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The meaning of severity – do citizensí views correspond to a severity framework based on ethical principles for priority setting?

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A B S T R A C T

The importance for governments of establishing ethical principles and criteria for priority setting in line with social values, has been emphasised. The risk of such criteria not being operationalised and instead replaced by de-contextualised priority-setting tools, has been noted. The aim of this article was to compare whether citizensí views are in line with how a criterion derived from parliamentary-decided ethical principles have been interpreted into a framework for evaluating severity levels, in resource allocation situations in Sweden. Interviews were conducted with 15 citizens and analysed by directed content analysis. The results showed that the multi-factorial aspects that participants considered as relevant for evaluating severity, were similar to those used by professionals in the Severity Framework, but added some refinements on what to consider when taking these aspects into account. Findings of similarities, such as in our study, could have the potential to strengthen the internal legitimacy among professionals, to use such a priority-setting tool, and enable politicians to communicate the justifiability of how severity is decided. The study also disclosed new aspects regarding severity, of which some are ethically disputed, implying that our results also reveal the need for ongoing ethical discussions in publicly-funded healthcare systems.

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1. Introduction

Resource allocation in a publicly funded healthcare system is inevitably linked with the setting of priorities between different groups of patients and service areas. Priority setting is a complex interplay between the processing of social values in civil society, political goals, facts, and the capacity of institutions [1,2]. Hence, the importance for governments of establishing ethical principles with criteria in line with social values (i.e. values held by the public in a certain society at a certain time), has been emphasised for the legitimacy of priority setting [1,2]. In e.g. Scandinavia, the Netherlands, and New Zealand, the severity criterion is highly valued both by citizens and by decision-makers, meaning that more of healthcareís resources should be given to those with the most severe ill health [3–7]. What is meant by "the most severe" is far from clear-cut, and agreement among different actors generally tends to decrease when vague criteria are more precisely defined [8]. However, unless ethical criteria are not operationalised, they face the risk of serving mainly as a political "decoration" and priority tools based on other (often implicit) values will be used instead [2,9–12].This paper focuses on citizensí views on severity in relation to how health professionals and experts have interpreted the priority-setting criterion in Sweden.

In 1992 a Parliamentary Priorities Commission was set up to propose basic ethical principles to guide necessary prioritisation of healthcare resources [13]. The Government bill, *Priority Setting in Health Care* [14], that followed the white paper of the Commission formed the basis for Parliamentís decision in April 1997. From this decision follows that all priority setting in Swedish public health care should be guided by the ethical principles of human dignity, needs-solidarity, and cost–effectiveness [14,15]. When in doubt on how these principles should be interpreted, actors in Sweden may consult the bill [15]. These overarching ethical principles have then, by Swedish authorities, been operationalised into a National Model for Transparent Prioritisation (Fig. 1). The model offers a structure for qualitative ranking of different conditions and their interventions. The ranking includes an evaluation of the severity level of the condition, but also of the patient benefits and the cost-effectiveness of the intervention, intended to serve as a base for informing resource allocation [16].

The model is used both by the government authorities for making recommendations on priorities, and by county councils in

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Condition	Inter-vention	Condition's severity level	Patient benefits	Quality of knowledge base	Costs/ effects	Quality of knowledge base	Ranking	Comments/ consequences
		Very high-low	Very high-low		Very high-low		1 (highest) 10 (lowest)	

Fig. 1. National Model for Transparent Prioritisation in Swedish Health Care.

Impact on health-related quality of life							Impact on life-length		Cumulated evaluation
Current ill health					Future ill health				
	Impairment of bodily functions	Activity limitations	Participation restrictions	Occur-rence	Duration	Risk of future ill health	Risk of pre-mature death	Time to death	
Very high									
High									
Moderate									
Low									
None									

Fig. 2. The Severity Framework.

different resource allocation situations in the highly regionalised Swedish health service [16–18]. However, over time users of the model have experienced a need for clarification on how to discriminate more severe conditions from milder ones. Multi-professional and interdisciplinary groups, involved in priority setting on local and national level, came together to interpret what was stated regarding severity in the Government bill. The bill states that both health-related *quality of life* and the *risk of premature death* should play a role concerning the severity level, as well as the *duration* and *risk of future ill health*. No aspect is explicitly deemed more important than any other for deciding the severity level [15]. Based on this interpretation, a Severity Framework (Fig. 2) was developed. The framework is aimed at providing a structured approach for qualitatively evaluating the severity level in accordance with statements regarding severity in the bill [19]. Even if this framework has been considered valuable when evaluated by multi-professional groups involved in priority setting activities at the National Board of Health and Welfare (unpublished material) it is considered to be a living document still open for reappraisal.

In the framework, the quality-of-life impact is considered to be covered by the aspects: impairment of bodily functions (including physical and psychological impairment), activity limitations (practical consequences of ill health), participation restrictions (social consequences), and the occurrence and duration of these problems, plus the risk of future ill health. The first three aspects are defined according to the classification of World Health Organizations‘ (WHO), The International Classification of Functioning, Disability, and Health (ICF) [20]. Occurrence refers to how often (constantly, monthly etc.) the patient group is usually aware of their health problem. Risk of future ill health includes both new symptoms and deterioration of an already diagnosed ill health. Impact on life-length comprises risk of premature death and time to death [19]. Due to the priority-setting situation, different instruments (e.g. different quality-of-life instruments) could be used to support the evaluations in the framework by providing measurements.

The Parliamentary Priorities Commission, when initially drafting the proposal for ethical principles in the 1990s, consulted the public and found substantial support for giving higher priority to those with the most severe ill health (without further defining what was meant by the most severe) [13]. However, neither patient groups nor representatives of the public were involved in elaborating the Severity Framework. The absence of public involvement is not unique to Sweden (a country ranked low in international comparison in terms of involving the public in health policy making) [12,21]. In their review of public participation in priority setting, Mitton et al. [22] pointed to the absence of studies which illuminate what citizens could contribute, when designing different priority-setting tools [22]. When it comes to studies that concern severity, citizensí have instead contributed with preferences on how to weigh different diseases (e.g. cancer vs psychosis), or priority setting criteria (e.g. severity vs cost-effectiveness) or preselected health dimensions (e.g. pain vs mobility) [5,23,24]. There is a lack of studies of citizensí views on how to actually operationalise severity criterion, especially when it comes to country-contextual studies [22,25].

To fill this gap, the aim of this study is to examine what Swedish citizens consider relevant when evaluating the severity level of ill health in resource allocation situations. It also addresses the question regarding how their views correspond with the way in which the Swedish severity criterion has been operationalised into a Severity Framework, and are used for qualitatively evaluating the severity level. Drawing on the results, we discuss the implications that studies of social values could have in the development of such frameworks in a priority setting context.

2. Method

2.1. Study design

We conducted face-to-face, individual interviews, and used directed content analysis. This method is used for studying a framework in relation to a new perspective, in our case the citizensí perspective. The deductive analysis in directed content analysis offer supporting or non-supporting evidence for the framework in the study, i.e. in our case the extent to which our data (both qualitative and quantitative) supported the Severity framework versus

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