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Research Paper

Compassion for individual and collective futures: An ethnographic study of prioritization dilemmas in the Danish welfare state

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In 2019, the Danish health authorities rejected a medicine targeting a small group of patients with a rare eye disease due to 'unreasonably high pricing'. Following sustained public pressure and continuing negotiations, the medicine was eventually approved as standard treatment. But the prioritization dilemma and public debate brought into sharp relief how seemingly contradictory collective and individual futures intersect in the Danish welfare state, and how affect shapes the articulations of these futures. In public health scholarship, the role of affect in prioritization dilemmas remains underexplored. This paper takes up this gap. Drawing on ethnographic fieldwork among patients, relatives, the pharmaceutical industry and state-bureaucrats, we show that decision-making is shaped by compassion directed both towards the individual and the collectivity. Compassion is not only mobilized through narratives of individual suffering and exceptionalism. Rather, prioritization stakeholders also frame the welfare state as an object of care, evoking compassion for the moral and economic sustainability of a future welfare state collectivity.

Introduction

In the last scene of a Danish documentary about patients suffering from an inherited eye disease, a father sits with his 16-year-old daughter in front of a laptop. Walls are white, the light beaming in through the big windows is grey, giving a glimpse of Danish spring. They look anxious. The father keeps refreshing the browser. He is impatiently waiting. The situation shows the climax of the documentary film, which is also the climax of a battle that he has fought for many exhausting months. He is fighting for medicine for his daughter, who is slowly turning blind. Children who are born with her disease keep staring at the light because their eyes have trouble producing the proteins vital for night vision. As the disease progresses, their vision deteriorates until they become completely blind at around 30-40 years of age. The genetically inherited eye disease is called Leber's congenital amaurosis with bi-allelic mutations in the RPE65 gene. The name sounds complicated and rare. So is the disease. Only about thirty people in the

Danish population of six million people have the disease. So, when Luxturna, a one-time treatment to halt the progression of the disease, was announced, people like the father and daughter in the documentary were excited. But when the treatment was rejected as standard treatment in the Danish tax-financed healthcare system, their excitement turned to anger. In 2019, the Danish Medicines Council (DMC), which is the de facto decision maker for what medicines to provide to the Danish hospital sector, found the price of the medicine 'unreasonably high' compared to its 'significantly uncertain' effect. After the father and daughter have gone through months of media involvement, such as interviews on talk-shows, writing opinion pieces, and even participating in the documentary in which this video clip is shown, rumor has it that the DMC, who had continued its price negotiations with the pharmaceutical company, would re-evaluate their decision. It is April 2020. Suddenly, something happens when the father clicks the refresh button. Text appears. He starts crying. He hugs his daughter. They grab their phones and call everyone in their family. They laugh. The one-time treatment has been accepted.

With this scene from the climax of the documentary, we open our study of how compassion shapes a political space in the context of the Luxturna treatment, which today is one of the most expensive medicines in the Danish healthcare system with the list price of approximately US$450,000 per eye (Medicin.dk 2025). Although the controversy was settled when the treatment was accepted in 2020, on the day when the father above refreshed his computer screen, the prioritization dilemma brought to the fore how different enactments of the future exist in a continuum between care for the individual and care for the welfare state collectivity, and how compassion influences these enactments. While public health perspectives on prioritization have been dominated by health economics (Hauge et al. 2022, Cromwell et al. 2015), there is little research on the role of affect and compassion. We show that not only stories of individual suffering come to shape decision making. In our ethnographic setting, the conception of the welfare state likewise evokes compassion for the moral and economic sustainability of a particular future collectivity, and in this way opens up political space.

Denmark is a welfare state built on principles of equal access and it offers expanded health coverage to ensure universal access for its citizens. In this way, the relation between state and individual is manifest by its high degree of mutual exchange, which facilitates a collectivity where citizens are both taxpayers and recipients of welfare (Svendsen 2022). Tax-based free universal healthcare in Denmark can be thought of as a 'system of lifelong generalized reciprocity', where citizens not only receive free healthcare but also 'reciprocate the free education they have received in their youth by paying high-income taxes during adulthood' (Rytter 2019, p. 686). In this set-up, citizens envision a future with the state in the sense that they expect the state to sustain their life trajectories and they themselves expect to contribute to the maintenance of future welfare through taxes. From its very beginning, the welfare state was built on reforms that institutionalize *substitution*—for example, in the middle of the 20th century, a law introduced in-home care by state-employed caregivers to substitute for an absent or sick housewife (Svendsen 2022). Here, the state literally stepped into the family and the house to care for citizens in need. However, since the 1980s, new public management reforms have restricted access to welfare support, making questions of prioritization a central battle in Danish politics. This battle is particularly prevalent in questions of *who* is deemed worthy of access to the benefits of the welfare state, discussions often targeting people occupying precarious positions, such as immigrants and individuals outside the labor market (Svendsen 2022).

To meet the challenges of prioritizing expensive treatments, Danish authorities established the DMC in 2016. The council works to determine what treatments to offer patients to ensure equal access for all by guaranteeing a 'balance between price and effect'. The allocation practice facilitated by organizations such as the DMC is largely built around values of egalitarianism and equality, which citizens have adopted as defining characteristics of Denmark (Jöhncke 2007, p. 37). Nevertheless, the collectivist state institutions also emphasize the importance of developing independent persons (Pedersen 2011). Hence, a tenet already present in Denmark is the ambiguous relation between a system of generalized reciprocity between state and citizen on one hand, and the ideal of autonomy and individual responsibility on the other. This ambiguous relation is also visible in the seven principles for prioritization that the

DMC has to follow (Sundheds- og Ældreministeriet 2016). According to these principles, the DMC should both optimize use-value for the majority *and* take the individual's needs into consideration (Wadmann 2017). The public debate that ensued with the initial rejection of Luxturna invites a closer scrutiny of this ambiguity between individual and collectivity: how does compassion for the collectivity play out in prioritization dilemmas for uncertain medicine in Denmark? And what particular futures for the individual and for the welfare state are imagined in questions of prioritization?

We start from the proposition that the social practice of imagining and enacting futures can be understood as what Oomen and colleagues (2021) term 'techniques of futuring'. This concept refers to both physical images of the future and non-tangible imaginative interventions that shape 'the possibility space for action, thus enacting relationships between past, present and future', and here, affect plays a crucial role in enacting these relationships (Oomen et al. 2021, p. 257). In this paper, we scrutinize the role of compassion as a particular type of affect in futuring techniques. In the documentary, the patient and her family's desired future seemed to be in reach if the welfare state accepted to pay for the medicine. The responses of the father and his daughter reveal how compassion in particular anticipatory situations concerns the state's recognition of suffering citizens. Thus, in the following, we investigate how techniques of futuring hold affective dimensions and come to be directed towards obtaining political recognition of one's biological constitution or health needs.

In analyzing the role of compassion in efforts to gain political recognition, we take inspiration from anthropologists who build on Hannah Arendt's (1963) work on the tensions that arise when emotion and affect form the basis of how citizens make claims on the state. The underlying question in this tension is: how to align care for the individual with care for the collectivity when faced with affect? In her work on paperless immigrants' struggle to obtain political recognition in France, Miriam Ticktin (2011) argues that a politics of care based on humanitarianism is evoked by compassion for the suffering body. Humanitarianism is about the 'exception rather than the rule', as it engages people in relationships of empathy to demonstrate their common humanity, promoting 'generosity rather than entitlement' (Ticktin 2011, p. 127). That is, rather than obtaining political recognition by making claims on the state based on for example technical and scientific knowledge about one's physical injuries (Petryna 2004), genetic make-up (Heath et al. 2007), or other biological characteristics (Rose & Novas 2005). Ticktin shows how immigrants make claims based on *sentiment* (Ticktin 2011, p. 13). In her study of voluntarism in Italy, Andrea Muehlebach (2012) takes Ticktin's perspectives further by showing that compassion is not just a feeling evoked for those situated at the margins of society, such as refugees, immigrants and recipients of humanitarian aid. Rather, compassion links intrinsically to exclusion and is becoming an integral part of what she terms 'ethical citizenship' (Muehlebach 2011, p. 64, Muehlebach 2012). Contributing to this literature, we explore how Danish patients, the pharmaceutical industry, and state bureaucrats envision the relationship between individual and collectivity in the future welfare state. Our study shows that these enactments are complex: rather than being either for or against treatment if the price is considered 'too high', contrasting enactments of the future exist simultaneously and may tack back and forth between all actors.

First, we show how debates over the prioritization of rare disease treatment in Denmark involve particular techniques of futuring in which affect and compassion become linked to political recognition for individuals. We call this technique of futuring *compassion for the individual*. Second, we show how actors in the welfare state express an abstract compassion-at-a-distance, in which the welfare state is perceived as an object to feel and care for. While Arendt (1963) argues that compassion has no capacity for generalization, we show that in the context of the Danish welfare state, compassion can be evoked for the welfare state as a personified object. We call this technique of futuring *compassion for the collectivity*. With this notion we demonstrate how compassion, in a time where the 'public is flooded with private emotion' (Muehlebach 2011, p. 74, see also Bauman 2000), may also present itself in a collective feeling expressing concern for an abstract imagined community in the present and future.

Empirically, we build our arguments on multi-sited fieldwork conducted by the first author as part of a larger study on prioritization issues of expensive medicines in the Danish welfare state. This study

draws on data collected in 2022 at the Danish hospital that carries out treatment with Luxturna, as well as on document analysis from public and social media sources, primarily official documents from the DMC and discussions on Facebook that erupted in the wake of the release of the 2020 documentary about Luxturna. Using an abductive approach (Tavory & Timmermans 2014), in which theoretical development occurs in parallel with gathering new data to nuance and deepen the analysis, the first author interviewed six patients that had been treated with Luxturna and their families,[1] four clinicians that carried out treatments with Luxturna, representatives from the Danish pharmaceutical industry, a representative from the Danish procurement organization for hospital medicines who negotiated access to Luxturna in Denmark, and a member of the professional committee under the DMC. The second author brings to the study a longstanding experience with studying citizen-state relationships in Danish healthcare. The study was approved by the Institutional Review Board of The Danish Center for Social Science Research.

Political Recognition and Compassion for the Individual

The documentary described in the ethnographic opening gained a life of its own. Not only was it broadcast on Danish television, the clip was also presented at a formal workshop hosted by the Danish Association of the Pharmaceutical Industry (Lif) in Copenhagen, in which the first author participated. Here, a spokesperson from the pharmaceutical company licensing access to Luxturna and a spokesperson from the Danish procurement organization that secures supplies of medicines to public hospitals held a joint presentation on Luxturna's innovative pricing agreement. Since most healthcare expenses are covered by taxes in Denmark, the latter acted as a representative of the Danish public – or the taxpayer's money. She introduced the documentary clip to the audience by saying: 'And now, what's important to remember: we actually do it for the patient'. As the clip ended, the representative of the pharmaceutical company likewise stated: 'I get teary-eyed when watching!', later elaborating: 'I get a bit emotional every time I see the impact it has on the patients'. In other words, both the representative of the pharmaceutical company and the representative of the Danish taxpayers' purse expressed sympathy for the families' situations.

Before we began our research on prioritization dilemmas for expensive medicine in Denmark, we had initially expected the pharmaceutical industry and the Danish welfare state to care for opposite interests. We thought that the pharmaceutical industry would care for the individual, entering an uneasy alliance with patients in what has been described as pharmaceutical 'consumer activism' or as constituting a 'pharmaceutical nexus' (Heath et al. 2007, p. 164, Petryna & Kleinman 2006, Biehl & Petryna 2011). We imagined that the pharmaceutical industry and the patients would want to make the treatment available no matter the cost, allying against the payer, in this case the Danish welfare state, who needs to care for the collectivity by making prioritization decisions for the majority faced with individual suffering stories of the few. But the presentation was held jointly by representatives of both private and public interests. Pricing agreements was the workshop's topic, but since Luxturna's exact price is confidential due to commercial secrets, Luxturna's economic value was not discussed. Rather, Luxturna's value was presented to us through the affective responses of the father and daughter getting treatment access.

Many others shared this kind of compassion. In the wake of the rejection by the DMC in 2019, two 16-year-old female patients, belonging to middle-class families, voiced their critique in many public media outlets. Politicians took up the matter in the Danish parliament as a critique of the current government. In the documentary, one of the girls said: 'That they choose to reject me because of a question of money – that makes me really sad'. In another interview, the second girl said: 'Apparently, my life is not worth the money' (Øjenforeningen 2020). Facebook sympathies swarmed for the two

[1] Names of patients and relatives are pseudonyms and some have changed gender, but names of professionals are not, since anonymization is impossible in such a small community. A draft manuscript was sent to informants for approval of quotes.

teenagers, lambasting the Danish state for not wanting to prioritize 'their lives', posing solutions such as 'of course the two girls should get the treatment, no matter the price' (DR1 et al. 2020). Expressing sympathy to the teenage girls made a 'Danish public' stand up for a particular representation of regular Danish citizens against a Danish state that was seen as apathetic, bureaucratic, and heart-less.

According to Sara Ahmed (2004), affect does not reside in objects. Rather, emotions 'stick' to things and people, creating the effect of a collectivity that binds communities together. From this perspective, affective responses inform people's sense of community and collectivity by 'align[ing] individuals with communities' (Ahmed 2004, p. 118). In the Danish case, DMC's rejection of the treatment evoked strong affective responses that informed a particular sense of community. In this emotional dynamic, the rejection became almost synonymous with letting the teenagers' lives become unbearable, consequently making the prospect of a good life with blindness unthinkable. Responding to this sentiment in one of the Facebook threads, another person offered an alternative perspective: 'As a blind person, I actually get really sad to read many of the comments in this thread. We are not automatically forced on early retirement [because we are blind], and a lot of us really want to contribute to society and we also do so' (DR1 et al. 2020). This person's statement illustrates how in the public debate, the imagined Danish community was created around a specific, ableist idea about who deserves care from the state, excluding other, less visible forms of a good life.

The person stressing that disabled citizens are able and willing to 'contribute to society' points to the moral dimension of the reciprocal, lifelong relationship that Danish citizens envision with the state. The moral dimension of contributing to society is the result of a slippage between ideas of entitlement and deservingness – whereas the former points to legal rights and assessments, the latter entails differentiating between deserving ('good') people and undeserving ('bad') people (Carrier 2022, p. 414). For example, in interviews with patients who received the Luxturna treatment, some of them expressed that its central value was that it enabled future productivity. Mia, who had received Luxturna reflected: 'By being able to see, you are able to work and pay taxes to pay back your surgery – [but] if you become blind, you will become an even greater burden for yourself […] and society'. Mia places herself in an imagined future with the state, highlighting both how citizens sustain the future of the welfare state and how the state is envisioned to sustain citizens' futures. In this perspective, contributing to society produces more 'deserving' citizens entitled to welfare services. The importance of paying one's taxes differentiates 'good' from 'bad' citizens, thus expressing a moral hierarchy based on 'productivist deservingness' (Streinzer & Terpe 2023, p. 122).

When Luxturna was not accepted for standard treatment, frustrated patients saw DMC's rejection as a breach in their reciprocal contract with the welfare state, where productivity is exchanged for treatment access. One patient, for example, said:

> [The Danish state] is not as good and sugary [*sukkersødt*] as one thinks. They make it sound like here in Denmark, everyone can get all treatments, we will help each other, and [we have] higher taxes [than elsewhere], because everyone gets all treatments if you get sick. But I've found out that it's not really like that!

This patient experienced being let down by the state, because of how 'higher taxes' in this case did *not* imply treatment access for its citizens. In other words, to this patient, the Danish state did not meet its obligation to reciprocate as implied by the productivist deservingness logic.

The struggle for access overshadowed another important factor in the (de)prioritization of Luxturna. To actors involved in the negotiation of the medicine, its *effect* was the main issue. At a workshop meeting with some of the representatives of the DMC in 2024, they summarized their most central concern in the dictum of ensuring 'balance between price and effect' as the importance of establishing certainty regarding a treatment's *effect*. This, according to some members, is getting increasingly more difficult, as treatments for small patient populations are entering the global market, targeting rare diseases and hence containing more uncertain evidence of a treatment's effect, since trial

populations are small. In the case of Luxturna, the DMC found the price too high compared to its effect, which was deemed 'low quality' because evidence could not be gathered from big populations due to the extremely small patient population (Danish Medical Council 2019). At the time of the decision-making by the DMC, the low data quality contained uncertain results: in the phase III clinical trial of the gene therapy, 52% met the US authority's threshold for minimally meaningful improvement[2], 5% experienced permanent vision loss due to the administration of the therapy and, at the time of rejection, no data existed that showed long-term improvement persistence (Darrow 2019). Toke, who is the chairman of the ophthalmology committee under the DMC and responsible for finding evidence regarding effect for eye treatments, reflected:

> If [Luxturna] had been a cheap treatment with a significant effect, you would think it was peculiar [to not accept the treatment]. And if you had an extremely expensive treatment with a doubtful effect, you would think that it was not peculiar. Here, I would say that we were in between.

What comes to the fore is that the affective response provoked by the struggle 'sticks' (cf. Ahmed 2004) to a willingness by the Danish state to pay, rather than to whether and how the treatment actually *works*. Both the patients' and the public's affective response, which we may see as enactments of compassion for the individuals' future, were directed more at state institutions' reluctance to fund the therapy than at assessments of its effectiveness. Yet, when Luxturna was finally accepted in 2020, not all patients who received the medicine experienced an effect of the treatment. At the workshop when the representatives from the private company and the Danish state showed the video clip that portrayed the patients' relief when Luxturna was accepted, they also did not linger on Luxturna's effect but focused on the experience of getting access as a testimony to Luxturna's value. Here, the state's willingness to pay elicited an emotional response by patients and sympathizers – access mattered more than effect. Why?

Aligning with Arendt (1963), Ticktin writes: 'By its very definition, compassion is unable to generalize,' (Ticktin 2011, p. 127). It is only in their capacity as individual case stories that the immigrants receive compassion and obtain political recognition. Ticktin's work demonstrates the real consequences of compassion evoked by exceptional stories of suffering individuals. In Denmark, when the two teenage girls went to the media, their individual suffering became pertinent as well. Although the rare eye disease is serious, it is also non-lethal. However, in the documentary, one of the girls subtly expresses a desire to die if she does not receive the treatment. In contrast, the larger context of prioritization decisions remains unseen: the consequences of who and what would be deprioritized if resources were put into Luxturna are not visible.

The individual stories of suffering enacted a particular future where political recognition is dependent on evoking *compassion for the individual*. Exceptionalism informs a 'politics of compassion' because exceptionalism 'abolishes the space between people in which political matters are located, shunning the processes of persuasion, negotiation, and compromise, which are the methods of law and politics' (Ticktin 2006, p. 44). This insight is particularly striking in the case of drugs for rare diseases, where exceptional stories about individual suffering are difficult to avoid as legitimate evidence because all other evidence is sparse. In light of evidence shortage, political efforts have aimed at making drugs targeting rare diseases enter regular administrative procedures. An example of this is the US Orphan Drug Act of 1983, which aims to ensure financial incentives to attract industry interest in rare disease drug development (Orphan Drug Act 1983). Luxturna was assigned the label 'orphan drug' due to its extremely small patient population.[3] Because of the small patient population, evidence of the treatment's effect needed to be supported by individual stories about the treatment's experienced effect (Johansen et al. 2024). Even the wording 'orphan drug', orphan meaning 'a child deprived by death of one or usually

[2] It was, however, discussed whether the trial design had a 'ceiling effect' that affected whether the patients could reach the threshold for minimally meaningful improvement (Russell et al. 2017).

[3] An equivalent wording does not exist in Danish, but the English term is often used.

both parents' or 'deprived of some protection or advantage' (Merriam-Webster 2024), expresses affect in suggesting that these are 'bereaved' drugs. Hence, framing something as an orphan drug may be seen as performing a particular 'affective strategy' (Ticktin 2017, p. 585).

As a technique of futuring, compassion for the individual mobilizes the emotionality of the suffering individual to stress her need to be politically recognized in the future. Ahmed states that 'emotionality involves movement or associations' (2004, p. 120). The emotionality of 'orphan drug' moves backwards in time by highlighting the 'motherless' past of potential treatments previously bereaved from funding, and sideways in time by sticking associations, figures, and objects together. In this light, the affective statement that lies in the wording of 'orphan' drugs spills into the patient population, who in a sense are also 'orphaned' because they are not automatically granted access to exceptional medicine. In addition, in our case, the emotionality of orphan drugs also moves *forwards* in time, restricting, opening up, or circumscribing that future. Affect is enacted around a group of patients, who experience a sense of being lost and without options. If the state granted access to the medicine, it would, in Ticktin's words, confer political recognition on these patients as legitimate citizens of the Danish state, while also, in Ahmed's words, take on the role of the caregiver for 'orphaned' patients. The two teenagers' public media appearance showed their experience of neglect as citizens who had expected care from the state. The breach of social contract concerned the state's unwillingness to substitute (Svendsen 2022) for the role of 'parent' for its citizens by helping patients out of their orphanage. Hence, from this perspective, the question was not whether the treatment was effective, but whether they would be recognized as legitimately suffering citizens deserving a livable future through access to a costly treatment in the here and now.

Visibility and Compassion for the Collectivity

Although affective responses were central in the accounts surrounding Luxturna, the opposite was also prevalent in our ethnographic encounters. The first author visited one of the families, where their daughter had received the Luxturna treatment. Her vision had improved dramatically. Sitting in their home, the family reflected on the life-changing effects that the treatment had for the family. Now able to navigate in darker surroundings, the daughter had recently been on a skiing trip with her school – something that would not have been possible before the treatment. They had stopped turning on the extra bright lights that were installed throughout the house. She had played table tennis for the first time in her life, now that she was able to *see* the ball. Reaching the end of the interview, the family discussed the implications of getting access to expensive treatments in general. 'What could be a legitimate reason for not offering treatment?' the first author asked. The mother, Lise, said probingly: 'Sometimes I think you save a lot of very small children. Way too early born [who hold great costs to society]…'. Her husband, Per, responded with a laugh: 'That's one hell of a tough one, Lise! Now – we have two big children, but you wouldn't have answered the same thing 18 years ago, that's for sure!'. Reflecting further, Per elaborated:

> It also comes down to what relations one has to these children – [if you know someone] who […] has a disability or who has cancer. It's a lot about feelings. And here, the Danish Medicines Council needs to be "ice cold", you know. They shall not have feelings. They *shall* not have, you know […] We would choose Luxturna any time for our daughter, no matter the price – maybe there were ten others who could get another surgery, but […] you are a parent, you know. That's how it is.

Highlighting the need for the DMC to be 'ice cold' and without feelings, Per emphasized the obligation of the state institution to make decisions that were *not* tainted by emotions and personal relations. He also described the situation of the parent doing what it takes to get the treatment—even if

it has negative consequences for other citizens in the collectivity. From his perspective, the positions of both the 'cold' state and the 'warm' parent are legitimate and coexist: the collectivity is seen as having space and moral support for both enactments. Yet, people representing state institutions should be *without relations* in order to care for the general public. The 'cold' state and the 'warm' parent belong to different domains and should not merge.

When asked a similar question, the representative of the Danish procurement organization, who participated in the workshop hosted by Lif, likewise highlighted the potential problems of affect guiding prioritization decisions: '[prioritization decisions] should preferably not become too emotional, you know. It should preferably be [done] without feelings.' It is not only Per who can position himself as the 'cold state' – the state representative does so as well. Both voiced concern that emotional responses would risk eschewing otherwise rational decisions made on behalf of society. In supporting the 'ice cold' state acting 'without feelings', they point to the importance of maintaining '*non*-stickiness' when assessing needs. That is, ensuring that sticky social relations do not impede efforts to care for the general public.

Ahmed's 'stickiness' metaphor is also useful in considering how a member of the DMC reflected on DMC's role. Discussing the best way to make prioritization decisions on behalf of the Danish population to sustain the future, the ophthalmology expert Toke emphasized the importance of not giving affective stories of individuals too much weight. He liked the way the DMC was set up, because they were detached from politicians, who have difficulties making decisions when faced with stories of individuals' suffering: 'With the DMC, the politicians can say: the professionals have spoken. [The politicians] push the monkey to something detached from themselves. There is an arm's length principle, and it becomes more objective.' Here, distance and depersonalization preserve non-stickiness. Because the DMC consists of many expert members, he elaborated, they are able to say that: 'a unified DMC decides […] In that way, the guilt [of making decisions that affect patients] is depersonalized. It becomes a collective decision, and in this way, you cannot attack single decision-makers' – attack them for being 'ice cold', to paraphrase Per.

Does this mean that depersonalized assessments, distance, and bureaucracy cannot produce compassion and stir emotion? In a polemic paper, David Graeber (2012) categorizes bureaucracy as a 'dead zone of the imagination' which by its qualities as 'boring' and 'dull' becomes left out of anthropological investigation since 'we tend to identify what is interesting with what is important' (Graeber 2012, p. 111). The DMC bases their assessments on documents describing the uncertain evidence of Luxturna's effect but, as we saw in the last section, these documents did not become the center of public attention. They did not stir emotion. An economist in the DMC, Dorte, framed it in the following way:

> When we accept a new medical treatment, it is very clear who wins: namely, the patient group that gets the treatment. […] But when we reject a treatment, it is very visible who loses. It is not clear who is winning, because we do not see the patients who keep the quality in the treatment they already have. […] We get positive reactions on selection and negative reactions on rejection, even though in reality, when we reject, we implicitly protect some patients somewhere in the health care sector.

Here, Dorte emphasizes how prioritization decisions help 'protect' patients that are not as publicly visible as the Luxturna patients campaigning their cause. Dorte, who is responsible for managing access to expensive medicines, envisions a particular future society that does not necessarily entail giving access to all medicines. She aims to 'protect' patients in healthcare by excluding some medicines. Her idea of fairness highlights an abstract formulation of citizens' rights and duties that prioritizes those who she sees as most in need of care by the state. To frame prioritization decisions as acts of patient protection suggests that Dorte does feel compassion in her 'ice cold' prioritization assessments. To her, being 'ice cold' is an important part of having solidarity with the greater collectivity. By not being partial to individual cases, moral decisions made on behalf of the population to 'protect' the invisible in most need

of care become possible. Here, Dorte shows compassion for a collective future for the Danish population. She and other interlocutors enact their own and fellow citizens' future as conditioned by the Danish state, not by compassion based on individual stories of suffering. This contrasts with how compassion is evoked for suffering subjects in the US where crowdfunding campaigns gain traction in the absence of a strong state (Kenworthy 2021).

In Dorte's struggle to 'protect' 'the patients who keep the quality in the treatment they already have', she cares about unnamed, invisible patients that no-one knows. We suggest that this compassion-at-a-distance for the imagined collective can be thought of as *compassion for the collectivity*: that is, a technique of futuring where compassion looks away from individual stories of suffering and instead involves affect for abstract principles governing shared resources for a collective future. In this context, compassion can be seen as emerging from an abstract solidarity to protect the collectivity of the welfare state. However, this collectivity entails specific borders. As Svendsen (2022) argues, the very existence of the imagined collectivity of the Danish welfare state is constituted by the matters that flows through it, such as tax income converted into welfare services through 'welfare state metabolism'. This metabolism requires permeable borders, where some kinds of matter become valuable contributions while others become 'life-draining material that threatens the state's metabolic processes' (Svendsen 2022, p. 149). Because of Luxturna's high price and uncertain effect, difficulty arose in deciding whether to let it permeate into Danish society as valuable material or leave it as too expensive and draining of the state's purse. But the value of human beings and their belonging to the welfare state were also put into question in this prioritization dilemma. When the mother Lise reflected whether 'way too early born' humans were legitimate enough members of the Danish society to be spent tax-money on, it shows that borders between those who belong and those who do not can be negotiated and renegotiated for those who inhabit the existing collectivity. This was also apparent when Luxturna was initially rejected in Denmark. At this point, one of the teenage girls from the documentary moved to the UK to get Luxturna in a country that had approved Luxturna as standard treatment, an action that can be seen as both a response to and protest against the rejection she experienced by the welfare state (Øjenforeningen 2021). Moreover, as we showed in the previous section, the debate surrounding Luxturna entailed ableist prejudice against blind people and ideas of productivist deservingness to legitimize who to spend money on. Similar to how Muehlebach (2011) links compassion to mechanisms of exclusion, we saw that compassion for collectivity is not only the caring for an abstract compassion-at-a-distance but also the caring for a particular imagined collectivity that contains negotiable borders of in- and exclusion.

Dorte's concern for the collectivity may seem unsurprising, as her role is to help securing a fair distribution of resources for the public. But as we saw, this compassion for the collectivity was also taken up by Per, the parent of the daughter, who received Luxturna. Even the representative from the private company licensing Luxturna, who shared her affective response of the video clip at the workshop presentation, stated in an interview that the company acknowledged that 'a form of prioritization *is* necessary'. Likewise, in an interview, Søren, who had recently received Luxturna, voiced a similar concern for the welfare state collectivity. A few months after his injection, he shared the extremely positive results that Luxturna had had on his life. It felt to him as if sunglasses had been lifted off his face – suddenly, things had more color. Discussing prioritization issues in general, the first author asked him what a legitimate reason could be for not providing access to medicines. He responded that a 'very small' patient population could also be a legitimate reason for not wanting to give treatment access. He elaborated:

> If we imagined I was told that I couldn't get [the treatment] because the state wouldn't support it [financially]. Then I would think it was extremely annoying [*røvtræls*] and unfair, but I would also [understand why] […] If they said: "if this group gets this, then a bigger group doesn't get something else" – I would think that was a legitimate reason [to say no to a treatment]. But if there was enough money and it wouldn't affect a much larger group, then I wouldn't think it was a legitimate reason.

Although Søren would have been annoyed with the decision, he would accept it. Similar to Dorte, he shared a compassion for the collectivity of the Danish health care sector and identified with the patients who would be victims if he was prioritized over them. However, because it is difficult to have compassion for the abstract, Søren needed to know *who* would be deprioritized.

In Denmark, the welfare state is often personified as something in need of care and protection. In recent public debates, messages such as 'the welfare state is under pressure' (Elmelund 2024) have been prominent. News media regularly bring calls for action on how to 'secure the welfare state's survival' and 'save the Danish welfare state' (Rosenkilde & Jensen 2015), or voicing concern that it is at risk of 'getting sick' (Sørensen 2024). The then-current Prime Minister (in 2019) framed the welfare state in even more compassionate terms in her opening speech to the Danish parliament after being elected. She said: 'Welfare is warmth. Well-being. Love. Opportunities. Many of us can thank the welfare state [*velfærdssamfundet*] that we have had the opportunity to climb the societal ladder' (Frederiksen 2019).

In these accounts, being able to 'thank' the welfare state, or experiencing the welfare state as 'under pressure', in need of 'survival' or at risk of getting 'sick' all point to a rhetoric where the welfare state is personified as something or someone in need of care. For Arendt, compassion cannot be 'touched off by the suffering of a whole class or a people,' (Arendt 1963, p. 85) but in the Danish context, we contend, compassion exists in a personified envisioning of the welfare state. People imagine the welfare state as 'a deep, horizontal comradeship' (Anderson 1983, p. 14). The political principles underlying the welfare state is heralded as a personified object for which a compassion for the collectivity becomes possible. When Per emphasizes state bureaucrats' obligation to be 'ice cold', when Toke highlights distance, and when Søren uses utilitarianist arguments, which speak against his own opportunity of treatment access, they all seek to protect the abstract principles of solidarity embedded in the welfare state. These abstract principles are personified into an object for which the Danish public have compassion, albeit this personified object also contains particular borders of in- and exclusion. Here, compassion for the collectivity is evoked by envisioning the future of the welfare state as a personified object that one feels and cares deeply about.

Discussion: Compassion and Politics

Our ethnography from prioritization dilemmas in the Danish welfare state shows that all actors wish to sustain a future with the welfare state. In some situations, compassion for the individual in need of treatment enables this future, in others compassion for a collectivity based on prioritization principles is seen as crucial to reach the wished for future. Thus, compassion is enacted in different ways depending on the object to which actors relate.

Public health scholarship on prioritization has been dominated by health economic approaches. Contributing to this literature, we have showed the role of compassion in how a new struggle for political recognition played out in the Danish prioritization debate over expensive medicine. In our ethnographic setting, both stories of individual suffering and the conception of the welfare state came to shape decision making by evoking compassion. First, we observed that affect called for action to demand justice for the patients who were refused access to Luxturna. We called this technique of futuring *compassion for the individual*. We argued that the categorization of Luxturna as an orphan drug eventually sticks to the patients themselves who experience abandonment from the state. The struggle for access to treatment is thus closely intertwined with the struggle for political recognition, as patients seek to assert themselves as legitimate future members of society.

Second, we brought attention to another way of anticipating the future in prioritization debates in Denmark, calling this technique of futuring *compassion for the collectivity*: the caring for an abstract idea of a welfare collectivity. While the boundaries of this collectivity may be opaque, it is governed by borders that leave some in and some out. With the compassion for the collectivity concept, we capture the perspective brought forward by some interlocutors, who express affective ties to the Danish welfare state

and its redistributive practices. The abstract principles of solidarity that underlie the Danish welfare state are synthesized into a personified object in need of care and protection, which in reflective dialogue can sometimes even exceed one's individual desire for access to treatment for oneself or one's child.

Representatives of both public and private interests showed compassion for the suffering of individual patients whose eye treatments were not accepted as standard treatment in 2019. Yet, as groups, they were also able to enact a range of futuring techniques, caring for a shared collectivity to which they both belonged. Depending on the social arena - whether a Lif-hosted workshop or interviews with social science researchers exploring the ethical dilemmas of introducing expensive treatments for small patient populations – they navigated the continuum between caring for the future collectivity and caring for the future individual.

In Arendt's terminology, compassion is subversive to the political realm, since it does not require dialogue among divergent opinions. As an affective reaction, it is described as mute (Arendt 1963). However, in our interview situations, compassion did not appear as mute. Rather, it was transformed into a form of compassion oriented towards the collectivity. Instead of subverting the space of political thought, compassion appeared to expand it. In her work, Arendt draws a line from pity to solidarity, situating compassion between the two. Similarly, we observed that compassion expressed both an affective sense of deservingness toward an individual future (closer to pity in Arendt's terminology) and a concern for the moral and economic sustainability of the welfare state (closer to solidarity in Arendt's terminology). Acknowledging these co-existing techniques of futuring allows us to see how participation in a welfare state intertwines compassion for the individual and compassion for the collectivity when taking a stance on the future.

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Conflicts of interest

The authors declare they have no conflicts of interest.

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