on-site care and support staff, emergency alarms and communal facilities) (King, 2004). All four of the relatives were spouses of residents who had developed dementia.

Table 1. Description of participants

	Relatives (n=4)	Prospective residents (n=23)	Total
Gender			
Female	2	15	17
Male	2	8	10
Age			
65-69	1	1	2
70-74	1	0	1
75-79	0	3	3
80-84	1	10	11
85-89	1	5	6
90-94	0	4	4
Marital status			
Married	4	3	7
Widowed	0	16	16
Single, never married	0	1	1
Divorced/Separated	0	3	3
Ethnicity			
White	4	22	26
Mixed	0	1	1

Two researchers facilitated each group workshop of four to seven participants. The relatives' workshop was held at the support organisation, and the service users' workshops were hosted by providers of care home, day care and extra care housing services. Consent forms and short socio-demographic questionnaires were completed at the start. Due to the time constraints and concerns about fatigue, we felt we could not include actual or self-perceived literacy and numeracy level questions, which often include multiple sub-questions. A structured workshop protocol was piloted with the Personal Social Services Research Unit's Service User and Carer Advisory Group at the London School of Economics and Political Science (LSE). The group suggested the workshops were long, but not overwhelmingly so, and approved the approach. We also consulted Dr Barbara Fasolo about the appropriateness of drawing on her hospital quality information study design (see above) for research with an older population, and she suggested allowing for frequent breaks and providing support for those with queries about the meanings of indicators. We built in multiple refreshment and comfort breaks, arranging timings flexibly with the venue providers, which allowed participants to eat their lunch with their friends outside the meeting room. We also offered ad hoc support to participants as needed by describing indicator definitions and sources. For consistency, researchers referred to a document of definitions, along with further explanation of data collection methods and interpretation advice to explain indicators, where required, during each activity.

The first activity was an open discussion in which participants were asked to describe aspects of 'good' care homes (i.e. what they might feel and look like). In the second activity each participant was given a stack of 15 randomly sorted cards. Each card displayed the name of one quality indicator and its data source (whether a person or organisation had provided the data informing the indicator, including, for example, a third party, regulator or provider assessment, or data that was collected directly from residents and/or relatives). The provision of data source alongside measures is recommended as good practice because it helps people make their own judgements about value (Marshall et al., 2006). Participants were asked to rank the cards in order of importance individually (or where challenging, just the top and bottom three) before discussing their choices. They were asked if they would change their ordering after the discussion.

The 15 indicators included 13 drawn from an extensive international review of care home quality indicators undertaken as part of the workshop design (see table 2). Two measures of user and relative/carer experience were created by the team in the absence of similar published measures. The goal was to create a balance of indicators, including a mix of sources, clinical/non-clinical indicators, structure/process/outcome indicators, and acknowledge the full range of quality of life domains, as developed by Netten

and colleagues in the Adult Social Care Outcomes Toolkit (Netten et al., 2009).

In the final activity participants were asked to select a care home for themselves, a family member or friend using a mock scorecard (see table 3) and then to explain their choice and how they made it. The scorecard showed quality information about three hypothetical care homes (A, B, C), with scores for all 15 indicators presented in the previous activity. To encourage a focus on quality information, participants were told to assume every home was in their desired neighbourhood, had a place available, and was within their budget. Each care home was given high, average and low scores across groups of indicators, creating strengths and weaknesses. Scores were drawn from the reported performance of real care homes in England, the Netherlands and the US. The presentation style of scorecards mirrored those available online through commercial and government organisations. We preserved natural framing – enabling participants to intuitively interpret both high and low scores as positive depending on the nature of the indicator. Evaluative labels were added ('excellent', 'good', 'adequate' or 'poor') to support interpretation and comparison across homes (for further discussion see Fasolo et al., 2010). No one care home was clearly better than another, to encourage participants to choose one that met or excelled at criteria that were important to them. At the end of the group workshops, participants were asked about their views and preferences for sources of quality information.

Group workshops lasted 100–150 minutes, were audio-recorded and transcribed, and fieldnotes were captured by the research team. Data were collected over five months, between August and December 2012. Each participant received a £20 shopping voucher.

Despite the breaks and the individualised support we provided to clarify the meanings of indicators, participants expressed fatigue or perceived inability to complete tasks. Only 17 participants were able to choose a care home from the mock score card. At the outset we knew the workshop would be challenging for some participants, but we also wanted the process to compel the necessary cognitive skills required to choose a care home in a real world setting. The challenges associated with undertaking complex data collection with older people are discussed in more detail in the findings and limitations sections below.

We developed a coding framework for quantitative and qualitative data in Microsoft Excel, drawing on the workshop protocol. To determine which indicators were most popular across activities we triangulated transcripts with participants' completed card sorts and mock scorecards using a content analysis approach. To gain a richer understanding of participants' perspectives and preferences, we also undertook thematic analysis of the transcripts using a Framework Analysis approach (Ritchie and Spencer, 2002). Key themes examined included participants' personal experiences with care homes and quality information; their understandings

Table 2. Quality indicators and sources

Indicator wording shown on cards	Who collected it? (shown on cards)	Source
Summary score of overall individual's current social care related quality of life	Third party/ regulator	Adult Social Care Outcomes Toolkit (ASCOT) (England) ¹
3 Star quality rating	Third party/ regulator	CQC (previously used in England) ²
Percentage of residents who would recommend the care home	Residents	Created by project team
Percentage of residents who answer 'yes' to 'The meals are tasty'	Residents	Quality Framework Responsible Care (QFRC) (the Netherlands) ³
Percentage of relatives who agree that 'The home is a pleasant place to be.'	Relatives/ carers	Adapted from ASCOT ¹ and QFRC ³
The building is designed to support people with sensory and cognitive impairment, particularly people with dementia, for example, with features for wayfinding, orientation and familiarity	Third party/ regulator	Sheffield Care Environment Assessment Matrix/Enhancing the Healing Environment (UK) ⁴
Assessment of the physical condition of a sample of residents, for example, skin condition, teeth, hygiene	Third party/ regulator	Used by German insurance companies
Percentage of residents who agree that 'Residents have enough opportunities to participate in social and leisure activities and physical exercise'	Residents	Adapted from QFRC ³
Percentage of residents with pressure sores	Provider	Nursing Home Compare (US) ⁵
Percentage of residents who lose too much weight	Provider	Nursing Home Compare ⁵
Percentage of clients who have been given anti-psychotic, anti-anxiety medication or hypnotics one or more days over the past week	Provider	QFRC ³ /PROGRESS ⁶
Overall number of staff compared to residents (adjusted to take into account how sick residents are)	Provider	Nursing Home Compare; similar measure also used in National Minimum Standards (England) ⁷
Percentage of residents who feel staff treat them with courtesy and respect for their dignity while providing health and personal care e.g. when administering your medication or helping you get washed and dressed	Residents	Adapted from User Experience Survey (England) ⁸
Percentage of relatives/carers who say that staff answer their questions well	Relatives/carers	QFRC ³
Care home providers manage their financial resources effectively to ensure their viability is maintained e.g. secure assets, sufficient liquidity, and contingency funds	Third party/ regulator	Created by project team

1. Netten et al, 2009.

2. Care Quality Commission, 2010.

3. Quality Framework for Responsible Residential and Domiciliary Care Steering Committee, 2007.

4. Parker et al., 2004.

5. Abt Associates Inc., 2004.

6. PROGRESS, 2010.

7. Department of Health, 2003.

8. NHS Information Centre for Health and Social Care, 2010

Note: Over 200 indicators were initially reviewed with academic researchers with expertise in quality and long-term care as well as international care home staff. We narrowed the list to 15 indicators that balanced nine domain areas: Food and Drink, Accommodation, Physical Care, Social Participation and Activities, Clinical Treatment, Staff, Management and Communication, Finances, and summary measures. We aimed to select indicators across three broad areas of quality: subjective, objective (non-clinical) and clinical indicators. We assigned values for high, middle and low performing providers based on the original sources, but sometimes changed method of presentation (e.g. from percentage to proportion) to expose participants to a wider mix of indicator presentation methods.

Table 3. Mock scorecard

	Care Home A	Care Home B	Care Home C
1. Percent of relatives and carers who think the home is a pleasant place to be	85% Excellent	73% Good	92% Excellent
2. How well is the building designed to support people with sensory loss and cognitive impairment, especially people with dementia	4.9/10 Poor	9/10 Excellent	6.9/10 Good
3. The care home can prove that it can manage its financial resources to ensure its viability is maintained, for example, secure assets, sufficient liquidity, and contingency funds	2.5/5 Adequate	3.5/5 Good	3.9/5 Good
4. Percent of residents who have lost too much weight in the past month	2% Excellent	9% Good	14% Adequate
5. Percent of residents who think the meals are tasty	68% Good	61% Good	88% Excellent
6. Percent of residents who have pressure sores	0% Excellent	11% Adequate	23% Poor
7. How well did the home score in a medical assessment of residents' physical care, for example, skin condition, teeth, and hygiene	58% Adequate	96% Excellent	82% Good
8. Percent of residents who feel they have enough opportunities to participate in social and leisure activities and physical exercise	78% Good	69% Good	79% Good
9. Residents' social care related quality of life	Good	Good	Excellent
10. What was the star rating given by Care Quality Commission?	* Adequate	*** Excellent	** Good
11. Percent of residents who have been given anti-psychotic drugs one or more days over the past week	4% Excellent	15% Adequate	35% Poor
12. Percent of residents who would recommend the care home	80% Good	73% Good	93% Excellent
13. Overall care staff hours per resident per day	2.1 hours Good	3.25 hours Excellent	2.9 hours Good
14. Percent of residents who feel staff treat them with courtesy and respect while providing health and personal care, for example, going to the toilet, administering medication	81% Excellent	63% Good	85% Excellent
15. Percent of relatives and carers who agree that staff answer their questions well	81% Good	62% Adequate	83% Good

of quality, quality information and data sources; and rationale for preferences for quality information and care home choice. Data saturation was reached in each activity across workshops, and both major themes and diverse cases are reported throughout the findings section.

The LSE and England's Social Care Research Ethics Committee approved the research. The Association of Directors of Adult Social Services recommended it to local authorities and participating councils approved the research using their own governance procedures.

Findings

Participants' views of 'quality'

In the first activity, the open discussion, participants described 'good' care homes as those that are clean, organise activities, have kind staff, provide good care and nice food, are aesthetically pleasing (e.g. high-quality carpets and furnishings), offer privacy to residents, are located close to

shops and public transport, and convenient for family and friends to visit.

The most popular features of a good care home (and the number of participants who mentioned them, of the 26 people who took part in this activity) all related to aspects of quality of life:

- cleanliness of home/no smell (21)
- opportunities to take part in social activities (16)
- caring staff (9).

Participants described the importance of care workers organising activities 'to make a bit of a life for you' (female prospective resident, GW2), and 'feeling control over daily life routines' and 'not having curfew time when you're expected to be in bed by' (female prospective resident, GW4). The initial value placed by participants on the importance of factors related to residents' quality of life, and resident and relative views about care home quality, identified during the open discussion, continued to be evident in the later activities exploring their quality indicator preferences and their use of them to choose between homes.

Many participants reported their opinions were based on their previous, mostly negative, experiences in care homes – some of which dated back decades to when their parents or other family members lived in care homes. Drawing on past experience has been noted in the literature as influential when choosing a hospital (Dixon et al., 2010; Gooding, 1995), and, unsurprisingly, appeared to also influence participants' descriptions of a good care home. For many, despite attending day centres located in care home facilities, it had been the first time they had thought about how they would evaluate care homes. They appeared to initially seek out factors that would be easily evaluated as a visitor, instead of information that would be collected by others and made publicly available, echoing previous research (Greenhalgh & Ogunye, 2016; Konetzka & Perrailon, 2016; Pesis-Katz et al., 2013). Very few wanted to think of themselves as potential care home residents, confirming the negative attitudes to residential care found in previous studies (Demos, 2014; Rubin et al., 2016). However, as conversations developed participants appeared more willing to take on a resident's perspective.

Participants' preferences for quality indicators

The card sort activity was for most participants their first encounter with quality indicators. Participants were asked to rank at least their top three indicators that they thought would be most helpful when choosing a care home from table 2, above. Most of the remaining 25 participants managed to complete the activity: 13 ranked all 15 indicators and another four ranked almost all; eight ranked the top and/or bottom three. Only one participant did not take part, saying it was too difficult. The most popular indicators (and the number of participants who chose the indicator in the top three) were:

- percentage of residents who feel that staff treat them with courtesy and respect while providing personal care (13)
- percentage of relatives and carers who believe the home is a pleasant place to be (10)
- resident's social care related quality of life (9).

There was a strong preference for customer ratings that covered multiple domains or aspects of quality, such as 'the care home being a pleasant place', 'recommendations for the home', and 'residents' quality of life'. One prospective resident also explained that these 'summative' measures helped narrow options down, and that the 'CQC star rating' indicator was particularly important because of the comprehensiveness of the regulator's inspection regime in healthcare organisations:

...it's what they do in the hospitals, they go in and see the cleanliness, the caring and everything, medication, everything, all comes under one. And if they have a star rating it's easier for our families, relatives and friends to go obviously to the higher rated one to see if it suits us, you know. (female prospective resident, GW1)

There was very little support for clinical and specialised measures, such as the prevalence of pressure sores and excessive weight loss. These indicators appeared to be least well understood among participants, echoing previous studies (Fasolo et al., 2010; Pesis-Katz et al., 2013). Prospective residents did not connect weight loss with poor practices in homes around nutrition and mealtimes, which is what the indicator is intended to highlight. Instead they viewed weight loss and gain through the lens of social norms, as resulting from choices made by residents about their food intake and exercise, and whether the food prepared for residents was appetising. Participants were also confused about who would collect data for specialist measures and how documentation would be produced. One participant said, 'I don't know how you're going to find certain things out really. Nobody's going to tell you they have sores and whether they're psychotic' (male prospective resident, GW3)

The indicator relating to the financial resources of the care home was also unpopular with participants. Many believed that carpets and decor or the relative newness of the home were indicative of a care home's financial resources, potentially making an indicator redundant if an in-person visit could be made to the care home. Others worried that most people would not have the accountancy skills required to interpret the indicator, therefore making it less relevant than others. Only one participant recognised the significance of financial stability and explained it to the other members of her group:

I think it's important that the care home can prove that it can manage its financial resources so that it remains viable because I remember, last year, seeing a programme on the television where a home closed down and a lot of people were moved, very suddenly, to another home. ... And, across the whole country, people had to be moved very swiftly and people died because of it: because it's such a shock to elderly people. (female prospective resident, GW1)

Facilitators explained the meaning of the indicator 'building design of the care home' after confusion arose in each workshop. Even after discussion, the importance for this indicator increased only for those with experience of caring for people with dementia. For example, one prospective resident, unfamiliar with the symptoms of dementia questioned, 'But how can the building be designed? [Residents with dementia] have just got to be well trained, haven't they?' (female prospective resident, GW1). Alternatively, the spouse of a current care home resident with dementia was adamant that design for people with dementia 'should be inherent now in all buildings'. It was apparent that personal experience influenced both the comprehension and perceived relevance of indicators, and how information on quality would be collected.

The card sorting exercise was followed by a discussion and participants were given the opportunity to change their rankings. Only one participant across all five group

workshops switched the ranked order of two indicators. All other participants appeared content in their ranked order of indicators, at least temporarily. One participant speaking on behalf of the group said that the decisions had been difficult and ‘if I was given the same sheet say in a month’s time and I looked at them I’d probably change my mind ... ’cause they’re not definite answers, but that’s what I feel at the moment’ (female prospective resident, GW1). Another said ‘You know the acid test with these is, come back in an hour, give us the cards again and you’ll get totally different answers’ (male prospective resident, GW2). Both comments suggest that it might be useful to revisit quality information multiple times before selecting a care home. They also suggest challenges in consulting on and planning which quality indicators to make available to the public.

Use of quality information to choose between care homes

Most participants struggled with the complexity of the mock scorecards, which included scores for each measure they had ranked and discussed in activity two (see table 3). Only 17 of the 27 participants who started this exercise completed the task of choosing a care home, and many of them needed a considerable amount of explanation and support. However, reflecting on the activity, participants reported that comparative quality information would be helpful in narrowing down care home options to visit, but an in-person visit was essential. They also suggested that the range of quality indicators could be used to create checklists and questions for care home visits – a conclusion also reached in recent US-based research (Konetzka & Perraiillon, 2016).

Most participants chose care home C (13/17), which had the highest scores out of the three hypothetical homes for three indicators: staff treat residents with courtesy and respect while providing personal care; recommendations from care home residents and relatives; and tastiness of meals. The first two of these indicators were in the ‘top three’ indicators in activity two. Only four participants chose care home B, and none chose A. Care home B had the highest scores for structural measures, and care home A had the highest scores for clinically-focused outcome indicators.

Strategies for choosing care homes varied, but participants rarely considered any information apart from the evaluative labels, that is, ‘excellent’, ‘good’, ‘adequate’ or ‘poor’. To make a choice most participants reviewed the same indicator across all three homes, row-by-row. Some participants added ticks to the home that had the best score on each row (and was labelled ‘excellent’) among the three. Five participants reported reviewing ‘all’ indicators and six reported using ‘a few’ (and two did not report their approach).

Four of the five participants who examined ‘all’ indicators reported they ‘summed the ticks given to each home and chose the home with the highest number of ticks’; a choice simplification heuristic called ‘tallying’ (Dawes, 1979; Goldstein, 1994). In addition to ticks, two male prospective

residents in group workshop four attached scores to labels (e.g. 0 for poor, 2 for excellent) and summed scores. They reported their approach had been informed by their previous careers in bookkeeping and management. Participants in other groups also suggested that their approaches were informed by their past employment.

Participants who used ‘a few’ indicators to choose a care home used up to five to choose their preferred care home, and ignored others. Across groups, some reported selecting one measure that eliminated choices because scores did not meet standards (an elimination-by-aspects heuristic) (Tversky, 1972). Describing her decision-making process, a participant who chose care home B said:

Well, the other things might be excellent but I wouldn’t tolerate, for instance, this antipsychotic drug thing, which I know is a problem because of the staff levels. So I thought, well, okay, C’s out for me because that’s important to me. As well as staff levels, it’s very important to me. (female prospective resident, GW4)

Despite the presence of four, multi-dimensional, summative indicators and customer ratings that participants reported ‘described the absolute essentials’, participants in one group still complained there was no indicator that captured the ‘whole essence of the place, A, B or C’, which should have covered ‘grounds and the facilities, the overall impression of comfort or friendliness’ (male prospective resident, GW2). Other participants in the group commented that these details were only possible to assess by visiting care homes, and one participant said, ‘I think your own personal feeling when you’re going round is a good one to go by. And if you feel that there’s something not quite right in the home, to go somewhere else’ (female prospective resident, GW2). Another said:

Everybody’s different, so you’ve got to appraise what that unit has got to offer that suits you, so you really need to spend a day there as a sort of a day inmate if you like. And eat your meals with everybody, see what goes on, watch people. Go back at different times and then, you know, eventually having looked at half a dozen you’ll probably assess one that really suits you, you get the feel for it, it feels right for you. (male prospective resident, GW2)

This sentiment was reiterated in other groups, but with less extensive discussion.

Views about information sources

Many participants expressed concerns that care home managers might influence data collection. Relatives and prospective residents were divided about the credibility of the information from care home inspections by the CQC, or the credibility of the opinions of other residents.

Participants also had mixed views about the regulator’s abilities to detect quality in their short and infrequent visits. One male prospective resident said that a star rating would be reliable because the CQC has ‘done their homework’. In

contrast, relatives were unconvinced of the integrity of a rating from a third party. One participant said, 'No committee or commission or whatever, in my opinion, can give a star, like a hotel star, or stars to a home' (male relative, GW5). Furthermore, for two relatives the CQC's ratings did not reflect their own assessments of a home, and these relatives were sceptical that residents' needs and preferences were considered in the scoring system. The international evidence examining the relationships between regulator ratings and public perceptions of quality is mixed. US studies have found little or no association between resident/family satisfaction and regulator's star ratings (Nadash et al., 2017; Williams et al., 2016), while UK-based studies have found a positive relationship between the CQC's quality ratings and residents' social care-related quality of life in care homes, but not in nursing homes (Netten et al., 2012; Towers et al., 2018).

Many prospective residents agreed that family and friends would be the best source of information to help choose a care home, followed by social services, GPs and voluntary organisations and charities. Prospective residents also believed that care home residents, 'the people who actually live it – not the ones who control the budget', would be best placed to give accurate opinions on the quality of the care home.

The views of the four relatives were different. They suggested that word-of-mouth recommendations from other relatives and carers, rather than residents, had been most influential when their spouses were admitted to care homes because most residents experienced fluctuating mental and emotional states that prevented them providing consistent information. One participant said, 'Trying to get answers or opinions from residents is not very conclusive' (male relative, GW5).

Discussion

While this paper is concerned with how older people and their relatives understand, and might be helped to use, care home quality information, it is important to note that informed decision-making is underpinned by a number of assumptions. First, the public being aware of easily interpretable comparative quality information, allowing them to seek out the data they need to make trade-offs between different features of care, and then between different providers. Then, for this to constitute a rational choice, the older person and their relatives must be able to identify their own preferences for different aspects of quality – a complex, multi-faceted concept – and subsequently understand that there is variation in quality between providers, and then believe that differences between providers can be revealed through information. Finally, they need to be able to use quality information to choose a provider that benefits the older person most (Marshall & McLoughlin, 2010). This is a lot to ask of decision-makers of any age or circumstance.

The ability to choose a care home also relies on there being a place available from more than one provider that meets an individual's needs, is affordable and in a suitable location. In England there are concerns that the sustainability of the care home market is being threatened by increased demographic pressure, the underpayment of care home providers by local authorities, care home closures which are often linked to this underpayment, and a lack of new capacity for state-funded residents and those with the greatest needs (Competition & Markets Authority, 2017; Institute of Public Care, 2017).

Despite the challenging assumptions surrounding the appropriate use of quality information and the real-life difficulties associated with exercising choice, older people and their families should still be able to benefit from quality information. At the very least, people ought to be able to see what quality information is known about a care home with a place available and be given support to navigate and understand it.

Many participants in our study struggled to understand how indicator data were collected, which aspects of quality indicators were measured, whether the scores reported positive or negative results, and ultimately how to use indicators to make an informed selection of care home. However, at the end of the workshops, participants told us they started to become aware of the value of comparative quality information once they understood its relevance, and we observed their understandings develop throughout the workshops.

Before exposure to our set of 15 indicators, participants' understandings of a good quality care home mirrored the quality of life domains seen in the Adult Social Care Outcomes Toolkit, namely clean and comfortable accommodation and opportunities for social participation (Netten et al., 2009). As participants became aware of the multi-dimensional nature of quality and the possible range of indicators used to describe quality in care homes through the card sorting exercise, they found clinical quality indicators challenging to interpret and indicators associated with building design irrelevant unless they had had personal experiences with its importance. There was most overall support for the summary measures we presented, which captured many aspects of quality they understood and believed were important. Most participants placed trust in resident and relative perspectives for building summary measures. During the mock scorecard exercise participants used either all scores presented or a small number of them and added them up, which in essence, developed a summary measure. Overall, they reported that comparative quality information would be most helpful in narrowing down care home options, but an in-person visit was still essential.

In England the development of a single source of information to bring together quality information on care homes is being debated. Below we describe three enablers that could help improve the uptake of existing or new quality information, and ultimately, the decision making process in the long-term care sector. However, in addition to quality

indicators it is widely recognised that better information on availability of a place and transparency about the costs of care, especially for self-funded residents, will be just as essential to improving the decision-making process.

Focus on indicators of interest to users: Publicly reported quality of life indicators, which report residents' perspectives of aspects of their daily lives, such as their social participation in activities (see Kane, 2001; Netten et al., 2009), are relatively rare even though they may be more relatable to potential care home residents and their families. This is because a high proportion of residential care users have dementia or cognitive impairment (Gaugler et al., 2014; Gordon et al., 2014), making data collection about quality of life challenging, but not impossible (Kane et al., 2003). The challenges inherent in measuring quality in long-term care can lead to a misdirected focus on measuring easily quantifiable structural indicators or aspects of clinical processes, for which we found little appetite in the group workshops. Unfortunately to date, there is less evidence of reporting indicators concerning aspects of user experience and quality of life (Rodrigues et al., 2014). Processes to collect resident-reported, multi-dimensional quality of life measures among nursing home residents, even with severe cognitive impairment, have developed over recent years (Brooker & Woolley, 2007; Kane et al., 2003; Netten et al., 2010), thus providing opportunities to develop this aspect of reporting in line with the preferences of the older people in this study and others (for example, Konetzka & Perrailon, 2016).

Improve the perceived trustworthiness of data and sources: We found that our participants were distrustful of data provided by care homes, a finding which echoes Magee and colleagues' (2003) assertion that the public is sceptical that health care statistics produced by hospitals and governments are free from manipulation. Equally in the US, there is uncertainty surrounding figures supplied by healthcare providers among various stakeholders, including policymakers (Sinaiko et al., 2012). Evaluators of a pilot of new indicators suggest that over half of the British adults they surveyed (52%) believe abuse and neglect in care homes is common, and these beliefs are tied to their underlying suspicions of care home environments and the abilities for interviewees to be forthcoming about their experiences during inspections (Independent Age, 2016). Similarly, the attitudes expressed about the regulator, and 'experts', suggests further work is needed to publicise and raise awareness of the value of specialised and professional judgement. Participants liked summary measures while simultaneously distrusting 'third party' assessment. There is, however, a fine balance between accurately providing source information and detailing so much about this that it detracts from the indicators themselves. Piloting of measures and the display of source information should be encouraged.

Build in decision-making support: High levels of numeracy are needed to process much of the quality information published about residential care, yet levels of

numeracy and literacy tend to be low in the general population (OECD, 2016). Most people also minimise effort when making decisions, potentially neglecting useful information (Payne et al., 1993). Older adults may be particularly disadvantaged, due to differences in how they often process information and make decisions (Finucane et al., 2002; Mata et al., 2007). Future approaches should leverage the many studies that have identified best practice approaches to decision support, from the use of summary measures through to the optimal use of colour and layout (Boyce et al., 2010; Kurtzman & Greene, 2016). Decision support will therefore be needed from carers, friends, family and professionals (e.g. social workers or dementia advisors) to ensure that older people and their relatives can make use of available quality indicators. This support should also acknowledge the lower levels of 'digital readiness' of older people and their lower access to internet-based information (Horrigan, 2016), and that information may need to be revisited multiple times to confirm preferences.

Limitations and reflections on methods

As a relatively small-scale piece of mixed methods research, using purposive sampling and time-consuming face-to-face data collection methods, the findings are necessarily of limited generalisability. Recruitment challenges and the challenging nature of some of the workshop tasks meant that the sample size was also smaller than planned. Research involving more relatives of care home residents would have been useful. While our workshops will not have mirrored how decision-making would occur in real life, we believe the issues raised – such as the type and usability of information available, and the perceived trustworthiness of sources – are still relevant. We believe the group workshops were successful in enabling a back and forth interaction between participants and facilitators, and among participants themselves, which brought to light misunderstandings they had about quality indicators and their data collection. These conversations helped participants gain a broader perspective of quality of care that helped them critically appraise quality indicators and develop preferences, something that may not have been achieved through 1:1 interviews or strictly discursive data collection (e.g. unstructured focus groups).

Finally, we also draw together our reflections on the methods used and lessons for further research in this area. We believe that participants' difficulties with completing the research activities may have been partly age-related, although some quality indicators were complex, as was the task of managing comparative quality information. Fasolo and colleagues (2010) presented a similar number of hospital quality indicators to their participants, nearly half of whom were aged 65 years or more. They reported that older and less numerate participants found making trade-offs during provider selection difficult, but the authors did not highlight this as a barrier to inclusion. Further, the decision-making challenges experienced by older people in research

settings are likely to be similar to those experienced in real life. Our sample was relatively old (the majority aged 80 years or older) and the relatives were all spouses rather than adult children. However, it is people of both age groups who are likely to be involved in care home selection and information should aim to be inclusive. If younger relatives are more likely to review online information, it would be helpful to include them in future research. Electronically displayed comparative quality information could also be explored. Future research could evaluate the preferences of prospective residents and relatives making real choices, as well as examine whether preferences vary across cohorts of different ethnicities, ages and levels of education, numeracy and literacy.

Implications

Providing information on quality is an essential part of supporting choice in residential care. The role of governments in providing this information varies across countries, and people seeking care are often confronted with conflicting information from multiple sources, including regulators, third party ratings and review organisations and providers themselves (Kumpunen et al., 2014). The issues concerning how the care market functions suggest there is a role for government in providing at least stewardship with respect to the validity and availability of this published data (Fung et al., 2007; Trigg, 2018). In addition, to improve the usability of this information, governments and other providers of information need to:

- raise awareness of different aspects of quality in care homes
- be aware of which indicators are of most interest to users
- build in decision-making support
- find better ways to communicate complex measures
- explore the optimal amount of contextual information needed to support interpretation and improve perceived trustworthiness
- encourage people to consider their own preferences about what is important before reviewing published quality indicators.

Conclusions

Social care policy in England has promoted the market principles of individual choice and provider competition in long-term care since the implementation of the Community Care reforms over 25 years ago (National Health Service and Community Care Act 1990). Since the start of national regulation in 2001 (Care Standards Act 2000), policies have focused on improving public information provision by providers and the regulator. The increase in the availability of public quality information about care homes has occurred at the same time as ideas about what constitutes quality, and how it can be measured and monitored have developed.

The underuse of an increasingly wide range of information suggests that there is still some way to go to help people exercise informed choice.

This research sought to explore the views of the ‘information users’ to see how they view and use comparative quality information and how it might be improved. The findings raise many questions about the usefulness of detailed care home quality information for older people. These arise from both the direct feedback we received in the group workshops, and from the challenges we faced in facilitating the exercises in the workshops. However, we also found that our participants valued comparative quality information once they understood its relevance and suggested it could be used to narrow down care home options before visiting homes. To improve quality information, we have provided insights around older people’s preferences for types and sources of quality information.

More broadly, however, consideration needs to be given to the question of how realistic it is to expect individuals to take on the role of the ‘informed consumer’ when choosing residential care. Having choice of residential provider is important so that people have control over where they live and how they live their lives (Scourfield, 2007). However, as this article has already pointed out, decisions about residential care are rarely made under optimal circumstances, and instead are often made during health crises. The health and cognitive status of potential residents also affects their capacity or ability to behave like empowered ‘consumers’ of care, with many potential residents living with dementia or with multiple health conditions (see for example, Braithwaite et al., 2007; Eika, 2009; Tanner et al., 2018). As a result, the selection of residential care provider is frequently made on behalf of the resident, with family members often taking on the role of decision-maker and ‘consumer’ in the process. These relatives may have different needs, expectations about quality, preferences for quality information and ways of using it to select a care home (Davies & Nolan, 2003; Milte et al., 2016; Trigg et al., 2018). If potential residents and their families are to take on a more active role in selecting care, it is essential that these issues are considered in policy design.

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