

Information and choice of residential care provider for older people: a comparative study in England, the Netherlands and Spain

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Abstract

This study compared how older people use quality information to choose residential care providers in England, the Netherlands and Spain (Catalonia). The availability of information varies between each country, from detailed inspection and survey information in the Netherlands, through to a lack of publicly available information in Catalonia.

We used semi-structured interviews and group workshops with older people, families and professionals to compare experiences of the decision-making process and quality information, and also to explore what quality information might be used in the future.

We found that most aspects of the decision-making experience and preferences for future indicators were similar across the three countries. The use of quality information was minimal across all three, even in England and the Netherlands where information was widely available. Differences arose mainly from factors with the supply of care. Older people were most interested in the subjective experiences of other residents and relatives, rather than ‘hard’ objective indicators of aspects such as clinical care.

We find that the amount of publicly-available quality information does not in itself influence the decisions or the decision-making processes of older people and their carers. To improve the quality of decisions, more effort needs to be taken to increase awareness and to communicate quality in more accessible ways, including significant support from professionals and better design of quality information.

Keywords: Quality information; Decision-making; Older people; Residential Care; Choice

Introduction

This study reports the results of interviews and group workshops on how publicly-available quality information is used to select residential care providers. The study was conducted in three European countries where the levels of publicly-available quality information vary: England, the Netherlands and Spain.

Over the last two decades, significant time and effort has been invested by governments in publishing information on the quality of public services, particularly in education, health and long-term care. This is often to support broader policies around promoting choice, put in place for two separate, but overlapping reasons: firstly, to increase the empowerment and autonomy of users, and secondly, to encourage providers to improve their quality and efficiency. For this to work, potential users of services need to be able to compare the quality of providers. Making quality reports available to the public is seen as one way to facilitate this process (Fasolo *et al.* 2010).

However, providing information for the public on the quality of long-term care is riven with challenges. Defining and measuring aspects of service quality are problematic (Malley and Fernández 2010), as are the tasks of finding and interpreting quality information (Kumpunen, Trigg and Rodrigues 2014). The idea that older people take on the role of empowered consumers in the care market has been strongly questioned (Eika 2009, Clarke 2006).

Research in long-term care shows that even in the home care sector where, by definition, people have lower levels of dependency, there is some reticence among older people to take control of decisions about their own care and budgets (Baxter, Rabiee and Glendinning 2013, Rabiee, Baxter and Glendinning 2015, Rodrigues and Glendinning 2014), despite the potential benefits (Glendinning *et al.* 2008).

For older people seeking residential care, these challenges are magnified, not least by the fact that this type of care is increasingly only sought when the person has reached a high level of frailty and dependency (Boyd *et al.* 2012). The timing and circumstances of seeking care are also a major contributory factor to these challenges. To begin with, people are often seeking care in a crisis, either health- or carer-related (Bebbington, Darton and Netten 2001). Family members often have to lead decisions about care because of the frailty of the older person. This process can cause conflict and is often accompanied by feelings of guilt and pressure (Castle 2003, Davies and Nolan 2003, Lundh, Sandberg and Nolan 2000, Baxter and Glendinning 2013).

Despite the challenges faced by older people and their carers, government investment in reporting continues to grow in the belief that more information will lead to better decisions. The overarching goal of this study is to shed light on how quality information is used and whether its use is more strongly influenced by individual factors or the broader institutional contexts. In doing so, we provide insights for how quality information might be developed and used in the future.

The study was conducted in England, the Netherlands and Spain (specifically the Autonomous Region of Catalonia). Each of these countries has invested differently in the generation and publication of quality information, in part driven by if and how choice is presented as a policy goal. In England, the system is highly marketised, with an emphasis on choice for service users, and open competition between providers, mainly in the for-profit sector. Policy decisions in the sector over the past two decades have been driven largely by a focus on reducing the amount of residential care and a focus on ‘ageing in place’ (Johnson, Rolph and Smith 2010). In the Netherlands, empowering users to choose between care

providers (all of whom are not-for-profit) has been driven by the focus within the health care system on empowering patients to make choices about their treatment and health care (Maarse, Ruwaard and Spreeuwenberg 2013). The provision of publicly-funded residential care in Spain is a relatively new phenomenon, with the bulk of care historically provided by the Catholic Church to residents who are self-funded, or alternatively the recipients of charitable provision (Comas-Herrera and Wittenberg 2003). Whereas the Netherlands has the highest use of residential care in Europe, Spain has among the lowest. Each country's residential system differs on a variety of other criteria, and these are outlined in the following section.

The article considers two questions:

- How do older people use quality information to choose residential care in each country and how do the experiences differ?
- What are the likely preferences of older people for quality information in the future and how do these differ across the three countries?

We find that, despite the increasing availability of quality reporting, there is little evidence to show that older people are able or ready to locate or use this data to inform their decisions about residential care. The experiences of our participants in all three countries were remarkably similar when considering the differences in institutional contexts and policies. Our study finds that the publication of this information has promise in terms of supporting choice, but that there is too much emphasis on how to collect and present information and not enough attention to the support older people need to use this information effectively.

We begin by providing some background on what is known about how information is used to make decisions about care providers and on the different institutional contexts in each country.

Using quality information to make decisions about care providers

The increasing focus in many European countries on transferring the responsibility for choosing care to the user (Lundsgaard 2005) has been mirrored by a corresponding increase in the generation and publication of quality reports on long-term care providers, most notably in the Netherlands and Sweden (Rodrigues *et al.* 2014). Despite this, the evidence around how this information is used to make informed decisions is sparse (Rodrigues *et al.* 2014). Looking to the health care sector, quality information is rarely used by patients to make choices about providers (Shekelle *et al.* 2008, Ketelaar *et al.* 2011).

In long-term care, previous studies have people choose residential care on basic criteria, for example, the home's location, the activities available, its 'look and feel' and whether or not it smells unpleasant (Castle 2003, Reed, Payton and Bond 1998, Netten *et al.* 2001, Shugarman and Brown 2006). Information on the provider's reputation or price might be used as an indicator of the quality of a provider, but in reality services have to be experienced for a complete understanding of provider quality (Darby and Karni 1973, Malley and Fernández 2010). Identifying meaningful quality indicators is seen as important to broaden decision-making to include more relevant indicators, yet most countries have struggled to find effective ways of communicating quality (OECD/European Commission 2013).

Institutional Context: The residential care sectors in England, the Netherlands and Spain

This section describes some of the main features of the residential care systems in each country. Firstly, the use of residential care varies between the three countries. The Netherlands has the highest proportion of people aged 65 years or more living in care homes in Europe (5 per cent) (Mot *et al.* 2010). This reflects a broad cultural acceptance of residential care and potential over-use – it is estimated that as many as 25 per cent of residents in residential care could be cared for at home (Alders *et al.* 2015). The over-use of residential care is partly due to the rapid expansion in residential care following its inclusion in the landmark 1968 Exceptional Medical Expenses Act, when residential care became available to all who met eligibility criteria in needs assessments. Co-payments apply, accounting for around 8 per cent of total expenditure on long-term care (both residential and community-based), with the level for each individual determined by income and assets, age and marital status (College voor de Zorgverzekeringen 2013).

A rapid expansion in the provision of residential care also took place in England in the 1980s, primarily due to perverse incentives in the social security system for local governments to choose residential care over other forms of care (Johnson, Rolph and Smith 2010). The use of residential care has declined significantly since the introduction of the Community Care Act 1993, which placed care in the community at the heart of long-term care policy and also introduced needs assessments for residential care (Laing & Buisson 2013). The proportion of over 65s in residential care is approximately 4 per cent (Comas-Herrera *et al.* 2010).

In 2006 the Spanish government introduced a universal system and positioned access to long-term care as an individual right. As in England, this is also subject to financial means-testing and needs assessments. However, implementation of the legislation in Spain has been patchy

due to economic conditions and the imposition of austerity measures (Patxot *et al.* 2012). As of 2013, the proportion of over 65s in residential care was estimated to be around 3 per cent (Instituto Nacional de Estadística 2013).

In contrast with the Netherlands, in England and Spain, it is estimated that over half of care home residents pay at least some, if not all, of the costs of residential care (Costa-Font and Patxot 2005, Passingham, Holloway and Bottery 2013). The reforms in Spain have been criticised for their focus on cash-for-care schemes, which continue to prioritise family care-giving (Fernández-Carro 2014). Recent economic conditions mean that in reality only the most disabled now receive care in both countries (Association of Directors of Adult Social Services 2014, Patxot *et al.* 2012), and even in the Netherlands reforms are underway to reduce the use of residential care and save costs (Maarse and Jeurissen 2016).

Table 1 shows the main features of the process of accessing residential care. Responsibility for the organisation of care in England is delegated to 152 county councils and local authorities (both referred to as ‘councils’ in this article). While councils are often the first point of call for potential users, whether publicly-funded or not, in practice people funding their own care are much more likely to approach providers directly (Miller, Bunnin and Rayner 2013). The Netherlands is divided into 32 care regions for the administration of long-term care, and each region has a care office (*zorgkantoor*), run by a single health insurer on behalf of all insurers in the region. In theory, the care office is the first point of contact, although people also approach providers directly. In Spain, the 19 autonomous regions and cities are responsible for the organisation of health and long-term care and the coordination of social services is managed by local authorities (Gutierrez *et al.* 2010).

< Insert Table 1 about here >

Needs assessment processes are developed at national levels in all three countries. While most assessment procedures are carried out by a specialised national assessment agency (CIZ) in the Netherlands, they are administered by local authorities in England and Spain. In all three countries, local bodies purchase publicly-funded care on behalf of individuals, and options are limited to the providers contracted by these authorities.

Choice policies and the provision of quality information

In England, following the creation of residential care markets (when councils relinquished their responsibility for care provision), choice policies have been implemented with the goal of promoting the independence of both publicly- and privately-funded users, as well as driving provider competition (Department of Health 2005, Department of Health 2010). Choice policies are currently being extended via the use of personal budgets for residential care, where users are allocated direct payments or managed budgets to allow them greater control over provider and service choice (Ettelt *et al.* 2015). A large proportion of people funding their own care has always been able to select their provider of choice, subject to their own financial limitations. Under the Care Act 2014, 'self-funders' will also be able to seek support from their council when choosing a provider (HM Government 2014). Since 2009 and the introduction of Deprivation of Liberty Safeguards guidance under the Mental Capacity Act, councils have also been responsible for ensuring that people who lack capacity are supported to make their own decisions wherever possible about care and care providers, although implementation of this has been uneven (Manthorpe and Samsi, 2016, Samsi, Manthorpe and Rapaport, 2011). Despite provider choice being available for over two decades in England, the sole national source of quality information about providers at the time of the study was inspection reports published online by the regulator, the Care Quality

Commission, which were conducted irregularly on a risk-based trigger system. These reports consist of inspector assessments of compliance or non-compliance against a set of minimum standards.

In the Netherlands, a core feature of the social insurance-based system is that in principle care users have choice of provider, as long as the provider has a contract with their insurer to deliver care services. To support choice, the government in the Netherlands has been at the forefront of information collection and publication in long-term care, launching the website *Choose Better* (Kiesbeter) in 2008. *Choose Better* details indicators related to the quality of care of each provider, its characteristics (e.g. the availability of qualified staff), and the satisfaction of users and their unpaid carers. Reports from the inspector of long-term care, the Healthcare Inspectorate (Inspectie voor de Gezondheidszorg) are also available. In theory, all 32 care offices are also required to publish quality information on their websites, although as of 2012, only one-third had done so (Nederlandse Zorgautoriteit 2012).

In Spain, the concept of choice has been largely absent from the discussion of public services and this is reflected in a lack of activity in terms of information provision. While information is collected by the Government of Catalonia on a range of indicators, it is not made available to the public (Ariño Blasco *et al.* 2014). The sole source of information is a list of local care providers published online (Rodrigues *et al.* 2014).

Data and Methods

This study used two qualitative data collection methods: semi-structured interviews and group workshops. The study was conducted in three English council areas; in the south east and central regions of the Netherlands; and in the autonomous region of Catalonia in Spain.

A key strength of the study is that each country used the same instruments for both forms of data collection, translated into Dutch and Catalan.

Interviews were conducted with 38 professionals involved in the process of selecting a care home. Professionals included social workers, care office staff and care home managers. The roles of the professionals interviewed in each country are shown in Table 2.

< Insert Table 2 about here >

Interviews with residents and relatives involved in recent care home admissions included questions on how they selected a care home and what information and advice they accessed. In Spain, resource constraints meant that only one interview could be held with a relative and so this interview was excluded from the results. Separate group workshops were held in each country with relatives and carers of older people already living in residential care, and with older people with existing knowledge of long-term care services. In England, the latter participants were drawn from users of services, including day centres and extra-care housing; in Spain they were recruited from users of day centres; and in the Netherlands, they were drawn from care home waiting lists. Across the interviews and group workshops we spoke to 132 residents, relatives and carers, and prospective residents as shown in table 3.

< Insert Table 2 about here >

The group workshop design was based on a methodology developed by Barbara Fasolo and colleagues to examine how people understand and use quality information to choose hospitals in England (Fasolo *et al.* 2010). The first exercise in the workshops was an open discussion on the attributes of ‘good’ care homes, in which participants were asked to ‘imagine that you

need to choose a care home for yourself'. The second activity was to rank 15 quality indicators in order of importance. These indicators are listed in the left-hand column of Figure 1. Most indicators were adapted from existing quality indicators in place in Europe and the United States, while two were developed by the research team.

The third exercise asked participants to select a care home from a choice of three. Each home had different scores for each of the 15 quality indicators (already included in the second exercise). The information provided on each of the care homes reflected different strengths and weaknesses and ensured no single care home was a clear leader in terms of quality, as shown in Figure 1.

< Insert Figure 1 about here >

The overall project was approved by the Research Ethics Committee of the London School of Economics. National approval was sought from the Social Care Research Ethics Committee and Association of Directors of Adult Social Care in England and local approval from the Ethics Committee of the Bioethics Observatory of the University of Barcelona. No further approval was required in the Netherlands. Analysis was conducted locally using the Framework Approach to thematic analysis developed by Ritchie and Spencer (2002). This approach to analysis is designed specifically for applied policy research and proved to be highly suitable for comparative qualitative analysis. A framework of five themes was developed for use in all three countries, namely market and care home context, circumstances, involvement, care home choice criteria, and overall quality. Each of these had a number of topics which could then be compared side-by-side. A sixth column, 'Emerging Themes', was used in the framework to allow new and country-specific themes to be recorded.

Results

In this section we report on how quality information was used –or not—in each country to support decision-making, first by examining individual factors, then by differences in the institutional contexts. Finally, we report on the preferences for specific quality indicators, the focus of discussion in the group workshops.

The availability and use of quality information

The type of information about residential care varies widely across our three study areas, as suggested by the country-level information. In Catalonia, information published on the internet is not publicly accessible and professionals had no expectation that participants would be aware of or have used quality information. In England, all three councils produced a brochure featuring a list of care homes available in their area: two were paper-based, with one directory appearing online, featuring functionality to capture and publish feedback from the public about providers. Social workers in England sometimes provided physical copies of inspection reports from the Care Quality Commission, or more frequently recommended that older people and their families and carers refer to the reports on the internet.

Each of the three care offices in the study in the Netherlands had set up a unit to assist prospective users and their families with information on the administrative aspects of accessing care and on residential care providers within the region. Despite the considerable investment in websites in some cases, staff commented that applicants did not use the information available to assess the quality of care homes and this was the cause of some frustration, something confirmed by residents and relatives. Care home staff said that applicants assume that there are no problems with the quality of care and focus on other

aspects such as the atmosphere, privacy and social activities. One family member reported using internet-based information, but this was from a site where residents or their families can post ratings for care homes, rather than the official *Choose Better* website. One intake officer at a care home commented that she had never even checked to see how her own establishment compared with others.

In both England and the Netherlands, however, councils and care offices are not allowed to go as far as recommending individual providers to avoid disrupting the local care market. Despite this, some social workers in England admitted to providing informal guidance or creating shortlists of homes for consideration. In Catalonia, paper lists of care homes are available from hospitals and community-based social workers, but only social workers hold up-to-date information on vacancies. Unlike in the other two countries, social workers sometimes made implicit or explicit recommendations about homes – there was no suggestion that this was not permitted.

In practice, the most important information was perceived as that gathered during visits to care providers. Older people and their families needed to experience the atmosphere of homes, to view the rooms and common areas, to meet the staff and to ask questions about aspects such as food, privacy and social activities. In England, many participants had visited two or more homes, sometimes multiple times, to see whether the experience varied at different times of the day or week or if the visit was unannounced. In the Netherlands half of our participants collected information through multiple means, for instance by visiting several homes, by going to open days, by contacting intake officers, by reading about care homes in the newspapers and by collecting brochures.

In contrast, in Catalonia, residential care is often not easily accessible and the opportunity for visits can be restricted to monthly open days. For the study participants, the level of access and transparency of the home was seen as a proxy for its quality; that is, if a home readily accepted visitors, it was assumed that the home was of a superior quality than those with restricted access.

The focus of this study was specifically the use of information on provider quality, however the experiences of identifying providers were negatively affected in all three countries by a lack of much more basic information, such as whether providers had vacancies. In the Netherlands, staff in care offices kept in contact with providers for an up-to-date picture of availability, but participants were sceptical about the reliability of this information.

In England carers in particular expressed frustration that even basic information in care home directories was omitted, for example, the types of services provided by homes, potential funding sources, prices of care home places and the availability of places. Many carers described the process of contacting homes individually to enquire about vacancies as onerous, especially in a few situations where urgent moves had been required from hospital or the resident had moved between care homes. Users and carers in the Netherlands were generally satisfied with the information they received, but expressed a lack of interest in information available on the internet, as they regarded it as being purely for marketing purposes. Across all three countries some professionals were sceptical about the accuracy and relevance of information on provider quality. In England, for example, some social workers recommended that people review the inspection reports from the regulator, while others were doubtful of their accuracy based on their own experiences of specific care homes. In the Netherlands, providers themselves were highly sceptical about the reliability and

validity of information. In Catalonia, social workers also commented on accuracy of information on waiting lists, with inconsistencies between the information provided to social workers and the situation regarding vacancies in reality.

What helped and hindered in using quality information – individual factors

Across all three countries, we found that by the time the older people in our study entered residential care, they were usually very frail with multiple health conditions, reinforcing previous research. Those people who moved directly from their homes (or more accurately their carers) had the opportunity to conduct more research. The move to residential care for these people was often triggered by a gradual decline in health or the ability of the carer, and meant that the time available to make a decision was often longer than for crisis admissions. At the extreme, one relative in England took a year to identify a home for her husband, and visited 20 homes. Relatives in all three countries spoke about using this time to refer to informal networks for information about homes, visiting homes and collecting brochures. These networks included relatives, care homes, home care providers and doctors. In Catalonia, many residents had time to consider options: the use and prevalence of waiting lists meant that residents had generally been admitted following a long wait while receiving informal care at home.

However, people had limited time to make decisions, and consider quality information if they moved from hospital. This was particularly the case in England and the Netherlands, where almost half and one-third respectively of the participants moved directly from hospital, usually following an emergency admission. In all three countries, for those older people discharged directly from hospital, making a considered decision about a home was overtaken by the need to find a place urgently. Four of the participants in England said that they had

one week or less to make the move from hospital, and in Catalonia also older people coming from hospital were given a maximum of a week to decide. In the view of a social worker in Catalonia, this was sufficient as the lack of information on homes meant that the person was unlikely to make a better decision even if they had more time.

The role of family carers merits specific mention here, and has implications for the design and communication of quality information and decision-making support. Many of the decisions about care provider were made by others either in conjunction with, or on behalf of, the older person. In England, only one-third of the residents had been involved in both decisions – families and care home professionals expressed strong feelings that the decision often had to be taken away from the individual as they were not aware of their reduced ability to live independently or did not have the capacity to make the decisions alone. Despite this, only three of the 13 social services staff interviewed proactively mentioned the role of independent advocates in helping individuals to make decisions, raising questions about the awareness and implementation of the Mental Capacity Act and the Deprivation of Liberty Safeguards legislation. There was only one example in the wider study – in the Netherlands – where relatives described the reverse, where they had attempted to dissuade their parents from moving to a care home. In contrast in Catalonia, perhaps reflecting the lower occurrence of urgent admissions, five out of the 10 residents said that they had made their own decision to move into residential care, and also decided on the specific home. In all three countries participants spoke about the importance of family and friends in the process. The use of formal support networks, such as health professionals and social workers, also figured highly, but varied widely even within each country.

One notable theme that emerged in England and the Netherlands was the extent to which information-seeking processes were enhanced by the previous experiences of the person and their families and carers. There were three groups of ‘insiders’ who were able to make use of previous knowledge and experience. The first group consisted of people who had some first-hand experience of living in a care home themselves through a short stay e.g. for rehabilitation or through respite care. The second group included people who had some experience of life in a care home gained through other means, e.g. working in a care home or as a regular visitor or volunteer. These people had clearer expectations and understood more about the technical aspects of quality in care homes. The third group included people who had expertise in other areas which they transferred to the process of information seeking and selecting a care home. In the Netherlands, two interviewees said they had searched for quality information on the internet; one relative had worked as a physiotherapist and was familiar with health information, and the other worked in an information technology role. One resident in England told us that her daughters-in-law were doctors and this made her confident that they had specialist knowledge of quality in residential care, despite them being in unrelated fields, with one working in paediatrics and the other in ophthalmology. Experience in other regulated sectors was also valid. In England, three participants were teachers who were familiar with school quality reports by the schools inspectorate (Ofsted), and transferred this knowledge when looking for residential care for their relatives.

Q. Did anyone provide any help or guidance in terms of choosing an individual home?

“ No. No, I had to do that for myself. I went online, I looked at what I would call the ‘Ofsted reports’. It’s the, I can’t remember.”

Q. The CQC?

A. And I looked at the areas and the schools and I was able to see how they fared, but then being a teacher I know the value of Ofsted reports anyway and how they can be very unreliable. And it was really having to just go to the place and know how I felt about everything around. It's using your senses really and based on my experience of hospitals and care homes. If I hadn't ever had any experience of hospitals or care homes I think I might have had difficulty in knowing what to look for. And that you are not advised on.

Group workshop participant, England

What helps and hinders in using information – institutional influences

Providing quality information becomes redundant if choices are restricted or do not exist due to a lack of supply of places in the person's preferred home. As one relative in the Netherlands stated 'My mother only wanted THIS home'. Where homes were parts of chains with multiple locations, older people were interested in specific homes, not in other locations in the same chain. In the Netherlands and England, respondents described how the options were often narrower than they first appeared due to the need to identify care homes which could provide specialist care, for example, for older people with dementia or with specific mental health issues. For individuals arriving directly from hospital, the availability of an appropriate place was often the overriding factor, meaning that choice of provider was either not available or extremely restricted in practice. Quality information was therefore ignored, regardless of whether it was easily available, even though two major, life-changing decisions were being made simultaneously and rapidly: the decision to move into residential care, as well as the specific choice of provider.

In Catalonia a lack of supply meant that the waiting times for the homes in our study were up to four years long. Once their needs had been assessed, older people joined a waiting list managed by social services. They nominated up to five homes in order of preference and were then obliged to accept the first place that becomes available in any of the homes, otherwise their name was removed from the list. The individual was able to relocate to the homes higher up their list of preferences (if they choose to) once places become available. Moving was therefore seen as a normal occurrence in Catalonia; it meant the resident can try different homes and get an accurate picture of quality. In many cases, social workers recommend taking ‘second-best’ options in the knowledge that the person can move if a place becomes available in the preferred home:

“No, the information given is not very good, but the decision is okay – the process works well because people receive informal advice from us or know which places have a better reputation. If not, they can always move to another care home.”

Social worker, Catalonia

In contrast, the study found little evidence that residents in England and the Netherlands are prepared to move between care homes until they find one that meets an acceptable level of quality. Both relatives and residents in England and the Netherlands said that residents generally make the best of whichever care home has been chosen. There were only a few examples of residents who had moved, either through choices made by families or carers, or at the request of the care home.

What type of quality information is preferred by older people

With the learning from the interviews that quality information was rarely used, the group workshops provided an opportunity to explore in more detail what type of information older people might prefer. The initial discussion in each group workshop was intended to explore what participants thought were features of a ‘good’ care home. Across all three countries, these features reflected an emotional response to the different ‘soft’ aspects of the home environment. None of the participants referred to the ‘harder’ quality indicators which are, or could be made, available. In Catalonia, participants focused on whether staff were kind and treated the residents well, the quality of the food, cleanliness, and the health status of the other residents. In England, participants mentioned good staff who provide quality care and good food. In the Netherlands, participants described good care homes as having a nice décor and appearance, a good reputation, friendly and competent staff, and having social activities available. Prices and fees were major factors in England and Catalonia, reflecting the amount of care funded directly by individuals. Discussion of what makes a ‘bad’ care home also ensued: some participants in England raised specific issues with care homes e.g. friends in care homes being given the wrong medication, or residents being left unoccupied for hours at a time. In Catalonia, all workshop participants knew someone who had had a bad experience in a care home. Participants widely reported that the main criteria for selecting a home across all three countries was its location, whether this meant proximity to the older person’s former place of residence or their family and friends, or the location of the home in a desirable area.

The second activity in the group workshops involved the ordering of fifteen quality indicators. The concept of quality indicators was new for most participants, and many found the process very challenging. Many of the indicators required explanation and some were particularly problematic. For example, across all countries, participants viewed a star rating

as more suitable for rating hotels and said that they were not convinced of the relevance for care homes:

“They may even have 10 stars, but if it is not personal ...um, give me one with only four stars”.

Group workshop participant, the Netherlands

Other quality indicators which were poorly understood in England and Catalonia or seen to be low priority were building design and the indicators specifically associated with the quality of care (e.g. the prevalence of pressure ulcers, weight loss and the overuse of anti-psychotic drugs).

“There’s one here [quality indicator] here that I don’t really understand. It says the building is designed to support people with sensory loss and cognitive impairment, especially people with dementia. But how can the building be designed? People have just got to be well trained haven’t they?”

Group workshop participant, England

In the groups in England and Catalonia, the indicator regarding the financial stability of the home required extensive explanation. Some participants felt that the quality of the carpets and décor or the relative newness of the home would be an adequate sign of financial stability and were not convinced of a need for more information on the provider’s financial health.

“Well this one about the care home can prove that it can manage its financial resources... Well, the normal person who goes into a care home wouldn’t know anything about that would they?”

Q: “But imagine you could get a report, some sort of a rating on how well they did that, how well they managed their finances, would that influence your choice of care home?”

“...No, because I mean half the time you wouldn’t know whether it was true or not and the other half of the time you wouldn’t understand it anyway.”

Group workshop participant, England

Selecting the top three and bottom three indicators was also difficult. However, with support and explanation from the facilitators, many managed to rank their top three, as shown in table 4. In Catalonia, participants in one of the workshops appeared to take it for granted that they simply would go to a care home close to their own home and found it difficult to rank the indicators. Eventually the individuals in the group followed the lead of one person in choosing ‘Residents’ social care related quality of life’ as the most important indicator, followed by ‘Percent of residents who feel staff treat them with courtesy and respect’. For this reason, their rankings are excluded from the table.

< Insert Table 4 about here >

Across the three countries, the most popular indicators were the ‘subjective’ indicators which took into account the views of the residents and relatives themselves. The only exception was in the Netherlands, where the third most popular indicator was the number of staff compared

to residents. Indicators which focused on clinical care were unpopular across the board, possibly because of a general lack of understanding of the more technical aspects of care.

The third activity, to select a care home from a list of three with different quality scores (as shown in Figure 1), proved too difficult for many of the participants. The problem was made harder by the fact that in designing the quality ratings against each indicator, the team had ensured that no care home was clearly better than the others. Where people had made a choice, they were often unable to articulate how they had approached the decision. The strategies varied between individuals, between groups, and between countries. In Catalonia, some participants attempted to concentrate on the scores against the indicators they had rated most highly in the second exercise in order to make a choice, but three people said that there were too many indicators to take into account. There was a range of strategies applied in England and the Netherlands, the most popular one being to put ticks next to the indicators that were scored 'excellent' in each column, and then simply adding up the number of ticks.

Care Home C was the most popular care home in the group workshops in England and the Netherlands. This was the care home which scored most highly against how residents rated their quality of life and respect, and how relatives felt the home was pleasant. These were the indicators consistently ranked highly in the second activity across all three countries. In contrast, in Catalonia the most popular option was Care Home A. Ironically, this was the care home that scored most strongly on the clinical indicators, despite these clinical indicators being the least popular in the second activity.

One issue which was specific to the Catalonia workshops was that the concept of distinct organisations providing information proved to be difficult for participants to understand. The idea of a regulator acting as a source of information was particularly problematic, probably

because no such body exists in Catalonia. A number of participants in all three countries assumed that they personally would be responsible for investigating issues such as the prevalence of pressure ulcers or other clinical indicators, not appreciating that data would be collected through formal processes.

In summary, even with careful support from the workshop facilitators in all three countries, most of the participants found the concept of quality information confusing and were challenged by the tasks of ordering indicators and choosing a care home in a systematic way. The varying levels of quality information available in each country did not seem to have any influence on this. The only exceptions to these were participants with relevant experience, albeit tangential. An example was an ex-accountant in one of the England workshops. One positive note which emerged was how, over the course of each group workshop, many participants became more enthusiastic about the indicators and strongly expressed the view that their new knowledge might be useful in the future. Many asked to keep the materials from the workshop for future reference in case they ever needed to find care for themselves or a family member or friend.

Discussion and Conclusions

This study set out to explore and compare how quality information is used to choose residential care in three different institutional contexts. It finds that the experiences of older people and their families are remarkably similar especially when considering that each government has taken a visibly different approach to the provision of quality information, and that there are also underlying system differences in how and when people access care. These system and information differences were not reflected in markedly different decisions.

Instead, provider location and the availability of places continued to be the main deciding

factors for choosing residential care providers in all three countries, regardless of whether quality information was publicly available. Even where information exists, the opportunity to use it to make better decisions was sabotaged by a number of factors: the limited time available to make a decision, the small number of places in appropriate or preferred homes, and the lack of awareness and understanding of information on quality. An overarching theme was that if there was no availability in a preferred home, individuals felt that choice was an illusory concept and therefore quality information lacks relevance.

The low awareness of the availability of quality information was also striking. This was true even among professionals, and even in the Netherlands where so much investment has been made in the *Choose Better* website. Work is required to raise awareness among providers, professionals, and users and their families. However, prior to this, more attention needs to be paid to how information can be devised and presented in a way which supports people to make decisions. This study found that quality information is poorly understood and rarely consulted. The difficulties encountered with sorting quality indicators in the group workshops reinforced research that on average people can only process around seven (plus or minus two) pieces of information at once (Miller 1956). Stressful circumstances – such as those around choosing residential care – are known to give rise to ‘bounded rationality’, where stress, fear and other negative emotions limit people’s usual decision-making abilities (Baxter and Glendinning 2013). Large amounts of information are therefore likely to be unhelpful and confusing, and support is required to navigate complex information.

Another issue is the distribution of information solely through the internet. The increase in the focus on information provision is strongly linked to advances in technology which facilitate more complex and timely data collection, as well as the ability to make information

available more easily. But older people have the lowest rates of access and use of the internet (Seybert 2012), and this should be considered when designing information in the future. The notion that this may be a cohort effect, and that this will become easier for future generations, does not take into account the stressful circumstances of the decision, nor the considerable physical and cognitive difficulties the older person has, which create the need for this level of care in the first place.

The participants in our study who were most quickly able to engage in the discussion around quality indicators had some type of insider knowledge, either of care homes, or in the use of quality information, whether it be through short or respite stays, experiences of visiting or working in care homes, or through an understanding of how quality information works in other sectors. These findings suggest that government efforts to create informed, knowledgeable consumers requires more than simply generating and presenting facts and figures in a way which may be appropriate for use by professionals and care home providers rather than by older people, and that more general support should be provided. The nature of this support was the subject of much discussion. There was a degree of frustration where professionals were not able to make recommendations about providers, as in England and the Netherlands. In Catalonia, in contrast, the social worker takes a more traditional and arguably paternalistic approach to guiding the older person through the process. This however, was regarded locally as working better than the processes in England and the Netherlands where our participants bemoaned the lack of information and guidance. There appears to be no doubt that older people seeking care would benefit from increased professional support to navigate this stressful and confusing decision, which could come from a number of formal or informal sources (Baxter and Glendinning 2013).

In terms of preferences for quality indicators, there were two indicators which were popular across all of the groups in all three countries, both focused on quality of life issues: how residents rated their quality of life, and whether relatives felt that the care home was a pleasant place to be. Many of the more technical indicators are not clear to the non-expert, particularly specific indicators associated with clinical care outcomes or other technical issues such as the design of dementia-friendly buildings. The question is whether it is practicable to expect the general public to understand these more complex indicators; again it is more likely to be an area where professionals would need to provide additional assistance.

Notwithstanding these findings, the experiential nature of quality in residential care creates the biggest challenge in selecting the right care provider, regardless of country-specific factors. Participants across all three countries repeatedly told us that visits (often multiple to the same provider) were the only way to gather information about a home to experience the atmosphere and staff attitudes. It could be argued – if somewhat controversially – that the importance of experiencing the home issue is dealt with more effectively in Catalonia, where residents only settle in a home once they have found one they feel meets their preferences. In England, there has traditionally been reticence to move older people between care homes because of a fear that relocation has a negative impact on health and can lead to early death, even though the evidence is mixed and outcomes depend on how the relocation process is managed (Leyland, Scott and Dawson 2014, Holder and Jolley 2012) . In England, interviewees said there should be opportunities for older people to try out care homes, either through short stays or through trial periods. At the same time, the option of moving residents multiple times, particularly those who are very frail or cognitively impaired, needs to be considered carefully to both manage the expectations of the older person, and to minimise disruption and distress to both them, their families and other residents.

Finally, it is important to mention that the negative perception of residential care was present in all three countries and very few residents in our study described the move to residential care as a positive change in their lives that would improve their quality of life. The move to a care home usually appeared to be unavoidable in our study, yet the positioning of residential care as a last resort meant that the move was accompanied by feelings of guilt and anxiety for many relatives. This created additional stress for people already struggling to find information, to visit care homes, and to make decisions about something they had never considered before.

Conclusion

In summary, our study suggests that a considerable gap remains between the policy ideal of the empowered consumer who actively seeks detailed quality information and the real experiences of older people in need of residential care. The supply of quality information may prove to be important in other ways, such as incentivising the quality improvement of providers through ‘naming and shaming’ or, more relevant to this study, to enable professionals to provide help and insight to those seeking care. However, the experiential nature of care, the circumstances surrounding the decision and the individual characteristics of the user are much more significant factors to consider than simply providing more and better information. Tackling these issues should be a priority over further investment in generating quality information – demonstrated by the fact that the amount of quality information in all three countries was an insignificant feature in the overall decision-making process.

Competing interests

The authors declare that they have no competing interests.

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Table 1: Key features of access to care

	England	The Netherlands	Spain
Responsibility for contracting with providers	Local authorities	Care offices	Regional governments
Responsibility for conducting needs assessments	Local authorities	CIZ (Centrum Indicatiestelling Zorg – Centre for Care Assessment)	Professionals and organizations accredited by the Regional Government
Official first point of contact for potential users	Local authorities	Care offices	Social services (Regional Government)
Actual first point of call for potential users	Multiple, often providers (especially for self-funded)	Multiple, often providers	Multiple, often providers

Table 2: Study participants in professional roles

Role	England n=21	NL n=13	Spain n=4	TOTAL N=38
Support workers	13 social services staff (3 local authorities)	4 care officers (4 care offices)	2 social workers (2 care homes)	19
Providers	8 care home managers	8 intake officers (5 care homes) 1 chief executive of a care organisation	2 care home managers (2 care homes)	19

Table 3: Characteristics of resident, relative and carer, and prospective resident participants

	England		The Netherlands		Spain		Total
	Interviews	Group Workshops	Interviews	Group Workshops	Interviews	Group Workshops	
	n=26	n=27	n=15	n=32	n=11	n=22	n=132
Role							
Resident	13	n/a	7	n/a	10	n/a	30
Relative	13	4	8	19	0	5	49
Prospective Resident	n/a	23	n/a	13	n/a	17	53
Gender							
Female	16	17	12	22	9	14	90
Male	8	10	3	10	2	8	41
Did not say	2	0	0	0	0	0	2
Age							
Under 64	6	0	6	15	0	6	33
65-69	2	2	2	4	0	4	14
70-74	3	1	0	3	0	6	13
75-79	4	3	2	6	1	2	18
80-84	1	11	2	4	0	3	21
85-89	4	6	2	0	6	1	19
90-94	4	4	1	0	3	0	12
Did not say/unknown	2	0	0	0	0	0	2
Marital status							
Married/civil partnership	12	7	9	22	1	12	63
Widowed	9	16	6	7	6	2	46
Single, never married	3	1	0	2	1	4	11
Divorced/Separated	0	3	0	1	2	4	10
Did not say/unknown	2	0	0	0	0	0	2
Ethnicity							
White	23	26	15	32	10	22	128
Mixed	0	1	0	0	0	0	1
Asian or Asian British	1	0	0	0	0	0	1
Black or Black British	0	0	0	0	0	0	0
Chinese	0	0	0	0	0	0	0
Other	0	0	0	0	0	0	0
Didn't say	2	0	0	0	0	0	2
Type of funding							
State funded	7	n/a	15	n/a	0	n/a	22
Privately funded	6	n/a	0	n/a	1	n/a	7
Mixed	9	n/a	0	n/a	9	n/a	18
Did not say	4	n/a	0	n/a	0	n/a	4

Table 4: Most and least important indicators as ranked by workshop participants

	England	The Netherlands	Catalonia (Spain)*
Most often mentioned as important	<ul style="list-style-type: none"> % relatives and carers who think the home is a pleasant place to be % residents who feel staff treat them with courtesy and respect Residents' social care related quality of life 	<ul style="list-style-type: none"> Residents' social care related quality of life % residents who feel staff treat them with courtesy and respect Overall number of staff compared to residents 	<ul style="list-style-type: none"> % relatives and carers who think the home is a pleasant place to be % residents who feel staff treat them with courtesy and respect
Least important	<ul style="list-style-type: none"> % residents who have pressure sores % residents who have lost too much weight in the past month The care home can prove that it can manage its financial resources 	<ul style="list-style-type: none"> The care home can prove that it can manage its financial resources % residents who have lost too much weight in the past month Star rating for quality 	<ul style="list-style-type: none"> Star rating for quality The care home can prove that it can manage its financial resources

* Three workshops only

Figure 1: Care Home 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