A severely fragmented concept: uncovering citizens' subjective accounts of severity of illness

Stenmarck, Mille Sofie; Jølstad, Borgar; Baker, Rachel; Whitehurst, David G.T.; Barra, Mathias

A severely fragmented concept: Uncovering citizens' subjective accounts of severity of illness

Mille Sofie Stenmarck [a,b,*], Borgar Jølstad [a], Rachel Baker [c], David GT. Whitehurst [d], Mathias Barra [a]

[a] *The Health Services Research Unit – HØKH, Akershus University Hospital HF, Lørenskog, Norway*
[b] *Faculty of Medicine, University of Oslo, Norway*
[c] *Yunus Centre for Social Business and Health, Glasgow Caledonian University, Scotland, UK*
[d] *Faculty of Health Sciences, Simon Fraser University, Canada*

ABSTRACT

Universal healthcare is constrained by national governments' finite health resources. This gives rise to complex priority-setting dilemmas. In several universal healthcare systems, the notion of severity (Norwegian: 'alvorlighet') is a key consideration in priority setting, such that treatments for 'severe' illness may be prioritised even when evidence suggests it would not be as cost-effective as treatment options for other conditions. However, severity is a poorly-defined concept, and there is no consensus on what severity means in the context of healthcare provision – whether viewed from public, academic, or professional perspectives. Though several public preference-elicitation studies demonstrate that severity is considered relevant in healthcare resource distribution, there is a paucity of research on public perceptions on the actual *meaning* of severity. We conducted a Q-methodology study between February 2021 and March 2022 to investigate views on severity amongst general public participants in Norway. Group interviews ($n = 59$) were conducted to gather statements for the Q-sort ranking exercises ($n = 34$). Data were analysed using by-person factor analysis to identify patterns in the statement rankings. We present a rich picture of perspectives on the term 'severity', and identify four different, partly conflicting, views on severity in the Norwegian population, with few areas of consensus. We argue that policymakers ought to be made aware of these differing perspectives on severity, and that there is need for further research on the prevalence of these views and on how they are distributed within populations.

1. Introduction

National healthcare systems operate with finite budgets, and priority-setting decisions are difficult and unavoidable (Hirose and Bognar, 2014). In a number of healthcare systems, severity is a key concept in priority setting. Treatments for 'severe' conditions may be prioritised even when evidence suggests there might be more cost-effective investments available for other conditions (Barra et al., 2019). Yet, severity is a multifaceted and arguably poorly-defined concept, and there is no consensus on what severity means in the context of healthcare provision – whether viewed from public, academic, or professional perspectives. In this paper, we contribute towards a more nuanced discussion of the meanings attached to 'severity' amongst the public in Norway.

1.1. Severity in priority-setting policy

Most jurisdictions with universal healthcare systems place value on and stipulate requirements for public consultation and transparency. This is also true of Norway (Norheim et al., 2019). Four separate government-appointed commissions have produced green papers (NOU 1987:23, NOU, 1997:18, NOU, 2014:12; NOU, 2018:16) that develop and establish statutory principles for priority setting in healthcare. Three priority-setting criteria have emerged: the first two relate to *cost-effectiveness;* the latter is *severity.* The purpose of the severity criterion is to allow for a higher priority than cost-effectiveness suggests for treatment options targeting conditions that are particularly severe. The severity criterion thus modifies standard decision rules used in cost-effectiveness analyses (Norheim, 2010).

In Norway, like many other jurisdictions, for the purpose of cost-

effectiveness assessments, the *quality-adjusted life year (QALY)* is the *de facto* measure of outcome in economic evaluation (Canadian Agency for Drugs and Technologies in Health, 2017; National Institute for Health and Care Excellence, 2022; Norheim et al., 2014). The QALY combines quality and quantity of life in a single outcome (Weinstein et al., 2009) and the cost-effectiveness of treatment options are given as cost-per-QALY estimates (Drummond et al., 2009). Severity criteria for priority setting are used in several European countries, including the Netherlands (Schurer et al., 2022), Sweden (Riksdagsförvaltningen, 2018), and England (National Institute for Health and Care Excellence, 2022). In Norway, a QALY-based operationalisation of severity – *absolute QALY shortfall* (AQS) (Magnussen et al., 2015) – has been adopted; NICE's approach combines AQS *and proportional QALY shortfall* (PQS); PQS is used in the Netherlands (Reckers-Droog et al., 2018). Sweden operates with a more qualitative approach to severity (Riksdagsförvaltningen, 2018).

1.2. Severity defined

The notion that health resource allocation should incorporate a concern for severity is often grounded in ethical theories of distributive justice, emphasising the claims of the worse off (Daniels, 1985; Rawls, 1999). Attempts at defining severity have focused largely on measurable interpretations of the term, based on QALYs (Drummond et al., 2009; Lakdawalla and Phelps, 2020; Nord, 1999). However, severity remains a controversial concept (Hausman, 2019): there is ambiguity in both policy and academic literature, where the term severity is often invoked but lacks a widely accepted definition (Barra et al., 2019; Stein et al., 1987). For example, a questionnaire distributed amongst Norwegian healthcare workers, decision-makers, and patient organisations found widely differing views on the meaning of severity and no unambiguous understanding of how it should be applied (Magnussen et al., 2015).

1.3. Public views on severity

Eliciting public views is central for policy decisions (Tenbensel, 2010) and increases the democratic legitimacy of those policies (Rutgers, 2015). There is an increasing interest in involving the public in healthcare priority setting (Mullen, 1999), and several public preference-elicitation studies have attempted to establish preferences for prioritising the severely ill (Diederich et al., 2012; Dolan and Shaw, 2003; Green, 2009; Gu et al., 2015; Linley and Hughes, 2013; Nord and Johansen, 2014; Skedgel et al., 2022). A systematic review of empirical studies of public preferences on severity in the context of health evaluation (Shah, 2009) captures studies ranging from small-sample focus groups (including Abelson et al., 1995; Dolan, 1998; Dolan and Cookson, 2000; NICE Citizens Council, 2008) to large population surveys (including Gyrd-Hansen, 2004; Oddsson, 2003; Ubel, 1999), with general population, healthcare worker, and researcher participants. The review illustrates the lack of coherence on severity and the studies use different definitions (e.g. based on QALYs; in terms of 'need'; or related to 'worse-off-ness'). Some studies do not provide any definition of severity, and some do not mention the term severity during data collection, but appear to assume that when asked about e.g. trade-offs between groups according to need, participants align 'need' with 'severity'. There is no sound foundation for the assumptions that (1) participants from these studies uniformly or conceptually associate greater QALY-losses with more severe conditions, or (2) that such a notion of severity is the same that features in a call for higher priority for the severely ill.

We know from empirical literature that severity matters, but we do not know *what the public take severity to mean*: many preference-elicitation studies explore the degree to which (a particular definition of) severity is valued, but not what participants mean by 'severe'. This is problematic because the term *severity* arguably invokes concepts from various domains. Severity can be associated with a poor prognosis, a high risk of fatal outcome, the degree of suffering, urgency, the burdens placed on family members, the magnitude of the estimated health loss (Olsen, 2013; Wittenberg and Prosser, 2013), or as moral impetus to act (Solberg et al., 2023). AQS, for example, might represent 'severity' for some, or it might be overlapping with severity. It might also be the case that participants in these studies are in favour of increasing priority for patients with a high AQS, but for other reasons than 'severity'.

The motivation behind this study is to investigate subjective views on the meaning of severity to paint a rich and detailed picture of accounts of severity. To this end, we use Q-methodology (Brown, 1993; Watts and Stenner, 2022) to study these accounts and locate shared viewpoints.

2. Materials and methods

Q-methodology combines qualitative techniques with exploratory factor analysis to study subjectivity. It is a well-established method used to identify and describe *shared* viewpoints on a topic, areas of consensus, and distinctions between viewpoints. We direct the interested reader towards seminal and introductory texts (Baker et al., 2014; Brown, 1993; Damar and Sali, 2022; McKeown and Thomas, 2013; Stephenson, 1935; N. van Exel and de Graaf, 2005; Watts and Stenner, 2022), as well as a vast array of applied studies using Q in a range of fields (Cuppen et al., 2010; McHugh et al., 2019). Our study was conducted in three stages. In Stage 1 we developed a *Q-set* of statements about the meaning of severity through facilitated group interviews with general population participants. In a second stage of *Q-sort*-exercises, participants sorted the Q-set of statements according to how much they agreed or disagreed with each statement. The third stage used factor analysis to identify similar patterns of Q-sorts and to interpret those factors.

2.1. Stage 1: deriving the Q-set

A Q-set represents the 'universe of opinions' on the topic of study (van Exel et al., 2015). There are several ways to develop a Q-set, either from existing sources or by generating statements through interviews. We conducted group interviews to generate statements for the Q-set. Ahead of the group sessions, a brief introduction to the topic of severity was prepared by authors MSS, BJ and MB (Supplementary material A). This introduction, as well as facilitation of the interviews, was piloted with a user panel at Akershus University Hospital consisting of eight members of the public across different demographic backgrounds. Due to SARS-CoV-2 pandemic restrictions, data collection commenced online using Zoom (Barbu, 2014), before converting to physical groups once restrictions were lifted.

Purposive sampling (Malterud, 2019) aimed to elicit views from participants expected to have differing perspectives. We hypothesised that age, education level, socioeconomic background, health status, and geographical region were relevant characteristics. We monitored variation across these characteristics throughout the recruitment process and sought to fill any gaps by seeking out individuals with underrepresented characteristics. We recruited through the project's social media platforms (Facebook and Twitter) by asking our professional and personal networks (snowballing) to disseminate a link to an online recruitment platform on the *Nettskjema* infrastructure hosted by the University of Oslo. Posters advertising the project were hung in public spaces and GP's waiting rooms in two large Norwegian cities (Oslo and Bergen). Recruitment lasted from February to July 2021, and group interviews were conducted February to May (online) and May to July (physical). We aimed for approximately 60 participants to reach saturation (Malterud, 2019). Inclusion criteria were Scandinavian-speaking adults (age ≥18). We determined saturation according to data redundancy, i.e. once participant viewpoints became repetitive (Saunders et al., 2018) and no new Q-statements were generated.

Group interviews were facilitated by one to three authors (MSS, BJ, MB). Participants submitted informed, written consent, and were subsequently introduced to the topic of severity during a brief presentation,

developed by authors MSS, BJ, and MB (Supplementary material A). As a note, direct translation of severity from Norwegian ('alvorlighet') to English is difficult, as it is a more all-encompassing term in Norwegian. We use the term severity in relation to 'illness', where we take illness to cover different descriptors of ill health, such as injury, illness, sickness, and disease.

A facilitated group discussion explored participants' views of severity, designed to allow discussions to develop uninterrupted, focused on perspectives participants brought up. Discussion was supplemented with topics from a pre-prepared list of possible aspects of severity, to prompt participants to discuss certain topics. The list was compiled following a comprehensive search of the literature (Barra et al., 2019), and was updated dynamically throughout the interview period as participants raised new issues (Supplementary material A). Finally, participants completed a questionnaire about socioeconomic status, health status, and situations that may have affected their views on severity (Supplementary material B). Participants in physical groups filled out the questionnaires on paper; online participants were contacted by a facilitator to complete the questionnaire by telephone.

All group interviews were audio-recorded and transcribed (in Norwegian) by MSS and BJ. The same authors coded the transcripts by highlighting (without judgement) every statement that expressed a view about what severity means. These candidate statements for the Q-set were examined for intelligibility and relevance, with the aim of achieving coverage of all the identified issues (Watts and Stenner, 2022). Duplicate statements were removed, very similar statements were merged, and those expressing several opinions were broken down (Baker et al., 2017). All statements were categorised using group and participant codes to ensure breadth in selected statements. The statement set was reviewed at multiple stages and discussed by co-authors to reach a final Q-set, with a view to representing the breadth of opinion expressed across the group interviews. The Q-set was piloted with a convenience sample of 14 colleagues, who are academics across different field, aiming to ensure the statements and instructions (Supplementary material C) were easy to understand. Pilot participants responded positively to the Q-set and did not identify any missing statements.

2.2. Stage 2: Q-sort exercise

The Q-sort is the main source of data in a Q-study. Participants are asked to rank statements onto a grid according to a standard instruction. A new set of participants were recruited for the Q-sort exercises, in the same manner as in Stage 1 (January to March 2022), seeking breadth of demographic profiles and recruiting in two locations (Oslo and Bergen). The exercises were conducted face-to-face. Participants were gathered in groups and introduced to the study and instructions together, then completed the Q-sort independently. They were presented with the Q-set (with each statement represented on an individual card) and a Q-sort grid (Fig. 1). Participants were first asked to sort all cards into three piles: 'agree', 'disagree', and 'neutral'; then to sort the cards onto the grid, with the placement of each card reflecting the degree of agreement, from most agree (+6) to most disagree (−6) (Supplementary material C). The grid forces distribution of cards into a particular number in each column, with one square for each card. This is standard in Q-methodology (Watts and Stenner, 2022) and although a forced (compared to free) distribution could appear to restrict participants' viewpoints, comparisons of the two indicate a negligible effect (Brown, 1993; Hess and Hink, 1959). Finally, participants were asked to elaborate on their rankings on a separate form (Supplementary material D) and answer questions about their sociodemographic status (using the same questionnaire as in Stage 1).

2.3. Stage 3: exploratory factor analysis and interpretation of Q-sorts

In Q-methodology, the 'best' factor solution is determined by the qualitative interpretability of each solution, as well as its statistical qualities (McKeown and Thomas, 2013). It is customary to fit models with varying numbers of factors and judge their merits according to qualitative readings of the resulting factor arrays, rather than purely on statistical grounds.

Data analysis was conducted using dedicated Q-methodology software (*KenQ-Analysis Desktop Edition (KADE) version 1.2.1*) (Banasick, 2019). Correlations between Q-sorts were calculated and clusters of participants identified using by-person factor analysis. KADE fits a centroid factor analysis (with Horst 5.5 centroid factors) with varimax rotation to identify shared viewpoints among the participants (Watts and Stenner, 2022). The resulting factors are represented by a factor array, or composite Q-sort, for each factor based on the Q-sorts of the factor exemplars (participants with high, pure loading on one factor only). These composite sorts represent a weighted (according to factor loadings) compromise between the Q-sorts of participants flagged as exemplars for that factor (Watts and Stenner, 2022) and form the basis for interpretation.

In determining a preferred factor solution, we considered the number of Q-sorts flagged for each factor to ensure that factors represent shared perspectives between Q-sorters – ideally at least four flagged Q-sorts to be satisfied the factor represents a shared viewpoint (Watts and Stenner, 2022). We considered the correlation between different factor solutions to see whether distinct new factors were identified in solutions with increasing numbers of factors (Watts and Stenner, 2022). Four authors
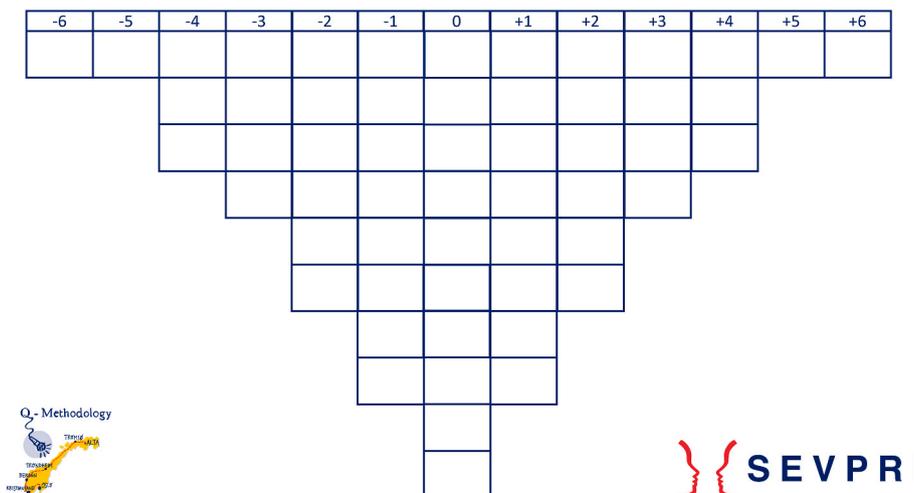

-6	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6

Fig. 1. The grid for the Q-sorting exercise.

(MSS, BJ, RB, MB) examined and produced initial factor interpretations based on the composite Q-sorts and qualitative information for each factor. All authors participated in the deliberative process of factor analysis and discussed interpretations in two separate workshops. All statements in the composite Q-sorts were considered, with particular focus on the salient statements (at either side of the grid), distinguishing statements (placed substantially differently between factors), and consensus statements (placed similarly across factors) (Watts and Stenner, 2022). Non-salient and neutral statements also contributed towards interpretation. Written responses (where participants elaborated on their rankings) uniquely associated with each factor were examined to enhance interpretation and ensure a rich understanding of participants' views.

2.4. Ethics

The Regional Committee for Medical and Health Research Ethics (Regional Ethics Committee South-East B) advised that SEVPRI falls outside their mandate (i.e., the aims and objectives are not regulated by the Health Research Act (Helseforskningsloven, 2008)). Consequently, the Data Privacy Officer at Akershus University Hospital evaluated the project's protocol and advised that the study could be conducted (*PVO. Nos 20_200 and 21_200*). Akershus University Hospital and the Principal Investigator (MB) are responsible for project oversight, including all aspects of ethical research conduct and data privacy.

3. Results

3.1. Stage 1 and stage 2

59 individuals at five locations (Oslo, Bergen, Trondheim, Tromsø, Alta) participated in Stage 1. There were 14 online groups (three with three participants; ten with two participants; and one individual interview) and seven physical groups (one with six participants; two with five participants; two with four participants; one with three participants; and one with two participants), lasting two to 3 hours.

The interview transcripts contained 450 statements on severity. Following coding and statement extraction as outlined above, 53 statements remained, representing distinctive opinions about severity. Three statements were added by the authors, representing viewpoints considered to have theoretical relevance that had not been expressed by participants (statements #54, #55, #56) (Barra et al., 2019). This resulted in a final Q-set of 56 statements.

Thirty-four participants completed the Q-sort exercise in Stage 2, across two locations (Oslo and Bergen). The characteristics of participants involved in the group interviews (Stage 1) and Q-sort exercises (Stage 2) are summarised in Table 1.

3.2. Stage 3: exploratory factor analysis and Q-sort interpretation

We computed and inspected factor solutions ranging from two to six factors and selected a preferred factor solution based on the interpretability of the factors as well as their statistical features. We attempted interpretation of the factors (by examining the composite Q-sorts) in the three-, four-, and five-factor solutions. With fewer than three factors, viewpoints were difficult to interpret. With more than five factors, the viewpoints were no longer distinct. We report the four-factor solution, where each composite sort had a coherent and interpretable narrative consistent with the written comments by exemplars. Table 2 shows the factor array for each of the four factors; the statement scores in the rightmost columns of Table 2 permit the positioning of the Q-set back onto the grid for each factor.

Table 3 sets out factor loadings for each participant, representing the correlation between their individual Q-sort and each of the factors. In the four-factor solution, at $p < 0.05$ significant loadings are $\geq$ 0.262 (McKeown and Thomas, 2013, p.51). Q-sorts were flagged by the

Table 1
Participant characteristics.

Age [a]	18–30	31–50	51–66	67+	NA
Q-interview	9	13	24	11	2
Q-sorters	16	9	7	2	–
Sex	**Female**		**Male**	**Other/prefer not to say**	
Q-interview	38 (64%)		19 (32%)	2 (3%)	
Q-sorters	24 (71%)		9 (26%)	1 (3%)	
Religious sentiment	**Religious and/or spiritual Active in a congregation**		**Religious and/or spiritual Not Active in a congregation**	**Neither Religious nor spiritual**	**NA**
Q-interview	11 (19%)		14 (24%)	33 (56%)	1 (2%)
Q-sorters	2 (6%)		4 (12%)	25 (74%)	3 (9%)
Highest education level	**Elementary/ upper secondary**		**BSc/Fagbrev**	**MSc/PhD**	**NA**
Q-interview	9 (15%)		21 (36%)	27 (46%)	2 (2%)
Q-sorters	8 (24%)		16 (47%)	10 (29%)	–
Experience of severe illness [b]	**Transient**		**Chronic**	**Terminal**	**NA**
Q-interview	18 (31%)		30 (51%)	42 (71%)	
Q-sorters	18 (53%)		20 (59%)	23 (68%)	–
Self-reported health	**Very good/ Good**		**Just fine**	**Bad/Very bad**	**NA**
Q-interview	37 (63%)		15 (25%)	6 (10%)	1 (2%)
Q-sorters	19 (56%)		13 (38%)	1 (3%)	1 (3%)

Notes: All percentages are rounded and might not sum to 100%. [a]Age was given in one of the listed age-brackets. [b] Personally or close acquaintance; categories not mutually exclusive. 'Terminal' relevant to acquaintance only.

following criteria: (i) a significant factor loading ($\geq$ *0.26*), and (ii) > 50% of the communality corresponding to the factor (the default in KADE). Participant 23 (R23) can be viewed as an exemplar, with a high loading on Factor III and very little in common with the other factors (Table 3). A flagging algorithm is applied to identify Q-sorts that will contribute to the composite Q-sort through which we interpret each factor. This takes into account the significance of loading on each factor, and the communality (the sum of squared loadings) (McKeown and Thomas, 2013).

Below, each factor is described based on the composite Q-sorts and written comments. These are (necessarily) summary descriptions of the factors. Statements are referred to by number # followed by their score for that factor's composite sort (−6 to +6). Distinguishing statements are indicated by * and **.

3.3. Factor I: 'natural lifespan'

The first factor represents a viewpoint focused on 'the natural course of life', reconciled with the idea that life is inherently finite, and that a life with dignity is preferable to longevity. Severity is associated with the loss of quality of life (#14, +3). Mental illness is particularly severe (#8, +4**), possibly associated with the value placed on autonomy and living life on your own terms and with dignity (#31, +3). People associated with this factor tend to view illness in the young as more severe than illness in older people (#18, +5; #33 + 3) who have already had the chance to live a full life. This is consistent with the notion of a natural lifespan and reinforced by the placement of statements pertaining to

Table 2
Factor arrays.

		I	II	III	IV
		Statement scores			
1	In my mind death is the most severe no matter how old you are. Death is death.	−6**	0	0	−1
2	Diseases that make you die before the life-expectancy in Norway, that is severe.	−1	+2	0	0
3	Severity is first and foremost just death.	−5	−6	−2**	−4
4	Loss of identity is severe. The stronger the loss of identity, the more severe we can say that an illness is.	+2	+1	−1	+1
5	I think it is severe when it's something to do with the brain, how you come across, what you think and stuff like that.	+1	0	+2	+2
6	For someone who has already had lots of illness perhaps more illness won't be a shock, and therefore not more severe than someone who's been well their whole life. So in my opinion illness is more severe for someone who was healthy before.	−3	−3	−3	−2
7	If life can have a good ending, then death feels less severe.	+4	+3	0	0
8	I think mental illness is very severe.	+4**	+1	−1	0
9	When I think of severe, I think of change.	−2	−3*	0*	−2
10	The greater the loss of function, the more severe the illness is.	+1	−1**	+1	+4**
11	Imagine if Arve Tellefsen [famous Norwegian violinist] lost his grip and can't play his violin anymore. That would be much more severe than if I lost a finger. I could still do almost exactly the same as I do now.	**−1**	**0**	**+1**	**0**
12	When you cannot take care of yourself, I think that's severe.	+2	0**	+4	+3
13	I think severity is if you fall out of professional life.	−1	−4**	+3**	−1
14	I think severity is defined from the sense of loss of quality of life.	+3	+1	0	+6*
15	It would be very severe for me with illness that prevents me from living the life I want to live.	+4	−1	+1	+5
16	That there are things that are more severe than dying, that I'm sure of.	+6**	0*	+1	+1
17	The younger, the more severe an illness must be considered to be.	0	+2	+2	−3**
18	A cardiac arrest or a stroke in an 18-year-old is much more severe than in a 98-year-old.	+5	+5	+1*	−1*
19	Severity must be defined by the individual. As in what is severe for each individual.	−1**	+3	−4**	+2
20	I think severity is something the professionals within that field should comment on, not the relatives, not the people who are ill.	0*	−2*	+2**	−4**
21	I think severity is mostly how you take it. That an event or a condition to an insufficient degree describes severity. It's not the event in itself that defines severity, but what it does to you and how you experience it.	0**	+3	−4**	+3
22	Many women survive breast cancer, and some get fully back to work and some have lots of side effects after. And I think that she who has lots of side effects has had a more severe disease.	0	+2	0	−1
23	To experience that you are different, that is severe. But if many others get the same illness, then I would say it becomes less severe.	**−2**	**−1**	**−3**	**−3**
24	It's severe if many others get it. So, severity has something to do with the amount, how many get ill from it.	−4	−5	−4	−2**
25	Pain is severe.	−4**	−1	0	0

Table 2 (*continued*)

		I	II	III	IV
		Statement scores			
26	Death is severe for those left behind, but it's not severe for the person who dies, I think.	−1	−1	−1	−2*
27	Illness isn't severe if it passes on its own, something that doesn't need an intervention from the health services.	+1	+3	+2	−1**
28	If you get immediate treatment and have zero ailments after, then it is not a severe illness.	+1	+2	−1	−3**
29	I think that if you handle a disease or a condition badly then it's more severe.	−1	−2	−2	+1**
30	I think an illness needs to have a closeness to us for it to feel severe.	−3	0*	−3	−2
31	I think it's very severe with a life without dignity.	+3	+4	0**	+4
32	Severity is about being taken seriously.	−3	0	−6**	−1
33	I think it becomes much more severe when it's about children.	+3	+4	+4	−1**
34	It is hard to say anything definitive about what severity really is, I think. There is no right answer.	+2*	+6**	+1	+1
35	All illness can be severe, I think.	−4	−3	−3	0**
36	I think severity is about what the consequence is of not treating.	−1	+1	+3	+2
37	I think how an illness affects everyone around you, that is part of the severity criterion, or should be.	0	−1	−1	+1*
38	If you fall out of the hobbies you've had, or out of the social network you've had. Then, I think it is a severe condition.	+1	−4**	−1	+2*
39	Illness becomes less severe for a resourceful person because she can buy help. So there's less severity when you're resourceful.	−2	−4**	−1	0
40	I think the more people it affects, the more severe the illness is.	−1	−3*	0	0
41	You can't say that because you live a successful life then your illness is more severe than if you're a drug addict. You can't begin to weigh these lives up against each other. Because a life is a life and has the same worth no matter how you've lived or have had to live it.	+2	+2	+6	+4
42	I hurts a bit to say, but I think it's more severe if a 35-year-old mother of two gets cancer than if a 35-year-old single woman gets it.	−3	+1**	−2	−5**
43	I think it's more severe that someone with children gets ill than someone without.	−2	+1**	−2	−3*
44	You can perhaps say that illness is a bit less severe if you have relatives who can support you.	+1	0	−2	−1
45	I think it's severe with illness where it just gets worse and worse. And it's certain that it will only get worse.	+1**	+4	+4	+3
46	As long as you have the possibility to get well, I don't think the disease is severe.	−2	+1**	−2	−4
47	Severity is about the threat of permanent damage.	0	−1	+3	+3
48	If it's an illness that needs to be dealt with very urgently, then it's very severe.	+2	0**	+5**	+2
49	It's as severe to get lung cancer whether you've smoked or not, I think.	+2	−1**	+3	+2
50	Immediately I think illness is less severe if it's your fault you have it. If it's your fault it's less severe.	−2	−2	−5*	−6*
51	If you live far away from the hospital, there's an insecurity in that you might not get help. That's severe.	+1	−2**	+1	+1
52	To get sick is less severe if you are close to the hospital.	0	−2	−1	−2
53	Stigma creates a more severe situation for the individual.	0	+2	+1	+1

Table 2 (*continued*)

		Statement scores			
		I	II	III	IV
54	How serious the loss of function is depends on the situation. For example, it's more severe to be in a wheelchair if you live somewhere that doesn't facilitate for it, than if you live somewhere where you can still easily get around.	0	0	0	0
55	To be kept alive when you're sick and you want to die, that's severe.	+3	+1	+2	0
56	I think an illness becomes more severe if the treatment becomes a big part of your everyday life. If you have to spend a lot of time in hospital, treatment and stuff.	0	−2**	+2	+1

Notes: * statement is distinguishing $p < 0.01$, ** statement is distinguishing $p < 0.05$. Consensus statements for $p < 0.05$ are highlighted in bold.
Translation: the statements presented here were translated from Norwegian to English by the authors, but were presented to participants in their original Norwegian wording.

Table 3
Factor loadings.

	Factors			
	I	II	III	IV
Participant ID				
R1	**0.53**	0.04	−0.13	**0.55***
R2	**0.34**	0.09	0.04	**0.62***
R3	**0.34**	0.08	**0.38**	**0.47**
R4	0.26	0.02	**0.32**	**0.29**
R5	**0.58***	**0.30**	0.23	0.12
R6	**0.47**	0.18	**0.53**	0.19
R7	0.18	−0.04	**0.66***	0.14
R8	**0.60***	**0.26**	0.17	0.03
R9	−0.21	0.17	**0.28**	**0.48***
R10	0.14	−0.09	0.23	**0.75***
R11	0.05	**0.55***	0.02	0.06
R12	−0.01	0.06	**0.41**	**0.65***
R13	**0.51***	−0.05	0.22	**0.29**
R14	0.13	0.23	0.08	**0.64***
R15	0.16	−0.23	0.37	**0.73***
R16	0.22	0.19	0.33	**0.43**
R17	**0.48**	**0.58***	0.07	0.22
R18	**0.36***	0.12	0.08	0.17
R19	**0.55**	−0.19	0.19	**0.50**
R20	0.24	−0.10	**0.43**	**0.49**
R21	**0.30**	0.13	−0.00	**0.69***
R22	**0.58***	**0.30**	**0.35**	−0.01
R23	0.09	−0.00	**0.64***	0.24
R24	**0.28**	0.23	**0.62***	0.23
R25	−0.05	**0.45***	**0.41**	0.11
R26	0.24	**0.31**	**0.39**	0.18
R27	**0.52***	0.09	0.24	0.11
R28	**0.67***	0.17	0.20	**0.30**
R29	0.26	**0.45***	−0.18	0.04
R30	**0.28**	0.08	**0.35**	0.24
R31	**0.40**	−0.02	**0.28**	0.30
R32	0.23	0.08	**0.60***	0.02
R33	0.17	**0.65***	0.21	−0.07
R34	**0.35**	**0.28**	0.11	**0.52***
Eigenvalues	10.24	2.49	1.80	1.32
Variance	30%	7%	5%	4%

Notes: Significant loadings showing in bold. Flagging indicated by *.

age. Death is seen as natural and not central to the meaning of severity. This is clear from the placing of statements #1 (−6**) and #3 (−5) and statements #16 (+6**), #7 (+4), and #55 (+3), all of which are distinguishing statements for this factor. A good end to life makes death less severe (#7, +4), and being kept alive against your wishes is severe (#55, +3). People associated with this factor tend to reject pain as severe (#25, −4**). This is distinguishing for this factor and fits with the

natural lifespan perspective: pain is part of life and does not define severity.

3.4. Factor II: 'severity is subjective'

A characterising feature of Factor II is the difficulty of defining severity (#34, +6**). Severity of illness is subjective, and degree of severity is determined by the individual and what *they* consider severe (#19; +3). As such, severity cannot have a general definition, and is not about types of illness or the prevalence of illnesses in a population, but depends on subjective self-evaluation (#21, +3).

In keeping with the explicit emphasis on subjectivity, this factor is largely defined by the rejection of more objective measures of severity. Almost all potential measures of severity are rejected: it is not about prevalence of disease, or loss of identity, nor one's ability to work and enjoy hobbies (#38, −4**), quality of life, or risk of death. Severity is linked to loss of dignity (#31, +4), is increased when there is stigma (#53, +2), and lessened if one can have a "good" death (#7, +3). The subjective experience of severity is connected to stage of life, and illness is more severe when it affects young people (#18, +5; #33, +4; #2, +2; #17, +2). Factor II is distinguished from other factors on the question of whether severity is linked to having children (#42, +1**; #43, +1**), with associated statements placed close to the centre of the grid but rejected by all other factors.

3.5. Factor III: 'objective measures and triage'

For Factor III severe illnesses are urgent, progressive conditions that require treatment and care (#48, +5**; #12, +4). This viewpoint might be characterised as a 'medical triage perspective', cognisant of how a doctor prioritises emergency patients. People associated with Factor III tend to consider urgency and prognosis – which are more objectively measurable – as important (#48, +5**; #45, +4). Conditions that effect children are more severe, and in the context of this factor this could be related to the importance of age to medical prognosis (#33, +4). Individuals associated with this factor are also the only ones to support the idea that health personnel have a central role in defining severity (#20, +2**). Statements asserting that severity is subjective, or defined by the individual, or that severity relates to loss of dignity, are ranked distinguishingly low (#19, −4**; #31, 0**). A possible interpretation is that individuals in Factor III consider dignity difficult to measure and consequently too subjective to be relevant.

In keeping with the sense that severity is medicalised in Factor III, issues of culpability or worthiness are not relevant: all lives are equal, and severity is not linked to how successful those lives have been (#41, +6; #50, −5*). This corresponds with a fundamental biomedical ethics principle of treating all patients as equals.

3.6. Factor IV: 'functioning and quality of life'

In the final factor, the individual's experience is central, as in Factor II. However, whereas severity is subjectively defined *by the individual* in the latter, in Factor IV severity is determined by the effect a condition has *on the individual*. While severity must be considered in relation to the individual, it is not defined by the individual. Severity is determined by the loss of quality of life (#14, 6*) and how an illness affects day-to-day life: whether you can live the life you want (#15, +5), your level of functioning (#10, +4**), and whether you can still enjoy your hobbies (#38, +2*). The ability to take care of yourself (#12, +3) and live with dignity is also important (#31, +4). Factor IV is distinguished from other factors in the rejection of age (#17, −3**; #18 -1**; #33, −1**). There is also a concern for how illness affects the individual, and a stronger rejection of the notion that next-of-kin or parental responsibilities affect severity. This is consistent with a view that people with equal need should be treated equally, regardless of blame, worth, or parenthood (#50, −6*; #41, +4; #42, −5**).

Interestingly, factors II and IV have a strong negative correlation: if you subscribe to Factor II, you are likely to strongly disagree with Factor IV, and vice versa. This is coherent with our interpretation: they are concerned with similar issues but have directly opposing views of them. While people associated with Factor II subscribe to severity as a subjective experience defined by the preferences of the individual, participants who agree with Factor IV are concerned with the individual experience according to measurable dimensions (e.g., functioning, hobbies, autonomy). Though both groups are concerned with age, in Factor IV age is not relevant, whilst in Factor II this is the only relevant objective measure.

4. Discussion

Severity is a central principle in several health jurisdictions, and has been discussed extensively in the academic literature (Drummond et al., 2015; Millum, 2023; Nord and Johansen, 2014; Shah, 2009; Skedgel et al., 2022). Yet, knowledge of how the public perceives this term is lacking (Barra et al., 2019). Previous preference-elicitation studies have focused on presenting participants with choices between prioritising different patient groups according to QALY-losses and -gains (Shah, 2009), but fail to explicitly connect qualitative explorations of severity with operationalisations that might, or might not, align with colloquial interpretation(s) of the term. In this context, our study is the first of its kind: it presents a rich, detailed analysis of public views on severity and contributes to a more nuanced understanding of the term by investigating subjective accounts on the *meaning* of severity. Our findings suggest that participants' views on the meaning of severity are diverse, at times contradictory, and may or may not overlap with any of the operationalisations of severity encountered in the health economics literature.

Our findings present health economists with a conundrum: is it possible to find a unifying operationalisation based on QALYs that represents the different viewpoints? For example, Factor III, focused on objective measures, and Factor IV, emphasising quality of life, align somewhat with an absolute QALY shortfall operationalisation of severity. However, they also contain elements that do not align with absolute QALY shortfall, such as the preference for the young and the role of dignity, respectively. Factor I, centred on the notion of a natural lifespan, and Factor II, viewing severity as entirely subjective, appear less amenable to QALY-based operationalisations of severity. This is not to say the task of operationalising the viewpoints within a QALY model is impossible. It does seem, however, that this task would prove difficult, and that any one operationalisation is unlikely to represent severity in a way that would be recognisable to all citizens.

The four viewpoints we uncovered are diverse and at times contradictory, with few areas of consensus. They load 'severity' with radically different characteristics, ranging from existential questions on what makes life meaningful, to objective, measurable attributes of illness. Our contribution is thus twofold: we have empirically established that the scholarly debates are not mere intellectual sophistry; these accounts of severity coexist in the colloquial uses of the term. Secondly, using Q-methodology, we have based our interpretations on evidence that can be examined and scrutinised. One of the advantages of Q-methodology when applied to complex qualitative questions is that data and analysis can be made explicit, transparent, and reproducible.

The only basis for consensus between the factors is the relevance of three facets of severity: death, age, and dignity. That is, these attributes matter in all the factors, although they matter in different ways. For example, participants loading on different factors disagree on whether death is severe, but each factor demonstrates strong opinions on death in relation to severity. As for age, people in factors II and III share the view that the severity of a condition varies by age, whilst those in Factor IV reject a relation between age and severity. Those in Factor I occupy a middle position, where age is relevant in determining severity in the young (more severe) and the old (less severe), but only in these extremities of age. The notion of dignity also appears central: in the medicalised viewpoint described in Factor III dignity is not central to severity, while those in the other three factors considered loss of dignity to be very severe.

When elaborating on what severity means, both explicitly during interviews and implicitly through Q-sorts, participants conveyed multifaceted accounts – jointly covering almost all related concepts we conjectured would emerge, including death, age, pain, equality, dignity, desert, quality of life, functioning, and hope. It is not the aim of this study to explore each of those terms, and we submit that *these* terms can be construed as ambiguous, under-theorised concepts. Yet these concepts are used by our participants to distil their subjective accounts of severity, and hence 'severity' invokes an abundance of *thick concepts* (Väyrynen, 2021). As with other thick concepts, severity is described by evaluating it, and evaluated by being described (van der Weele, 2021).

Because interpretations of severity lean on so many different concepts, there are many ways in which our findings could be placed in the literature. We could compare the factors to Western vs. Eastern conceptualisations of health (Sayed, 2003; Tsuei, 1978), where factors I and II are perhaps consonant with Western conceptualisations and factors III and IV closer to Eastern. We could assess them against the social and medical model of disease (Barbour, 1997; Engel, 1992), where Factor III certainly belongs in the medical model while factors I, II and IV arguably contain elements of both. One framework that provides a good background for understanding the factors is Twaddle's analytic triad 'disease', 'illness', and 'sickness'. These represent, respectively, 'medical', 'personal', and 'social' accounts of illness (Hofmann, 2002). According to Twaddle's analysis, 'disease' signals a biomedical view on illness and resonates with the focus on triage and objective evaluations in Factor III. Illness "*is a subjectively interpreted undesirable state of health. It consists of subjective feeling states (e.g. pain, weakness), perceptions of the adequacy of their bodily functioning, and/or feelings of competence*" (Twaddle, 1994, p.10), which aligns with Factor II. 'Sickness' is defined as what afflicts a social identity, and on one account the relationship between the ability to function in society given one's health problems. The focus on objective functioning and illness' impact on quality of life in Factor IV can be construed as existing in the intersection between the biomedical (disease) and the social (sickness), and between disease and illness as these terms are employed by Twaddle and elaborated on by Hofmann. Factor I falls less organically into the triad, but considering this Factor's emphasis on the natural life, it arguably aligns with the narrative of 'sickness'.

While the theoretical relevance of these factors is interesting, the distinctiveness of the factors and the heterogeneity between them highlight a more important issue: there is no consensus on what severity means, neither in academia, in policy, or in public conceptions of severity. This points to our most critical finding: when we as a public talk about severity, we are not all talking about the same thing.

4.1. Strengths and limitations

Q-methodology enables rich descriptions of subjective viewpoints and is well-suited for our study. We went to lengths to ensure variation in our sample by conducting online and physical group interviews, and recruiting participants in cities and rural areas. However, it is possible that there are views that are not identifiable in our data. Because the Q-sort sessions were conducted in Oslo and Bergen, citizens from these urban areas are over-represented, and viewpoints of inhabitants of rural areas could be missing. Despite our best attempts, there is also an overrepresentation of women in our sample. Finally, without exception our respondents had some personal experience as patient, caregiver, or both. On the other hand, most people do. Interestingly, the topics on the list of attributes of severity covered all topics discussed by the participants, apart from proximity (represented by statement #52). This suggests that the listed topics, based on the literature, were fairly exhaustive.

Our Q-set was the result of a careful and deliberative process. Nonetheless, the selection and wording of statements could have resulted in a different Q-set depending on decisions made by the research team. Although we sought to extract a Q-set that represents the 'conversational possibilities' (Baker et al., 2014), we may have missed some aspects. However, we asked all participants if there were viewpoints they felt were missing and, overall, participants were satisfied with the topics covered. Though the author team is multinational with varied academic backgrounds, we were wary of potential biases affecting out results. We strived to identify our biases (Guest et al., 2012) and had a reflexive approach to the research process (Flick, 2013). We spent time during all stages of the study reflecting on perspectives we could be missing, and made substantial efforts to include participants with non-majority backgrounds. During the processes of coding statements and interpreting findings, we worked independently before comparing results. We also attempted to reduce social desirability bias during interviews by emphasising that there were no right or wrong answers. While it is never possible to eliminate all sources of interpretive bias, these precautions are likely to have helped us avoid several interpretive pitfalls.

This study posed the question 'what does severity mean'. The results might be different, however, if we asked the public 'which views on severity should be applied in priority setting'. Though this fell outside the scope of this study, it is an important question that should be explored in further work. Finally, future research should explore how the four views we have elicited and described are distributed in a representative population survey.

Author contributions

MB conceived of the study, and RB, DGTW, and MB planned the study design. All authors contributed to the analysis with oversight from MB and RB. MSS wrote the manuscript with input from BJ, MB, DGTW, and RB. All authors discussed the results and contributed to the final manuscript.

Funding

Declaration of competing interest

None of the project collaborators have any conflicts of interest, nor any financial interests in the project.

Data availability

Data will be made available on request.

Acknowledgements

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2023.116046.

References

Abelson, J., Lomas, J., Eyles, J., Birch, S., Veenstra, G., 1995. Does the community want devolved authority? Results of deliberative polling in Ontario. CMAJ (Can. Med. Assoc. J.): Canad. Med. Assoc. Journal de l'Association Medicale Canadienne 153 (4), 403–412.

Baker, R., Wildman, J., Mason, H., Donaldson, C., 2014. Q-ing for health—a new approach to eliciting the public's views on health care resource allocation. Health Econ. 23 (3), 283–297. https://doi.org/10.1002/hec.2914.

Baker, Rachel, McHugh, Neil, Mason, Helen, 2017. Constructing statement sets for use in Q methodology studies. In: Coast, J. (Ed.), Qualitative Methods for Health Economics. Rowman & Littlefield.

Banasick, S., 2019. KADE: a desktop application for Q methodology. J. Open Source Softw. 4 (36), 1360. https://doi.org/10.21105/joss.01360.

Barbour, A., 1997. Caring for Patients: A Critique of the Medical Model. Stanford University Press.

Barbu, C.M., 2014. Zoom: A Spatial Data Visualization Tool (2.0.6).

Barra, M., Broqvist, M., Gustavsson, E., Henriksson, M., Juth, N., Sandman, L., Solberg, C. T., 2019. Severity as a priority setting criterion: setting a challenging research agenda. Health Care Anal. 1–20. https://doi.org/10.1007/s10728-019-00371-z.

Brown, S.R., 1993. A Primer on Q Methodology, vol. 26.

Canadian Agency for Drugs and Technologies in Health, 2017. Guidelines for the economic evaluation of health Technologies: Canada (4th edition). https://www.cadth.ca/sites/default/files/pdf/guidelines_for_the_economic_evaluation_of_health_technologies_canada_4th_ed.pdf.

Cuppen, E., Breukers, S., Hisschemöller, M., Bergsma, E., 2010. Q methodology to select participants for a stakeholder dialogue on energy options from biomass in The Netherlands. Ecol. Econ. 69 (3), 579–591. https://doi.org/10.1016/j.ecolecon.2009.09.005.

Damar, E.A., Sali, P., 2022. Q Methodology: A Concise Overview [Chapter]. Methodological Innovations In Research And Academic Writing; IGI Global. https://doi.org/10.4018/978-1-7998-8283-1.ch001.

Daniels, N., 1985. Just Health Care. Cambridge University Press.

Diederich, A., Swait, J., Wirsik, N., 2012. Citizen participation in patient prioritization policy decisions: an empirical and experimental study on patients' characteristics. PLoS One 7 (5), e36824. https://doi.org/10.1371/journal.pone.0036824.

Dolan, P., 1998. The measurement of individual utility and social welfare. J. Health Econ. 17 (1), 39–52. https://doi.org/10.1016/S0167-6296(97)00022-2.

Dolan, P., Cookson, R., 2000. A qualitative study of the extent to which health gain matters when choosing between groups of patients. Health Pol. 51 (1), 19–30. https://doi.org/10.1016/s0168-8510(99)00079-2.

Dolan, P., Shaw, R., 2003. A note on the relative importance that people attach to different factors when setting priorities in health care. Health Expect. 6 (1), 53–59. https://doi.org/10.1046/j.1369-6513.2003.00210.x.

Drummond, M., Brixner, D., Gold, M., Kind, P., McGuire, A., Nord, E., 2009. Toward a consensus on the QALY. Value Health 12, S31–S35. https://doi.org/10.1111/j.1524-4733.2009.00522.x.

Drummond, M.F., Sculpher, M.J., Claxton, K., Stoddart, G.L., Torrance, G.W., 2015. Methods for the Economic Evaluation of Health Care Programmes. Oxford University Press.

Engel, G.L., 1992. The need for a new medical model: a challenge for biomedicine. Fam. Syst. Med. 10, 317–331. https://doi.org/10.1037/h0089260.

Flick, U., 2013. The SAGE Handbook Of Qualitative Data Analysis. SAGE.

Green, C., 2009. Investigating public preferences on 'severity of health' as a relevant condition for setting healthcare priorities. Soc. Sci. Med. 68 (12), 2247–2255. https://doi.org/10.1016/j.socscimed.2009.03.020.

Gu, Y., Lancsar, E., Ghijben, P., Butler, J.R., Donaldson, C., 2015. Attributes and weights in health care priority setting: a systematic review of what counts and to what extent. Soc. Sci. Med. 146, 41–52. https://doi.org/10.1016/j.socscimed.2015.10.005.

Guest, G., M MacQueen, K., E Namey, E., 2012. Applied thematic analysis. SAGE publications, inc. https://doi.org/10.4135/9781483384436.

Gyrd-Hansen, D., 2004. Investigating the social value of health changes. J. Health Econ. 23 (6), 1101–1116. https://doi.org/10.1016/j.jhealeco.2004.02.002.

Hausman, D., 2019. The significance of 'severity'. J. Med. Ethics 45 (8), 545–551. https://doi.org/10.1136/medethics-2018-105058.

Hess, R.D., Hink, D.L., 1959. A comparison of forced vs. Free Q-sort procedure. J. Educ. Res. 53 (3), 83–90.

Hirose, I., Bognar, G., 2014. The Ethics of Health Care Rationing: an Introduction. Routledge.

Hofmann, B., 2002. On the triad disease, illness and sickness. J. Med. Philos.: A For. Bioethics Phil. Med. 27 (6), 651–673. https://doi.org/10.1076/jmep.27.6.651.13793.

Lakdawalla, D.N., Phelps, C.E., 2020. Health technology assessment with risk aversion in health. J. Health Econ. 72 (102346) https://doi.org/10.1016/j.jhealeco.2020.102346.

Linley, W.G., Hughes, D.A., 2013. Societal views on nice, cancer Drugs fund and value-based pricing criteria for prioritising medicines: a cross-sectional survey of 4118 adults in great britain. Health Econ. 22 (8), 948–964. https://doi.org/10.1002/hec.2872.

Magnussen, J., Aaserud, M., Granaas, T., Magelssen, M., Syse, A., Celius, E.G., Klovning, A., Syversen, I.D., 2015. På ramme alvor—alvorlighet og prioritering (p. 71) [Rapport fra arbeidsgruppe nedsatt av HOD]. Department of Health.

Malterud, K., 2019. Qualitative Meta synthesis: A Research Method for Medicine and Health Sciences, first ed. Routledge.

McHugh, N., Baker, R., Biosca, O., Ibrahim, F., Donaldson, C., 2019. Who knows best? A Q methodology study to explore perspectives of professional stakeholders and community participants on health in low-income communities. BMC Health Serv. Res. 19 (1), 35. https://doi.org/10.1186/s12913-019-3884-9.

McKeown, B., Thomas, D., 2013. Q methodology. SAGE Publications, Inc. https://doi.org/10.4135/9781483384412.

Millum, J., 2023. Should health research funding be proportional to the burden of disease? Polit. Philos. Econ. 22 (1), 76–99. https://doi.org/10.1177/1470594X221138729.

Mullen, P.M., 1999. Public involvement in health care priority setting: an overview of methods for eliciting values. Health Expect. 2 (4), 222–234. https://doi.org/10.1046/j.1369-6513.1999.00062.x.

National Institute for Health and Care Excellence, 2022. NICE Health Technology Evaluations: the Manual, p. 181.

NICE Citizens Council., 2008. Quality adjusted life years (QALYs) and the severity of illness. National Institute For Health And Care Excellence (NICE). http://www.ncbi.nlm.nih.gov/books/NBK401693/.

Nord, E., 1999. Cost-Value Analysis in Health Care: Making Sense Out of QALYS. Cambridge University Press.

Nord, E., Johansen, R., 2014. Concerns for severity in priority setting in health care: a review of trade-off data in preference studies and implications for societal willingness to pay for a QALY. Health Pol. 116 (2), 281–288. https://doi.org/10.1016/j.healthpol.2014.02.009.

Norheim, O.F., 2010. Priority to the young or to those with least lifetime health? Am. J. Bioeth. 10 (4), 60–61. https://doi.org/10.1080/15265161003697305.

Norheim, O.F., Allgott, B., Aschim, B., Førde, R., Gjul, G.K., Gundersen, T., Kakad, M., Kjellevold, A., Kvinsland, S., Melberg, H.O., Moen, A., Mæland, Ø., Olsen, J.A., Sjøli, S., 2014. Åpent og rettferdig—Prioriteringer i helsetjenesten (NOU 2014:12; p. 219). Helse- og Omsorgsdepartementet. https://www.regjeringen.no/no/dokumenter/NOU-2014-12/id2076730/.

Norheim, O.F., Emanuel, E.J., Millum, J., 2019. Global Health Priority-Setting: beyond Cost-Effectiveness. Oxford University Press. https://doi.org/10.1093/oso/9780190912765.001.0001.

Oddsson, K., 2003. Assessing attitude towards prioritizing in healthcare in Iceland. Health Pol. 66 (2), 135–146. https://doi.org/10.1016/s0168-8510(02)00211-7.

Olsen, J.A., 2013. Hva menes med «sykdommens alvorlighetsgrad»? Tidsskrift for Den norske legeforening. https://doi.org/10.4045/tidsskr.12.0659.

Rawls, J., 1999. A Theory Of Justice (Revised). Harvard University Press.

Reckers-Droog, V.T., van Exel, N.J.A., Brouwer, W.B.F., 2018. Looking back and moving forward: on the application of proportional shortfall in healthcare priority setting in The Netherlands. Health Pol. 122 (6), 621–629. https://doi.org/10.1016/j.healthpol.2018.04.001.

Riksdagsförvaltningen, 2018. Prioriteringar inom hälso- och sjukvården Kommittédirektiv 1992:8—Riksdagen. https://www.riksdagen.se/sv/dokument-lagar/dokument/kommittedirektiv/prioriteringar-inom-halso-och-sjukvarden_GGB18.

Rutgers, M.R., 2015. As good as it gets? On the meaning of public value in the study of policy and management. Am. Rev. Publ. Adm. 45 (1), 29–45. https://doi.org/10.1177/0275074014525833.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., Jinks, C., 2018. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual. Quantity 52 (4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8.

Sayed, M.A., 2003. Psychotherapy of arab patients in the west: uniqueness, empathy, and "otherness". Am. J. Psychother. 57 (4), 445–459. https://doi.org/10.1176/appi.psychotherapy.2003.57.4.445.

Schurer, M., Matthijsse, S.M., Vossen, C.Y., van Keep, M., Horscroft, J., Chapman, A.-M., Akehurst, R.L., 2022. Varying willingness to pay based on severity of illness: impact on health technology assessment outcomes of inpatient and outpatient drug therapies in The Netherlands. Value Health 25 (1), 91–103. https://doi.org/10.1016/j.jval.2021.08.003.

Shah, K.K., 2009. Severity of illness and priority setting in healthcare: a review of the literature. Health Pol. 93 (2/3), 77–84.

Skedgel, C., Henderson, N., Towse, A., Mott, D., Green, C., 2022. Considering severity in health technology assessment: can we do better? Value Health 25 (8), 1399–1403. https://doi.org/10.1016/j.jval.2022.02.004.

Solberg, C.T., Barra, M., Sandman, L., Hoffmann, B., 2023. Severity as a moral qualifier of malady. BMC Med. Eth. 24 (1) https://doi.org/10.1186/s12910-023-00903-2 article 1.

Stein, R.K., Perrin, E., Pless, I.B., Gortmaker, S., Perrin, J., Walker, D., Weitzman, M., In, R.C.O.C.I., 1987. Severity of illness: concepts and measurements. Lancet 330 (8574), 1506–1509.

Stephenson, W., 1935. Technique of factor analysis. Nature 136 (3434), 3434. https://doi.org/10.1038/136297b0.

Tenbensel, T., 2010. Virtual Special Issue Introduction: public Participation in health policy in high income countries - a review of why, who, what, which and where? https://doi.org/10.1016/j.socscimed.2010.08.005.

Tsuei, J.J., 1978. Eastern and western approaches to medicine. West. J. Med. 128 (6), 551–557.

Twaddle, A., 1994. Disease, illness and sickness revisited. In: Twaddle, A., Nordenfelt, L. (Eds.), Disease, Illness and Sickness: Three Central Concepts in the Theory of Health, pp. 1–18.

Ubel, P.A., 1999. How stable are people's preferences for giving priority to severely ill patients? Soc. Sci. Med. 49 (7), 895–903. https://doi.org/10.1016/S0277-9536(99)00174-4.

van der Weele, S., 2021. Thick concepts in social research: what, why, and how? Int. J. Qual. Methods 20 (16094069211066164). https://doi.org/10.1177/16094069211066165.

van Exel, J., Baker, R., Mason, H., Donaldson, C., Brouwer, W., 2015. Public views on principles for health care priority setting: findings of a European cross-country study using Q methodology. Soc. Sci. Med. 126, 128–137. https://doi.org/10.1016/j.socscimed.2014.12.023.

van Exel, N., de Graaf, G., 2005. Q Methodology—A Sneak Preview, p. 30.

Väyrynen, P., 2021. Thick ethical concepts. In: Zalta, E.N. (Ed.), The Stanford Encyclopedia of Philosophy (Spring 2021). Metaphysics Research Lab. Stanford University. https://plato.stanford.edu/archives/spr2021/entrieshick-ethical-concepts/.

Watts, S., Stenner, P., 2022. Doing Q Methodological Research. SAGE Publications Ltd. https://uk-sagepub-com.ezproxy.uio.no/en-gb/eur/book/doing-q-methodological-research.

Weinstein, M.C., Torrance, G., McGuire, A., 2009. QALYs: the basics. Value Health 12, S5–S9. https://doi.org/10.1111/j.1524-4733.2009.00515.x.

Wittenberg, E., Prosser, L.A., 2013. Disutility of illness for caregivers and families: a systematic review of the literature. Pharmacoeconomics 31 (6), 489–500. https://doi.org/10.1007/s40273-013-0040-y.