Social Science & Medicine 128 (2015) 301–308

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

It takes a giraffe to see the big picture – Citizens' view on decision makers in health care rationing

Mari Broqvist*, Peter Garpenby

Department of Medical and Health Sciences, The National Centre for Priority Setting in Health Care, Linköping University, Linköping, Sweden

ARTICLE INFO

Article history:
Available online 27 January 2015

Keywords:
Sweden
Health care
Rationing
Programme level
Decision maker
Citizens' view
Interview
Phenomenography

ABSTRACT

Previous studies show that citizens usually prefer physicians as decision makers for rationing in health care, while politicians are downgraded. The findings are far from clear-cut due to methodological differences, and as the results are context sensitive they cannot easily be transferred between countries. Drawing on methodological experiences from previous research, this paper aims to identify and describe different ways Swedish citizens understand and experience decision makers for rationing in health care, exclusively on the programme level. We intend to address several challenges that arise when studying citizens' views on rationing by (a) using a method that allows for reflection, (b) using the respondents' nomination of decision makers, and (c) clearly identifying the rationing level. We used phenomenography, a qualitative method for studying variations and changes in perceiving phenomena. Open-ended interviews were conducted with 14 Swedish citizens selected by standard criteria (e.g. age) and by their attitude towards rationing.

The main finding was that respondents viewed politicians as more legitimate decision makers in contrast to the results in most other studies. Interestingly, physicians, politicians, and citizens were all associated with some kind of risk related to self-interest in relation to rationing. A collaborative solution for decision making was preferred where the views of different actors were considered important. The fact that politicians were seen as appropriate decision makers could be explained by several factors: the respondents' new insights about necessary trade-offs at the programme level, awareness of the importance of an overview of different health care needs, awareness about self-interest among different categories of decision-makers, including physicians, and the national context of long-term political accountability for health care in Sweden. This study points to the importance of being aware of contextual and methodological issues in relation to research on how citizens experience arrangements for rationing in health care.

1. Introduction

To impose restrictions on health services is agonizing for everyone involved – decision makers as well as those affected by the decisions. When available resources fail to meet public expectations, efforts to regulate the consumption of health services turn into political drama, which challenges health care as a right. Setting limits in health care tends to evoke strong feelings of injustice among citizens. Since justice plays a major role in all social relations, it is commonly alleged to be essential that people perceive the process (Daniels and Sabin, 1997) or the outcome (Beauchamp and Childress, 1994) related to limit setting as fair. Yet another crucial component – apart from process and outcome – in the concept of democratic legitimacy is public confidence in those who decide; a single decision maker or those included in a decision-making arrangement (Peter, 2009). Having said this, it is not surprising that scholars' interest in citizens' perceptions of rationing in health care has increased, not least concerning the issue of who the decision maker should be. This paper reports selected findings from a study on Swedish citizens' views about justice in resource allocation and issues related to rationing. Perceptions on what brings about acceptance for standing aside in public health care have been reported elsewhere (Broqvist and Garpenby, 2014). In this paper we focus on the complicated issue of who should decide on the rationing of health services.

---

* Corresponding author. The National Centre for Priority Setting in Health Care, Linköping University, SE- 581 83 Linköping, Sweden.
E-mail address: mari.broqvist@liu.se (M. Broqvist).

http://dx.doi.org/10.1016/j.socscimed.2015.01.043
0277-9536/

The dominant picture in previous research on this topic seems to be that citizens prefer physicians as decision makers for rationing in health care (Richardson et al., 1992; Myllykangas et al., 1996; Bowling, 1996; Kneeshaw, 1997; Busse, 1999; Litva et al., 2002; Wiseman et al., 2003). Some studies indicate that citizens themselves believe they could have a role in rationing decisions (Bowling et al., 1993; McIver, 1998), while politicians are seldom mentioned as important actors (Bowling et al., 1993; Wiseman et al., 2003). Few studies have reported Swedish citizens' views on appropriate decision makers, but they show results similar to those mentioned above (Mossialos and King, 1999; Rosén, 2006; Werntoft et al., 2007).

Although the results are seemingly consistent, the findings are far from clear-cut. Hence, this should be treated as a complicated area of research. Other researchers have identified at least four problems with interpreting the results. First, that rationing is carried out on multiple levels, which complicates the issue. Litva et al. (2002), distinguishing between three different levels. Making decisions at the systems level refers to different welfare systems, e.g. education, culture, health care, and infrastructure. At the programme level, the choices are between groups of patients or population groups with different needs. Furthermore, at the patient level the choices are between individuals and their treatments. Most studies reporting on citizens' views of decision makers do not differentiate between those levels – as is the case in all studies reporting from the Swedish context. Questions like *"With whom should the responsibility of health care rationing rest?"* provide little clue to respondents regarding what rationing is all about (Wiseman et al., 2003). Litva et al. (2002) focus on public involvement in rationing and highlight the importance of specifying the decision level, explaining that citizens' views might vary according to the level being addressed. Mitton et al. (2009) point to the programme level as under-researched with regard to studies of citizens and priority setting. Accordingly, the focus of this paper is exclusively on rationing at the programme level.

Secondly, *rationing* and *priority setting* are elastic concepts, often used interchangeably. In surveys, failing to clearly distinguish between situations of priority setting in general and rationing in particular make it difficult to depict public judgements (Busse, 1999). We use *priority setting* to denote a process of scoring or ranking that could be used for disinvestments as well as investments, while rationing is entirely about limiting the possibilities to optimally satisfy health care needs. In this study we address issues related to rationing.

Thirdly, scholars have drawn attention to the differences in questions about citizens' willingness to participate in rationing processes (Bowling, 1996; Mossialos and King, 1999; Litva et al., 2002; Lee et al., 2002; Wiseman et al., 2003). In the 1960s Arnstein pointed to the importance of clarifying the degree of participation, ranging from manipulation to real control (Arnstein, 1969). Without this information, the results related to citizen participation in rationing would be difficult to interpret and compare. In this study, however, we take a broader view on the choice of appropriate decision makers – beyond just the degree of public involvement.

Fourthly, studies of appropriate decision makers often present citizens with hypothetical rationing situations (Heginbotham, 1993; Busse, 1999; Mossialos and King, 1999; Litva et al., 2002; Wiseman, 2005). Traditionally, such studies (including those reporting from the Swedish context) have used closed questions where respondents were asked to choose between alternatives, e.g. physicians, politicians, patients, relatives, health service managers, health insurers, and the public (Bowling, 1996; Busse, 1999; King and Baynard, 1999; Dolan et al., 1999; Mossialos and King, 1999; Wiseman et al., 2003; Rosén, 2006; Werntoft et al., 2007). Arguments for a more open-ended approach allowing for the exploration of alternative decision makers in rationing situations have been put forward (Coast, 2001). Moreover, some scholars claim that surveys that fail to give respondents the opportunity for reflection are of doubtful value (Dicker and Armstrong, 1995; Dolan et al., 1999; Busse, 1999; Litva et al., 2002; Wiseman et al., 2003). It is worth noting that most studies in this research area are surveys using quantitative data, aiming to generalize the result to the population level. In line with Coast (2001) we argue that quantitative and qualitative studies should be looked upon as complementary. The latter are particularly useful for understanding the reasoning behind complex phenomena like rationing, not least regarding decision making and decision makers.

We found four studies that in one way or another address the methodological issues highlighted above, which in turn is reflected in their design. In contrast to our study, however, three of them focus particularly on citizens' preferences for public involvement in rationing situations (Litva et al., 2002; Bruni et al., 2010; Coast, 2001). The remaining study by McKie et al. (2008) used focus group interviews to compare the views of citizens with those of health professionals and administrators at three different decision levels. Here the study participants favoured a solution that involved a range of parties collaborating, viewing this as the best approach towards making decisions for rationing. However, this study reports results from a health care context that differs from the Swedish; namely that in Australia. Wiseman (2003) noted that public preferences on limit setting in health care are not necessarily the same worldwide. Hence, the results from one country cannot easily be generalized to another national context (Busse, 1999; Coast, 2001). Following Mossialos and King (1999), we argue that perceptions on rationing should be interpreted within a political, cultural, and time context. Our findings should be considered within the Swedish context, which is characterized by universal health care funded mainly by taxes, where responsibility for providing health services rests with 21 directly elected regional bodies (county councils). Political responsibility for health service delivery has a long tradition in Sweden (Ham and Coulter, 2001; Magnussen et al., 2009). Hence, regional politicians are formally accountable to the public for distribution between different service areas at the programme level. Resource allocation decisions at the regional level are supported by national guidelines for clinical standards and ethical principles for priority setting decided by the Parliament (Socialdepartementet, 1996/97). It is worth noting that in Sweden, as in many other countries, the public is only marginally involved in health policy making (Coulter and Docteur, 2012; Sabik and Lie, 2008). In summary, previous studies point to the importance of clarifying the decision level, clearly distinguishing between rationing and other phenomena related to limit setting, allowing for participants to reflect freely on appropriate decision makers, and being aware of contextual influences. Drawing on these experiences, this paper aims to identify and describe different ways Swedish citizens understand and experience decision makers when it comes to rationing in health care at the programme level.

2. Material and methods

To examine how citizens understand and experience decision makers, we analysed qualitative interview data using phenomenography. Instead of focusing on finding the most representative views, this inductive method aims at capturing *variations* in how people experience a phenomenon. In contrast to what is the case in some other qualitative methods (e.g. phenomenology), *experience* could encompass conceptual thoughts about the phenomenon being studied, not just "lived" experience. The method is built on the epistemological assumption that there are a limited number of