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Abstract

User choice and personalisation have been at the centre of health and social care policies in many countries. Exercising choice can be especially challenging for people with long term conditions (LTC) or disabilities. Information about the quality, cost and availability of services is central to user choice. This study used systematic review methods to synthesise evidence in three main areas: 1) how people with LTC or disabilities and their family carers find and access information about the quality of services; 2) how is quality information used in decision making; 3) what type of quality information is most useful? Quality information was defined broadly and could include formal quality reports (e.g. inspection reports, report cards etc.), information about the characteristics of a service or provider (e.g. number and qualifications of staff, facilities etc.) and informal reports about quality (e.g. personal experience etc.).

Literature searches were carried out using electronic databases in January 2012. Thirteen papers reporting findings from empirical studies published between 2001 and 2012 were included in the review. The majority of papers (n=9) had a qualitative design. The analysis highlighted the use of multiple sources of information in decision-making about services and in particular the importance of informal sources and extended social networks in accessing information. There is limited awareness and use of 'official' and on-line information sources. Service users or family carers place greater emphasis on general information and structural indicators. Clinical or quality of life outcomes are often difficult to interpret and apply. Trust emerged a key issue in relation to quality information. Experiential and subjective information are highly valued and trusted. Various barriers to the effective use of quality information in making choices about services are identified. Implications for policy and future research are discussed.

Key words: decision-making, long-term care, social care, systematic review

What is known about this topic?

- Quality reporting for health and social care providers was introduced in response to concerns over the quality of services in various countries over the past decades.
- Studies in the general population and user surveys found limited awareness and low use of available quality information in health and long-term care.

What this paper adds?

- There is a mismatch between the provided quality information and the information needs of service users.
- Trust is a key issue in relation to quality information. Experiential and subjective information are highly valued and trusted.
- Most barriers to the effective use of quality information are associated with the decision process – timing and individuals’ lack of knowledge or understanding of the process – or the characteristics of information – accessibility, content and perceived trustworthiness.

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Introduction

User choice and personalisation have been at the centre of government policy in health and social care in the United Kingdom for a number of years (Le Grand 1991). Personal budgets and direct payments have been the main mechanisms to deliver these reforms. In 2012 over half of eligible users of social care in England had a personal budget (Boyle 2013). There were also over 500,000 'self-funders', people aged 65+ who were paying for their own care (Dilnot 2011). Other countries also introduced a variety of consumer choice and quasi-market reforms in health and social care (Leichsenring 2004, Rostgaard 2011, Costa-Font & Zigante 2012).

There is a wealth of literature on choice and decision-making (see Beresford & Sloper 2008 for an overview of main psychological theories). The political and policy implications of user choice have been discussed extensively (Knapp, Hardy & Forder 2001, Clarke 2006, Le Grand 2007, Dowding & John 2009, Stevens *et al.* 2011). Consumer choice is thought to have various benefits. Choice can improve service quality and effectiveness, lead to better individual outcomes and it has intrinsic value in that it enables autonomy and self-determination (Dowding & John 2009, Wilberforce *et al.* 2011). The idea of choice is also popular and highly valued by users themselves (Le Grand 2007, Boyle 2013).

Negative aspects of choice have also been highlighted. Dowding & John (2009) identify four types of cost associated with choice: welfare, information, transition and psychological costs. The effectiveness of choice as a mechanism of allocating goods and services is dependent on the knowledge of those making choices: the awareness of available options and understanding of own needs. Welfare costs arise from choices that do not maximise the welfare of the individual. Service users can make decisions that do not maximise welfare for a variety of reasons such as lack of information, personal preferences etc.

Psychological costs are associated with the variety, complexity and importance of the decision. Decision-making about care is characterised by "severe uncertainty" (Schwartz, Ben-Haim & Dacso 2004). There is a substantial gap between what is known and what needs to be known in order to assess the merits of the different options. Social care is characterised by information asymmetry and its quality and impact on people's life can be hard to measure (Knapp, Hardy & Forder 2001). Exercising choice can be particularly challenging for people with long term conditions or disabilities who have sudden-onset, multiple or fluctuating needs (Rabiee & Glendinning 2010).

If a decision is not successful, markets can offer the possibility of switching from one option to another. However, transition can be costly and it might not always be possible, for example in the case of health interventions. In long-term care transition costs can be prohibitively high. Relocation has been associated with a higher risk of adverse outcomes for nursing home residents (Holder & Jolley 2012).

People need understandable, high quality and relevant information to make informed choices (Dowding & John 2009), however finding and accessing information can be time-consuming and costly, especially for those with fewer resources or for complex decisions. These are the information costs of choice.

Information on the quality, cost and availability of services is central to user choice and decision-making about personalised supports. The opportunity to make choices is meaningless unless there is adequate and accessible information (Baxter, Glendinning & Clarke 2008).

Consumers often express interest in quality information; however studies of health care consumers have found limited awareness and use of quality reports (Boscarino & Adams 2004, Faber *et al.* 2009). There is little evidence of the use of quality information on long-term care either: a US study found that few people used the Internet to search for nursing facilities and, even those who used on-line sources, they used them mainly for generating a list of potential homes (Shugarman & Brown 2007). A survey (Commission for Social Care Inspection 2009) of users and commissioners of adult social care services in England found low awareness and limited understanding of quality ratings. When asked about selecting a home, the majority stated that they relied on informal sources of information. A more recent study (Darton 2011) reported higher level of awareness and use of Care Quality Commission (CQC) inspection reports among the relatives of care home residents, with the majority finding them useful. Many people rely on local information provided by councils when selecting a care home and many find it difficult to compare their quality (GHK 2011).

Issues around the use of quality information to inform choice in health and social care among people with long-term conditions / disabilities are complex and potentially controversial (Anderson *et al.* 2013). This paper aims to answer three broad questions by synthesising available quantitative and qualitative evidence using systematic review methods:

1. How people with long-term conditions and their family carers find and access information on the quality of care or service providers to help decision making?
Quality information is defined broadly and it can include formal quality reports (e.g.

inspection reports, report cards etc.), information about the characteristics of a service or provider (e.g. number and qualifications of staff, facilities etc.) and informal reports about quality (e.g. personal experience etc.).

2. What is the role of quality information in choice making? How information is used to help making choices about service providers? What are the main issues associated with the use of quality information in decision-making?
3. What type of information is found most useful in choice making? Are there any characteristics associated with need or preferences for quality information?

Methods

An initial scoping exercise explored the existence of literature on the use of quality information in decisions around health and social care services for people with disabilities or long-term conditions, and identified key words. Search terms consisted of combinations of the following key words, using no more than two search terms at a time: social care, choice, quality, decision, use of information, information need, consumer decision, user choice, consumer choice, choice behaviour / behavior, outcome information. The detailed inclusion and exclusion criteria are summarised in Table 1.

Table 1 Systematic review: inclusion and exclusion criteria

Area	Inclusion	Exclusion
Date of publication	2001 - 2012	Before 2001
Language	English	Non-English
Design	Primary research, no restriction on study design	Non-primary research, including reviews
Publication type	Peer reviewed articles	Non peer reviewed articles, grey literature, books, book chapters
Population, participants	Adults with a long term condition/s or disability, family carers of people with disabilities or long term conditions, care managers or commissioners (or similar in non-UK studies)	Children and adolescents under 18.
Focus of the paper	Choice of a social care or health care provider. Choice defined as the assessment of different options and a decision to select one of them.	Decision whether to use social or health services or undergo a medical intervention Decision about the type of service / intervention (e.g. decision whether to use residential or domiciliary care).

There were no geographical restrictions so studies from any countries could be included in the review. Publication date ranged from 2001 to January 2012; 2001 was used as a cut-off point for inclusion because public reporting of social care quality began in the late 1990s. Due to the complexity of the intervention and the exploratory nature of the review that sought to address

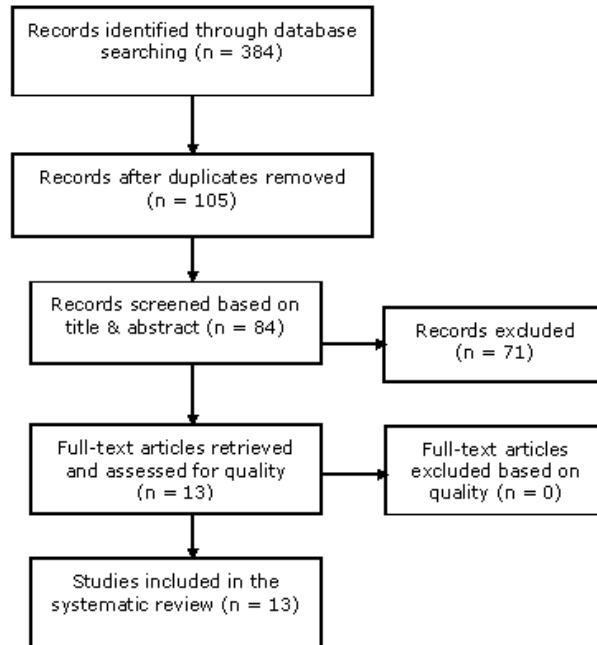
questions beyond effectiveness, study design was not a feature of the search (Oliver *et al.* 2005). Any empirical studies – qualitative and quantitative – were eligible for inclusion in the review.

The search was carried out in January 2012 and consisted of a combination of electronic searches and follow-up of sources in related publications. The electronic databases searched were:

- EbscoHost (Abstracts in Social Gerontology, Academic Search Complete, PsycARTICLES, PsycINFO);
- the Cochrane Library
- PubMed
- Scopus
- Social Care Online
- Web of Science (Social Sciences Citation Index).

Searches returned a total of 384 potentially relevant results. After the removal of duplicates, this produced a list of 105 publications. Full references were then checked and non-peer reviewed publications excluded. The remaining 84 papers were reviewed based on their title and abstract by one member of the research team. Where there were queries or concerns as to inclusion, full text was obtained and papers were reviewed by a second member of the team and consensus was reached through discussion. Seventy-one papers were excluded at this stage (See *Fig. 1*). The most common reasons for exclusion were: study design (n = 22); participants were not people with disabilities or long-term conditions or their family members (n = 9), and focus of the paper (n = 40). Thirteen papers were marked for inclusion in the review.

Figure 1 PRISMA flowchart



The quality of each full paper was assessed by one of the reviewers and checked by another researcher using quality appraisal checklists (National Institute for Health and Clinical Excellence 2009). The quality of randomised controlled trials and qualitative studies were assessed with the relevant Critical Appraisal Skills Programme (CASP) tools. No CASP tool was available for non-comparative quantitative research (e.g. survey etc.); therefore a simple quality appraisal checklist was devised and used to assess the quality of the two survey studies included in the review (see *Fig. 2*). To be included in the review studies had to meet at least five out of 10 quality criteria and have no “fatal flaws” (Dixon-Woods *et al.* 2006).

Figure 2 Questions to guide the critical appraisal of survey studies

1. Did the study address a clearly focused issue?
2. Is the study design appropriate to answer the research questions?
3. Is the selection of the sample appropriate? Did they use a probabilistic sampling method?
4. Is the sample size adequate? Did they present any power calculations?
5. Was data collected in a way that minimised bias? Did they report the validity and reliability of measures?
6. Was the data analysed in a way that minimised bias, and was scientifically rigorous and systematic? Were the appropriate methods used?
7. Have the authors identified all important variables?
8. Did the analysis rule out alternative explanations?
9. Were the findings supported by the results?
10. Are the findings generalizable?

A data extraction table was devised to assist the systematic analysis of papers. A combination of descriptive mapping and thematic summary was used to synthesise the findings (Thomas *et al.* 2012). The information extracted from studies included study design, number and characteristics of participants, methods of data collection and analysis, main findings of the paper relevant for the review questions, and policy lessons. The review questions were used as a thematic framework to extract the findings of the studies. The extracted findings were coded and organised into themes that were used to answer the review questions (Snilstveit, Oliver & Vojtkova 2012). The analysis was carried out by the first author with discussions and feedback on findings from the second author.

Results

1 The literature on the use of quality information

The primary aim of the mapping was to provide an overview of the characteristics of research on the use of quality information on health or social care services for people with disabilities or long-term conditions, and highlight what has been and has not been studied.

A total of 13 studies were included in the review; two of these studies (Moser *et al.* 2010a, 2010b) reported on the same research, however on different aspects of decision making.

Studies came from three countries – United Kingdom (n = 3), United States (n = 6) and the Netherlands (n = 4). Approximately half of the studies focused on decision making in health care and the other half on social care. There was one study that considered both (see Table 2).

Table 2 Aims and focus of studies included in the review

Study	Country	Context of choice	Use of quality information discussed
Baxter & Glendinning (2011)	UK	Health and social care	Explored how people with disabilities and older people find and use information to help decision-making about health and social care.
Castle (2003)	USA	Long-term care (nursing facility)	Examined 1) who searches for a nursing facility (NF); 2) when and why the choice is made; 3) the most important factors in the selection of a NF; 4) satisfaction with the choice.
Castle (2009)	USA	Long-term care (nursing facility)	Looked at whether consumers used the Nursing Home Compare (NHC) website. Also explored their understanding and use of quality information provided there.
Davies & Nolan (2003)	UK	Social care	Explored the experiences of family caregivers when helping a relative to move into a care home.
Magasi <i>et al.</i> (2009).	USA	Long-term care (nursing facility)	Examined rehabilitation patients' and their care partners' understanding of rehabilitation quality indicators.
Moser <i>et al.</i> (2010a)	Netherlands	Health care (elective surgery)	Explored how health care consumers interpreted and used comparative consumer information on hospitals for elective surgery.
Moser <i>et al.</i> (2010b)	Netherlands	Health care (elective surgery)	Examined actual experiences of decision-making to select a hospital for elective orthopaedic surgery.
Nieboer (2011)	Netherlands	Social care	Investigated the effects of decision-support information and personal decision-making supports on choice of social care.
O'Day <i>et al.</i> (2002)	USA	Health insurance plan	Examined how people with mobility impairment selected health care plans.
Palsbo & Kroll (2007)	USA	Health insurance plan	Explored the perceptions of quality health care, access to health information and report card preferences of people with disabilities.
Ryan <i>et al.</i> (2012)	UK	Social care	Explored rural family carers' experiences of the care home placement of an older relative.
Stein <i>et al.</i> (2009)	USA	Health care (mental health)	Investigated mental health care users' preferences for comparative performance data and other information about providers.
Van Nie, <i>et al.</i> (2010)	Netherlands	Social care	Tested an internet report card and whether display and content influenced participants' assessment of quality of care.

The majority of studies had a qualitative design (n = 9) and explored the experiences of decision making using semi-structured interviews or focus groups. There were only two experimental studies that tested understanding or use of quality information, and two studies had a non-comparative quantitative design. Studies included a broad range of participants: elderly people and their family carers / relatives, people with long-term conditions (e.g. multiple sclerosis, osteoarthritis etc.), people with mental health problems and parents / carers of young people with disabilities. Seven out of 13 studies met nine or 10 quality criteria, five studies met seven or eight and only one study met five. The main characteristics of included studies are summarised in Table 3.

2 How people find and access information about the quality of services?

Two key issues emerged in relation to finding and accessing quality information: an awareness and understanding of the choice process as a pre-condition for effective information seeking, and the use of multiple information sources, particularly informal channels.

2.1 Awareness

Having some knowledge about services and an understanding of the process and implications of choice are a key factor in finding information. Often people with disabilities were not aware that they were eligible for services and they could choose from a range of options. Sometimes they discovered this by chance, sometimes they just accepted the option offered to them without considering alternative options (Baxter & Glendinning 2011). Some people were happy to delegate decision-making entirely to professionals (Moser *et al.* 2010b).

Searching for a suitable service was described as "working in the dark" by relatives of elderly people in the UK. The majority were only provided with a list of homes but no guidance on what to look out for. Some people described having to rely on phone directories. There was very little awareness of existing quality information, such as inspection reports, and very limited knowledge about quality of care and indicators of a quality service (Davies & Nolan 2003).

Another study found that the lack of understanding of the rehabilitation process compromised the information seeking behaviour of people undergoing joint replacement surgery as they simply did not know what to look for or expect in the process (Magasi *et al.* 2009).

Table 3 Characteristics of reviewed papers

Study	Design	Data collection methods	Participants	Key findings	Quality appraisal
Baxter & Glendinning (2011)	Qualitative	Semi-structured interview	50 adults with disabilities and older people with fluctuating or sudden onset support needs. Included a variety of LTCs such as SM, arthritis etc.	Use of information is a complex process and it is a precondition of choice-making. Participants used multiple information sources. Three key issues: trust, ease of access and timeliness.	7/10
Castle (2003)	Non-comparative quantitative	Postal survey, face-to-face questionnaire	306 family members and 306 residents who had lived in the facility for 90 days or less	Both residents and family members used multiple sources of information. There were very few proactive facility choices. Location, quality and price were most important factors. Length of time spent searching for and choosing a facility was positively associated with satisfaction.	10/10
Castle (2009)	Non-comparative quantitative	Postal survey	4,754 family members of older people recently admitted to a nursing home	Only 12% recalled using NHC website. Mean comprehension score was 5 (on a scale of 0-8). Younger family members and those with a higher income and education level were more likely to have a higher comprehension score.	9/10
Davies & Nolan (2003)	Qualitative	Semi-structured interview	48 people who identified themselves as a close relative of an elderly nursing home resident and were involved in the admission process.	Identified five dimensions of relatives' experiences of decision-making: 1) under pressure or not 2) working together or alone 3) being in control or losing control 4) working in the dark or being in the know 5) feeling supported or unsupported	8/10
Magasi <i>et al.</i> (2009).	Qualitative	Semi-structured interview	17 patients and 12 care partners. Patients aged 50 or over and with a diagnosis of stroke, hip fracture or joint replacement.	Participants had difficulty understanding and using quality information in decision-making. They tended to rely on informal and non-quality information when choosing a facility.	7/10

Moser <i>et al.</i> (2010a)	Qualitative	Semi-structured interview, focus group	18 people who had undergone a total hip or knee replacement within the previous 5 years	Thematic analysis identified four themes: 1) how participants used quality information in decision-making; 2) the perceived benefits of using quality information; 3) unmet information needs; 4) trustworthiness of information.	9/10
Moser <i>et al.</i> (2010b)	Qualitative	Semi-structured interview, focus group	18 people who had undergone a total hip or knee replacement within the previous 5 years	The analysis identified three categories that influenced the selection of hospitals: information sources, criteria in decision making and decision-making styles. Various contextual factors identified.	9/10
Nieboer (2011)	RCT	Questionnaire	147 parents of children and young people with disability facing a choice of service provider for day supports, residential supports or both.	Very low levels of information use among parents. Less than 15% used the on-line information provided and just over 70% used the counselling session with a professional.	5/10
O'Day <i>et al.</i> (2002)	Qualitative	Focus group	57 adults with significant mobility impairment and at least one of the following conditions: multiple sclerosis, cerebral palsy, rheumatoid arthritis or spinal cord injury.	Participants reported receiving general information that they found not very useful. They expressed a need for more disability-specific information.	9/10
Palsbo & Kroll (2007)	Qualitative	Focus group	49 people aged 18-64 entitled to Medicaid care. Included a variety of LTCs such as arthritis, cerebral palsy, TBI, epilepsy, mental health etc.	Participants defined quality in terms of choice and how well providers accommodated disability-specific needs. They expected report cards to provide more disability-specific information.	7/10
Ryan, McKenna & Slevin (2012)	Qualitative	Semi-structured interview	29 family members of elderly people	Most placements resulted from transfers from acute hospital. Family members relied on informal information and local knowledge in the decision-making process. Family members who did not live locally were faced with difficulties without local knowledge in the absence of formal information.	9/10

Stein <i>et al.</i> (2009)	Qualitative	Focus group	41 mental health consumers and family members	Participants expressed the need to have easily accessible information. They were interested in a broader range of information that is normally available. Information needs to be up-to-date.	6/10
Van Nie, Hollands & Hamers (2010)	Non-randomised controlled trial	Questionnaire	278 adults from three groups 1) members of a national organisation of service users and their relatives (n = 181); 2) "future care consumers" (students) (n = 38); 3) representatives of nursing homes (n=59).	There were significant differences between the three groups in terms of finding the report card complete and easy to understand.	7/10

2.2 *Multiple sources of quality information*

Those who used information reported a wide variety of sources and often used more than one source (Castle 2003, Magasi *et al.* 2009, Moser *et al.* 2010b, Baxter & Glendinning 2011).

Elderly residents and their family members used advertising, media guides, professionals' advice, information provided by agencies when selecting a nursing home (Castle 2003).

Patients with osteoarthritis used multiple information sources to select a hospital for elective hip or knee replacement surgery: medical sources (mainly their GP), their social network and the mass media (e.g. television reports etc.) (Moser *et al.* 2010b). Similarly rehabilitation patients selected the facility based on word of mouth, doctor's referrals, familiarity with the facility and perceived reputation and the location (i.e. proximity to maintain contact with family or existing social networks) (Magasi *et al.* 2009).

Information obtained through informal networks was particularly important for older people (Davies & Nolan 2003, Baxter & Glendinning 2011). Friends' advice was the most important source of information for elderly nursing home residents, while family members relied more on advertising in the US (Castle 2003). Family carers in rural areas of the UK had a residual knowledge about nursing homes in the local area and they "took comfort in the knowledge that the home was recommended by friends and acquaintances" (p. 9, Ryan *et al.* 2012).

The internet was a common source of information for younger people (Baxter & Glendinning 2011). Castle (2009) in his survey of family members of older people recently admitted to a nursing home found that nearly a third (31%) used the internet at some point during the decision process to search for potential facilities and 18% had someone else provide them with information from the internet. However, in a randomised controlled trial with parents of children and young adults with disabilities Niebor *et al.* (2011) found very limited use of on-line decision aids: less than 15% of parents used the on-line information provided.

On-line information had the potential to offer accessibility by removing transport, some other barriers and reduce costs. However, the amount of information available on-line can be overwhelming and hinder decision-making (Baxter & Glendinning 2011).

Information provided by professionals was especially valuable for those whose condition deteriorated suddenly or had a sudden onset problem as they did not have the opportunity to search for information themselves. However, information from medical professionals and printed information were often not provided in a timely manner, only following requests (Baxter & Glendinning 2011).

3 How is quality information used in decision making?

Studies in the review suggested that most choices were based on general information (such as location) or subjective impressions (e.g. perceived reputation). Proximity of the facility – to maintain contact with family or friends – was a main factor but familiarity with the facility and reputation, “word of mouth” and professional referrals or recommendations were also very important (Davies & Nolan 2003, Castle 2003, Magasi 2009, Moser *et al.* 2010b, Ryan *et al.* 2012).

While quality was important, people tended to use their own definition of quality in the absence of formal information or when this proved too difficult to interpret. “Everyday” indicators of quality included cleanliness and the absence of odours, friendliness of staff, good décor and comfortable furnishing, other residents (level of need and how “well looked after” they seemed) and the general “feel” of the home (Castle 2003, Davies & Nolan 2003).

Various aspects of the decision making process were found to influence the use of quality information. The timing of the choice was a key issue alongside the decision making strategies followed by the individual. A few studies considered the benefits of having access to quality information in the choice making process.

3.1 Timing

Whether the choice had to be made under time pressures seemed to be a key factor in the use of quality information. For example, the sudden onset of a condition (e.g. a fracture or a stroke) often meant that decisions had to be made under pressure (Magasi *et al.* 2009). Most placements of older people in care homes or nursing facilities resulted from transfers from acute hospitals; fewer people were placed from their own home or transferred from another care home (Castle, 2003; Ryan *et al.* 2012). There were substantial differences between the process of moving from home or being transferred from a hospital. Castle (2003) found that family members began the choice process 133 days in advance and spent a total of 21 hours making the choice for elderly people moving into a nursing facility from their own home. In contrast, this only took 4.2 days and 11 hours in the case of transfers from hospital. Sometimes there were similar time pressures for those whose condition deteriorated slowly because they delayed thinking about services and choices in the early stages of their illness or before the need for service (Baxter & Glendinning 2011).

3.2 Individual differences

The use of quality information was associated with a variety of personal factors such as education and age (Castle, 2009, Van Nie *et al.* 2010). Individuals processed and used quality information in the light of their personal context and adapted different strategies (heuristics) to process the information. Moser *et al.* (2010a) reported different heuristics that people with osteoarthritis used when selecting a hospital for elective surgery: some identified key indicators that were important to them for various reasons while others considered all indicators equally important. Some used exclusion criteria and would not even consider certain service providers (e.g. that they did not know from personal experience, or had low scores on certain indicators). Some disregarded the quality indicators for which multiple hospitals had equal scores or quality indicators that they considered "subjective". There were also some "camouflaged" decisions when individuals made a choice on the basis of their pre-existing personal preferences but justified this with quality information. Sometimes assumptions and decisions were made based on partial understanding of information (Magasi *et al.* 2009).

In a study with rehabilitation patients and their care partners, Magasi *et al.* (2009) identified five barriers to the use of quality information: 1) expectations of full recovery, some patients had unrealistic expectations of the rehabilitation process; 2) the complex nature of service quality, trade-offs between different aspects of quality and the limited utility of individual indicators; 3) the need for a case-mix adjustment, to compare like with like); 4) some quality indicators were seen as 'beyond control' by the facility; 5) the lack of understanding of the causal links between individual quality indicators and the link between quality indicators and quality of care.

3.3 Benefits of using quality information

Access to information had a number of benefits: people considered themselves to be well-informed and were generally more satisfied (Davies & Nolan 2003, Palsbo & Kroll 2007, Niebor *et al.* 2011), felt empowered and had greater awareness of personal needs (Moser *et al.* 2010a). However, in a survey of elderly people who had recently moved into a nursing home and their family carers, over 70% indicated in retrospect that having done something differently would have been very useful and 91% of residents and 87% of family members said they would do the search and selection process differently if they had to do it again (e.g. be better prepared, gather more information etc.) (Castle 2003).

A Dutch study found that family carers who received decision support to select a day or residential service for their children with disabilities were less likely to switch care providers than those who received less information or no support at all. However, the presence or absence of decision support and quality information had no effect on satisfaction with care; this was generally high and over 90 per cent of family carers – regardless the use of decision support – believed that they made the optimal choice (Niebor *et al.* 2011). A study of nursing home residents in the US found a significant association between satisfaction and the timing of the decision, whether the resident/family carer visited the selected facility, and the length of time spent choosing a facility (Castle 2003).

4 What type of quality information is found most helpful?

Various issues were highlighted in relation to the type of quality information that fall into three broad categories: format and presentation, content, and source.

4.1 Format and presentation

Written sources of information, such as leaflets, were generally considered useful by service users as well as family members. Verbal information was also welcome, particularly from certain professionals and experiential information from other service users (Baxter & Glendinning 2011).

In terms of the presentation of information, people preferred easy-to-use formats with visual markers, written percentages and graphs, while star ratings and composite measures were difficult to interpret (Palsbo & Kroll 2007). Using warning signs (e.g. action necessary etc.) was found to be a good way of reporting inspection results (Van Nie *et al.* 2010).

4.2 Content

Various studies highlighted unmet information needs in the decision-making process (O'Day *et al.* 2002, Palsbo & Kroll 2007, Stein *et al.* 2009, Moser *et al.* 2010a). Generally the lack of specificity of quality information – vague indicators, general results and little difference between scores of different providers – was seen as a barrier. Aggregate quality scores were considered less useful as they might conceal difference in the quality of individual units (Palsbo & Kroll 2007, Moser *et al.* 2010a).

Service users and family members were interested in a broader range of information that was normally available. This included more disability-specific information (e.g. building accessibility, availability of assistance) (O'Day *et al.* 2002, Palsbo & Kroll 2007), and information such as the level of expertise within a health or social care service, range of services provided, opportunity to be involved in choices about care, waiting times/waiting lists, and communication with members of the care team (Stein *et al.* 2009). Some of these were often easier to understand than clinical outcomes.

Consumer satisfaction was found to be the most important quality information, followed by inspection reports and formal quality indicators in a study testing internet report cards for care homes by Van Nie *et al.* (2010). The presence or absence of quality indicators and inspection results on the report card did not influence the perception of quality. When included, however, positive quality indicators and inspection results had a positive impact on consumer ratings. It was also suggested that further information on facilities (e.g. location, size etc.) was useful for decision making (Van Nie *et al.* 2010).

However, complexity and use of technical terms limited the usefulness of quality information (Magasi *et al.* 2009, Van Nie *et al.* 2010). For example, terms such as pressure ulcers or cognition proved difficult to understand and interpret but when they were replaced with colloquial terms, such as bed sores, it increased understanding (Magasi *et al.* 2009).

4.3 Source

Not all sources of information were seen as equally important and useful; the perceived trustworthiness of information was a key issue. Generally, medical professionals were more trusted than social care and housing professionals who were perceived less knowledgeable and biased. People also trusted information from their social network and official websites (Baxter & Glendinning 2011). Carers of elderly people living in rural areas assumed that if there were problems with the home or the quality of care, they would soon hear about it. Familiarity with staff and other residents also gave re-assurance about the quality of care (Ryan *et al.* 2012). Information about subjective experiences (e.g. Consumer Assessment of Healthcare Providers and Systems; CAHPS) was generally regarded more trustworthy and impartial than quality information supplied by service providers or publicly reported quality information that were considered at risk of bias by provider motives (Magasi *et al.* 2009, Moser *et al.* 2010a). Time lag between data collection and the publication of data negatively affected the perceived trustworthiness of the information (Moser *et al.* 2010a).

Discussion

The quality reporting agenda in health and social care has so far been politically driven and responded to concerns about the quality of services (Mukamel & Spector 2003, Beadle-Brown *et al.* 2008). It was thought that the publication of quality information would drive up standards by creating a market for high quality provision and highlighting sub-standard care (Stevenson 2006). In reality it has had very modest impact on the quality of provision or occupancy of care homes so far (Stevenson 2006).

Recent emphasis on choice and personalisation in health and social care policies in the United Kingdom has increased the importance of quality reporting. Limitations of choice in social welfare and health care are also increasingly well understood (Davies *et al.* 2002, Botti & Iyengar 2006, Wilberforce *et al.* 2011). Making effective choices about services requires information about quality, cost and availability (Stevens *et al.* 2011).

The current review set out to synthesise available evidence around the use of quality information in decision making about health or social care services for people with disabilities or long-term conditions. The main findings are summarised here:

Multiple sources of information are used in decision-making about services; informal sources and extended social networks are central in accessing information. Information from professionals is highly valued although it is not always provided in a timely manner. There is a limited awareness and use of 'official' information sources, such as internet report cards and inspection reports, even when these are provided with the explicit aim to aid decision making. Only a minority of those searching for services use on-line resources. This finding is confirmed by research with the general population not included in this review (Boscarino & Adams 2004, Shugarman & Brown 2007, Commission for Social Care Inspection 2009, Abraham *et al.* 2011).

Service users or family carers place greater emphasis on general information (e.g. size and location of a facility etc.) and structural information (e.g. expertise of staff etc.). Clinical or quality of life outcomes can be difficult to interpret and apply. Trust is a key issue in relation to quality information. Certain sources are seen as less trustworthy than others. For example, certain professionals are perceived as biased towards their employers' interest and indicators reported by providers as easier to manipulate. The perceived quality of information is also important. Experiential and subjective information (e.g. user ratings etc.) are highly valued and trusted.

The lack of understanding of the process can hinder information seeking or the effective use of available information. In the absence of personal experiences or strong preferences, quality information might be more difficult to interpret or use. Decisions are often made under time constraints. For example, families are put under pressure by hospitals to move relatives out of to free up beds (Bernard 2011). The timing of the decision process can thus create challenges, although, and as it is pointed out elsewhere, it also has the potential to increase the usefulness of readily available quality information to facilitate the decision process (Stevenson 2006).

Decisions about long-term care can be emotionally difficult and stressful: they tend to have multiple dimensions and involve trade-offs. Iyengar and Lepper (2006) suggest that psychologically excessive" choice situations can lead to "choice overload" or "choice fatigue" that has been associated with "myopic decision-making" among people with disabilities (Baxter 2012).

The review has had a broad scope and included both health and social care literature. On the one hand this was justified by the focus on disabilities and long-term conditions. On the other hand, the boundaries of health and social care are less clear-cut around long-term (nursing) care. There are important similarities and differences in terms of decision making that have been noted in the literature (Stevenson 2006). Both care home placement and hospitalisation often happen under stress and narrow time constraints, such as a discharge from acute hospital treatment, and choice might be restricted by a variety of factors, such as funding and availability of services in the local area. There are significant cost and personal barriers to transferring between facilities. Although consumers of social care, in general, are more likely to have cognitive limitations and / or low skills, other actors (family carers or advocates, hospital discharge planners, social workers etc.) are often involved in the process. Consumers of health care are more likely to have previous experience (such as earlier hospitalisation etc.) so they might be more sensitised to the concept of quality and motivated to seek consumer information.

1 Limitations of the review

The focus on peer-reviewed journal articles published in English meant that any relevant research reported in the grey literature or in other languages were missed. At the same time, the inclusion of studies from different countries might have affected the validity of the synthesis. Differences in the organisation of health and social care, including access to services,

could have influenced the findings reported by the studies; however these variations were not accounted for in the analysis.

2 Implications for policy and future research

Research on the use of quality information to inform decision making about health or social care services is at its relatively early stages. The mapping and the thematic synthesis of the papers highlighted gaps and limitations in the evidence base. These, together with the experiences of research in the general population, draw attention to some of the issues that can constitute the future research agenda on the use of quality information by people with long-term conditions or disabilities if choice is to become a reality rather than a rhetoric in health and social care. First, effective approaches to the provision of quality information need to be developed that maximise its use. Second, a better understanding of the experiences and needs of different vulnerable consumer groups (e.g. people with cognitive impairments, family carers, people with long-term conditions, ethnic minorities etc.) is needed to underpin effective policies.

The main focus of existing research seems to be on the selection of nursing homes or rehabilitation facilities for elderly people or the selection of hospitals for elective surgery. Very few papers – and no UK studies – were identified in other areas, such as decision making around services for people with intellectual and developmental disabilities, or extra care housing for older people (Bäumker *et al.* 2011). No research explored differences between the decision-making characteristics of self-funded and publicly funded service users although previous research has found significant differences in admission to long-term care (Netten & Darton 2003). More research is necessary to explore the use of quality information to inform decision making in different contexts and groups of social and health care users.

The majority of reviewed papers were qualitative and explored the experiences of using quality information. Experimental research looking at how the comprehension and use of quality information can be improved in groups with long-term conditions was limited not only in number but also methodologically. More research is necessary to better understand the quality information needs of people with different long-term conditions, including those with lower skills or cognitive limitations, and to investigate whether current approaches to collecting and reporting quality information and supporting individuals to make decisions about services are adequate to maximise user choice.

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