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Making patients political: Narrating, curating, enacting, and navigating the ‘idealised policy patient’

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ABSTRACT

In this article we develop the concept of the ‘idealised policy patient’ to contribute to a better understanding of patient-family activism and the mechanisms through which powerful and persuasive patient narratives are facilitated and mobilised. The context through which we explore the idealised policy patient is the UK debates about the legalisation of mitochondrial donation, which primarily took place between 2011 and 2015. In our example, the idealised policy patient was constructed around a culturally persuasive narrative of patient suffering, where mitochondrial donation was presented as a desirable and ethical solution. We draw on interviews with patient-families and stakeholders, and documentary analysis to identify four dimensions of the idealised policy patient – narrating, curating, enacting and navigating. Narrating describes how the idealised policy patient appears in public and policy spaces, as a culturally available narrative which conveys certain meanings and is designed to invoke an emotional and practical response. Curating identifies the multiple forms of labour and facilitation involved in supporting patient-families in activist activities which strengthen the dominant narrative and its embodiment. Enacting focuses on the work of patient-families themselves in supporting and contributing to the idealised policy patient in a way that enlivens and embodies the specifically curated narrative. Finally, navigating considers how those offering an opposing viewpoint position themselves in relation to the idealised policy patient. To conclude, we argue that medical sociology has often given insufficient scrutiny to how the capacity of patients to leverage their status for political ends is bolstered through alignment with existing powerful groups, particularly in hegemonic campaigns. We encourage future researchers to examine how the idealised policy patient is reproduced and reorientated within different policy contexts.

1. Introduction

We introduce and develop the concept of the ‘idealised policy patient’ to contribute to a better understanding of patient-family activism in policy debates. The context through which we explore the idealised policy patient is the UK debates about the legalisation of mitochondrial donation, which primarily took place between 2011 and 2015. This time period represented an extensive period of calls for evidence, reviews, and debates to explore whether the techniques were safe, ethical, and whether there was broad public support for legalisation. As a result of the debates and a final parliamentary vote, in 2015 the UK became the first country in the world to legalise mitochondrial donation as a reproductive technology which could enable women with maternally inherited mitochondrial disease to have healthy genetically related

children. The debates featured a culturally persuasive narrative of patient suffering, where mitochondrial donation was presented as a desirable and ethical solution. Patient-families played a crucial role in explaining to others, including the Members of Parliament (MPs) who would have the final say on the matter, the impact of mitochondrial disease on family life and the imagined benefits of legalising mitochondrial donation. Our work highlights that there is greater depth to the patient-family role, beyond being a witness to suffering. The concept of the idealised policy patient is a way of making visible the mechanisms through which a powerful and persuasive narrative was produced, facilitated, and orchestrated by a range of different actors working in alignment, and through a very particular policy context which invited contributions by patient-families.

In what follows, we first highlight the literature on patient activism

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and new medical movements. Our work contributes to this field by extending ideas about patient activism to include the role of persuasion, the politics of alignment between patient-families and broader institutional goals, and the context which gives meaning and purpose to patient-family activities. We then explain the concept of the idealised policy patient in greater detail. In developing the concept we draw on interviews with patient-families and stakeholders, and documentary analysis, undertaken through two different projects which aimed to explore the experience of patient-families with mitochondrial disease and to track the process of legalisation of mitochondrial donation within the UK. We identify four dimensions of the idealised policy patient – narrating, curating, enacting and navigating – and apply each to our empirical case. The section on narrating the idealised policy patient describes how the idealised policy patient in the mitochondrial debates was based on a culturally available narrative which conveyed certain meanings, and was designed to invoke an emotional and positive response towards legalising mitochondrial donation. The section on curating the idealised policy patient identifies the multiple forms of labour and facilitation involved in supporting patient-families in activities to strengthen the dominant narrative of the imagined benefits of mitochondrial donation. The section on enacting the idealised policy patient focuses on the work of patient-families themselves in supporting and contributing to the legalisation. Patient-families willingly gave their voice and energies in promoting this specifically curated narrative, even when this did not correspond with their own experience of living with mitochondrial disease. Finally, we consider the work of those who campaigned against legalisation, to analyse their ultimately unsuccessful attempts to deliver effective counter-arguments while being positioned in opposition to the idealised policy patient. We highlight how attention to the dimensions of narrating, curating, enacting, and navigating, alongside the context which shapes and gives meaning to patient-family activism, are critical for understanding contemporary patient power. In our conclusion we highlight how medical sociology has often given insufficient scrutiny to how the capacity of patients to leverage their status for political ends is bolstered through alignment with existing powerful groups, to shape certain outcomes. We encourage future researchers to examine how the idealised policy patient is reproduced and reorientated within different policy contexts.

2. Patient activism and new medical social movements

There is an extensive body of literature that attempts to understand patient experience and activism. This is vital work that seeks to address unwarranted power imbalances within the medical world that too easily marginalise or misrepresent patient voices, rendering them subordinate to other actors who wield stronger sources of expertise or influence. Patient narratives are recognised as valuable, and essential, for communicating and understanding the experience of illness. It is through studying narratives of illness and adjustment that medical sociology has been able to conceptualise the meanings of health and illness in society (Bury, 1982; Frank, 1994). As Hydén (1997 p49) noted, the value of the patient voice is that it provides an authenticity to the experience of illness, which is not accessible to the biomedical voice. But it is the context which makes such authenticity meaningful. Williams and Gajevek's (2013) work on controversial developments in genetic technologies identified how health charities contributing to the UK debates about animal-human hybrid embryos at the turn of the 21st century linked willing patients with reporters to tell their story and highlight their support. Such stories work because they are socially-embedded accounts of named individuals, who are able and willing to talk about their experience for a clearly defined purpose. Thus patients can provide a 'human face', rooted in emotion, providing a vital accompaniment to the rational accounts of other actors such as medical professionals and scientists in order to persuade a particular audience (Boyce, 2007 p85). This work, of framing, persuading and harnessing hope, is a frequent feature in debates about new or controversial

reproductive technologies (see for example, Plows, 2011; Martin and Turkmenoglu, 2021).

In focusing on the context through which patient-family accounts and efforts are directed and given meaning, our work aligns with Buchbinder and Timmermans' analysis of 'affective economies'. Drawing on (Ahmed, 2004), who developed the concept to link the individual with the collective, Buchbinder and Timmermans (2014 p104) define affective economies as "systems of exchange in which people enact and elicit emotional responses for social and political ends, such that affect comes to serve as its own currency and yield its own profits and costs". Affective economies have been used as an analytical tool to explore the role of activists, particularly at the intersection of the market place with health technologies, such as bloodbanking (Metcalf, 2022) and human milk exchange (Lee, 2019). In the context of health activist campaigning for genetic screening in the US, Buchbinder and Timmermans highlight how social institutions can facilitate socially meaningful and productive forms of emotion in public arenas. They highlight key dimensions of the affective economy to show the orchestration of emotion for political purposes. First, activists draw on their emotional experiences to elicit an urgent, compassionate response, where stories about children in particular are most powerful. Second, the narratives of activists construct policy makers as those with the power to find a solution to their suffering, and third, that activists distinguish their own expertise from that of scientific and medical experts.

The work of patients does not just involve persuading others through mobilising emotion. Patient-families and allies have played a fundamental role in developing scientific knowledge and medical advances. Those who documented early activism work by patients and allies identified how this necessarily involved patients fighting to make their voices heard. This was the case for example with early AIDS activism, which has become an exemplar for how patients and communities organised themselves to challenge prevailing authority about the nature of the newly emerging disease, and to force authorities to recognise and prioritise patient care (Epstein, 1996). The result for medical sociology has been profound, particularly in shifting sociological understandings and expectations about the nature of expertise. Identifying 'lay' people as experts was considered a critical first stage in encouraging wider participation in policy discussions and decision making about genetics (Kerr et al., 1998). The history of patient collectives highlights the considerable power of groups and individuals in securing change, for example, ensuring access to assisted reproductive technologies (Thompson, 2005) and highlighting the challenges of working with others to advance genetic knowledge (Navon, 2019).

While Epstein explained the significance of claiming a 'seat at the table', later well documented examples highlighted greater possibilities for patient groups in directing their own research agenda, including hosting their own events for dialogue, making funding decisions, and co-authoring academic papers and research grants (Gibbon and Novas, 2008; Rabeharisoa, 2006). Such activities are particularly prominent in relation to rare genetic diseases, where patient-families seek to harness advances in scientific knowledge and medical treatment made possible through new developments in genetics (Terry et al., 2007). By forging new kinds of working collectives, including patients, scientists, scientific institutions, industry and funders, patient-families are able to "elaborate novel norms relating to the conduct of medical research" (Novas, 2006 p289). These are examples of 'embodied health movements' (Brown et al., 2004) which draw on patient bodies and experiences as a resource, collaborate with scientists and health professionals, and most importantly for our emphasis in this article, challenge existing scientific and medical knowledge or practice.

While this important activist work continues, there are traces of a different kind of patienthood emerging in current literature, which recognises patient agency while moving away from the politics of activism. Petersen et al. (2019 p478) for example, has characterised 'bio-digital citizenship' through attempts to raise publicity and attract funding, rather than fighting for rights and challenging prevailing

scientific knowledge. In this case patient-families are described not as activists, but more as ‘social entrepreneurs with leadership capability’ (Allsop et al., 2004 p751), or ‘entrepreneurial experts’ (Kerr et al., 2021 p250). The space in which these patient groups operate is important to note. Patient-families have been described as ‘guests’ within an ‘invited space’ of patient activism, a space where the rules and expectations of behaviour are established by other authorities (Mosse, 2019 p450). Developing the concept of invited activism in the context of genomic data-sharing activities, Galasso and Geiger (2021 p48) identified how this constituted “those voices that do not arise spontaneously among concerned actors, but that are initiated by organisations to make up for the lack of ‘spontaneous’ activism”. Although we disagree that activism should ever be described as ‘spontaneous’ considering the extensive amount of work and organisation it often requires, we acknowledge the main point. While institutions welcome patient-family engagement because their contributions are seen as valuable, such participation, and we would add, such spaces, can be shaped and therefore limited through this social contract between patients and institutions.

3. The idealised policy patient

The core conceptual contribution of this paper is our development of the ‘idealised policy patient’ to understand how patient-family experience can be mobilised to fit existing culturally available narratives through a process of curation and enactment. The ‘idealised policy patient’ describes a dominant narrative that exists in public, media, and policy spaces that frames how patients are understood. The narrative captures a morally deserving individual or group of individuals who experience undue suffering due to health issues. This undue suffering, in this narrative, warrants action, support, or concern, from others, particularly around political and policy activity. Our contention is that medical sociologists should analyse the form the idealised policy patient takes in each case study they research. In order to critically analyse the patient voice and situate its power, we encourage future researchers to ask: How are patient-family voices and experiences narrated, curated, enacted, and navigated?

We use the term ‘*narrating*’ to describe how the idealised policy patient appears in public and policy spaces, as a culturally available narrative that conveys certain meanings, invokes certain emotional and practical responses, and is deployed to mobilise support of a particular form, dependent upon the specifics of the case. The idealised policy patient here is a discursive construction that builds upon existing tropes around patienthood and collective moral commitments to patient suffering. However, as we show, the construction of this narrative, and its embodiment within a specific patient or set of patients, can require multiple forms of labour and strategic facilitation, that we term the ‘*curating*’ of the idealised policy patient. This involves alignment work to match the culturally available narrative of care towards patient suffering to the specific circumstances of each instance. This labour can be conducted by patients themselves, but, as we will show, can also involve wider networks of stakeholders who also curate the suffering narrative for a specific purpose. This leads to what we call ‘*enacting*’ the idealised policy patient, the work of patient-families themselves to perform the idealised policy patient in public and policy spaces in such a way that enlivens and embodies the specifically curated narrative. Enacting is what patients *do* in attempts to support and conform with the dominant narrative of the idealised political patient. Importantly here, as we will show in our case study, there can be a misalignment between the culturally available narrative of the idealised policy patient and the lived experiences of those patients entrusted to enact it in public. Finally, we explore how those campaigning against legalisation were required to *navigate* the idealised policy patient, which they did with care and attention to the needs of patients-families.

The idealised policy patient can be understood as a generic narrative form that is instantiated differently in specific contexts. These varied contexts bring with them different forms of narration, curation,

enactment and navigation, and through these different forms, we can read the broader politics of each specific case. Key elements of the generic form are suffering, individuals who are morally deserving, and a form of assumed social contract of care between the suffering and morally deserving individuals and society to do something to alleviate suffering. In our case, this is made explicit through the linking of suffering and tragic narratives with the hope of a specific technological solution. Here the idealised policy patient invokes an imagined role for an audience. That is, publics, policy makers and patient-families were invited to demonstrate solidarity by expressing their support for legalising mitochondrial donation. The success of this invocation and alignment between societal duty by an audience of policy makers and publics, and the enacted narratives of suffering, can be core to the success of policy and political campaigns focused on patients.

4. Methods

This paper draws on data collected for two projects focusing on the experience of patients with mitochondrial disease and tracking the UK policy debates about the legalisation of mitochondrial donation (Dimond and Stephens, 2018a; Herbrand, 2017). This section provides a brief overview of the two projects. Further details about each project and their methods can be found in (Herbrand and Dimond, 2018). The two projects involved ninety-three interviews in total, supplemented with sustained documentary analysis. Project One (CH) involved interviews with forty-two people including twenty-eight female patients, recruited through a national patient cohort database and a national support group. Half of these were interviewed with their partner, or a female relative. Project Two (RD, NS) involved interviews with fifty-one people, thirty-one of whom were patients recruited through a national patient cohort database or their family members, and twenty of whom were professionals, medics and campaigners. In relation to patient-family interviews, the inclusion criteria for both projects was women at risk of transmitting mitochondrial disorders to their children, and their relatives. Interviews with patient-families took place in 2015, in participants’ homes, lasted between 45 min and 2 h, and were audio recorded and transcribed. There were two main limitations for the patient-family interview data collection, both of which relate to conducting qualitative research with patients with rare disease. First, researchers experienced time and resource restrictions in conducting face to face interviews spread across the UK. Second, both projects relied upon a specialist clinic or national support group as a gatekeeper for recruitment. This meant that people with mitochondrial disease but unconnected to these networks were not represented in our datasets.

Both projects involved interviewing stakeholders. However in this article we only refer to the stakeholder interviews conducted for Project Two, where the explicit focus for the interviews was the policy process of assessing and legalising mitochondrial donation, with the aim to understand their role in political campaigning and the challenges they experienced. Stakeholders were selected through a targeted recruitment strategy based on purposive sampling that identified specific organisations and individuals with a high public profile in the debates, or were known to be particularly active. This recruitment specifically targeted campaigners both for and against legalisation, as well as clinicians and healthcare professionals working in mitochondrial medicine, and representatives of key UK institutions including the HFEA and the Nuffield Council on Bioethics. Interviews took place in 2015, mostly conducted face-to-face in the person’s office, with some by telephone, lasted between one and 3 h, and were audio recorded and transcribed. This article also draws on an additional data set collected through both projects, which consisted of documents collected in ‘real time’ (Jaspal and Nerlich, 2017), while mitochondrial donation was undergoing a period of scientific, ethical and public assessment. This data set includes publications produced by prominent UK institutions (such as the Department of Health, the HFEA and Nuffield Council on Bioethics), Hansard transcripts of parliamentary debates, and UK media coverage. This data set

was collected between 2011 (when the first scientific reviews were conducted) and 2015 (when the final political debates were held and mitochondrial donation was legalised).

Data collected has been analysed previously. For the purposes of this article, data was reanalysed using Clark and Braun's (2021) phases of reflexive thematic analysis, with the specific purpose to explore how patients were represented within the public sphere, how they described their activities and how this was supported within the policy debates. To gain familiarity with the data each transcript or document was read several times, with key sections highlighted and commentary added. All authors then met to generate a list of initial codes, with similar examples across the data brought together in one document, and ordered according to broad themes. These themes were developed and refined, with analysis continuing through writing and through the selection and inclusion of relevant extracts. Ethical approval was gained through London NRES committee and De Montfort University (Project One) and the North Scotland NRES Committee and Cardiff University (Project Two).

5. The legalisation of mitochondrial donation in the UK

In 2015 the UK became the first country in the world to legalise mitochondrial donation as a reproductive technology which could enable women with maternally inherited mitochondrial disease to have healthy genetically related children. Mitochondria provide energy for the cell, are inherited through the female line, and when faulty can cause a wide range of mild to extremely severe problems including muscle fatigue, deafness, cardiac failure, or infant death. As there is no cure, and treatment options are limited, the development of reproductive options which can prevent future generations from inheriting the disease has been welcomed by many. However, mitochondrial donation is controversial, mainly because any child born, and their children following a maternal line, would inherit genetic material from three people—nuclear DNA from the intended mother and father, and mitochondrial DNA from an egg donor.

As reproductive technologies involving embryos and genetic intervention are highly regulated in the UK, a change in law was required to enable mitochondrial donation to be offered to those at risk. The UK takes a liberal yet scrutinising approach to new reproductive technologies, which shapes how they are assessed, legalised and licenced. Legalisation in the UK followed an extensive period of calls for evidence, reviews, and public and political debates to explore whether the techniques were safe, ethical, and whether there would be public support for changing the law. Ethical questions were identified and reviewed by the Nuffield Council on Bioethics in 2012. The UK regulatory body for research and use of human tissue and embryos, the Human Fertilisation and Embryology Authority (HFEA), organised several iterations of safety and efficacy reviews, and also conducted a public consultation to assess public understanding and attitudes towards changing the law. Following their own public consultation, the Department of Health concluded that the techniques were at an appropriate stage of development and assessment to be put before parliament.

During the final parliamentary debates in 2014, members of the House of Commons and House of Lords voted overwhelmingly in favour of legalisation. The reports of the key UK institutions involved in assessment, and those speaking in favour of the techniques during the political debates, all pointed towards the appropriateness of legalising mitochondrial donation, anchoring the imagined benefits of legalisation to a specific and clearly defined patient population. That is, mitochondrial donation was widely represented and supported as an ethical and desirable way for women with mitochondrial disease to have a genetically related, healthy child (Haimes and Taylor, 2017; Herbrand, 2022; Dimond and Stephens, 2018b; Herbrand, 2023; Dimond and Stephens, 2023).

6. Narrating the idealised policy patient

The key characteristics of the narrative of the idealised policy patient - of suffering, of morally deserving care, and the invocation of an assumed social contract of care between these individuals and society in alleviating that suffering - was evident across the UK mitochondrial donation debate. One of the most prominent examples was the case of Sharon Bernardi. In early media coverage, she described her experience of mitochondrial disease:

"I wasn't diagnosed until after my fifth baby had died, no one knew why it was happening, they had no answers. I would get pregnant again and just pray this time would be different. My mum sat me down and told me it had happened to her. The previous generation lost 11 children in total. [The development of mitochondrial donation] will be too late for me but it would be an amazing thing if scientists and doctors can prevent this in the future." (Sunderland Echo, 2012)

The experience of Sharon Bernardi was the first key reference point for those explaining the importance of legalising mitochondrial donation. Her story was often told by the most prominent scientist in the mitochondrial debates, Professor Sir Doug Turnbull. In one public meeting, he explained that he tells Bernardi's story "to remind you this is something important", and that "I think we can see why I personally feel we need to move ahead". Bernardi's story was also referred to in the Wellcome Trust's evidence submitted to HFEA public consultation 2012, and in subsequent news coverage.

Another prominent family were Vicky Holliday and Keith Newell, whose daughter Jessica was seriously ill with Leigh syndrome. Jessica's story featured extensively in media coverage, including at the time of the final parliamentary debates (Driscoll, 2015; McVeigh and Sample, 2014). Her story was shared by MP Alex Cunningham during an early Parliamentary debate, in which he described it as a "factual story demonstrating the devastation that mitochondrial DNA diseases can cause" that "demands action from Ministers and this House of Commons." (House of Commons debate, 1 September 2014). These stories were not told simply to explain the nature of mitochondrial disease and the impact on patients-families. They were told with a broader purpose, to make an explicit link between human suffering and the call to legalise mitochondrial donation. Through their telling, those named in the stories became representative of a wider population, of unnamed women at risk of having a child with mitochondrial disease:

The techniques provided for by these regulations offer the only hope for some women who carry the disease to have healthy, genetically related children who will not suffer from the devastating and often fatal consequences of serious mitochondrial disease. (Earl Howe, House of Lords Debate, 24 February 2015)

Whether anchored to a specific person's account or a broader claim, patient-family experiences were presented through a suffering and tragic narrative, noted as having emotional resonance and rooted in fact, that positioned mitochondrial donation as the most reasonable response. This singular patient-family narrative of suffering, and the representation of mitochondrial donation as a ubiquitous solution, remained dominant throughout the UK debates.

7. Curating the idealised policy patient

The narrative of suffering discussed above became ever-present in discussions of the legalisation of mitochondrial donation. However, the narrative was developed and delivered through a process of curating the idealised policy patient. This involves the collective and strategic planning and optimisation of a particular vision of what patient-family experience and engagement should look like within the context of a specific political or policy campaign. In the mitochondrial donation case this work was led, and initially conceived, by a cluster of influential

organisations, including mainstream UK institutions such as the Wellcome Trust, Muscular Dystrophy UK, and the Centre for Mitochondrial Research at Newcastle University. This centre at Newcastle is the mitochondrial disease clinic where Prof Sir Doug Turnbull was based, and the only centre in the UK with the capacity to deliver these techniques at the time. Their existing patient networks proved essential in framing the broader debate, but they did not act alone. The Wellcome Trust, with its well-established policy and media teams, and other groups such as Muscular Dystrophy UK, provided experience of mounting successful policy campaigns. Finally, patient-led charity the Lily Foundation also became increasingly active. Importantly here, we can see that the activism and engagement of mitochondrial disease patient-families was well aligned with, and indeed actively orchestrated by, key institutions of mainstream UK biomedical science. These efforts supported a policy that the Government and Department of Health wanted to succeed, and with many mainstream UK institutions onside. This was not counter-hegemonic activism. It was patient-family activism driven by and in support of the existing central power structures of UK biomedicine.

This cluster of medics, patient-families, and policy professionals orchestrated a media campaign centred on a set of willing patient-families who were trained and prepared for public performance. The Chief Executive of Muscular Dystrophy UK explained in interview some of the considerations that go into this, recognising a tension between protecting patients while supporting them on a public platform:

“We have trained, and we do train, some media spokespersons on occasions ... We will put them up and we'll support them. But the danger is we burn them out because the media will take someone like this who is very articulate and ‘telegenic’ ... And so we have a responsibility to families too. So families are very keen to help on these sorts of issues. They're driven. I mean imagine [the] parents; they're driven to get a treatment. And we are part of this and we're giving a platform and we're giving them a voice in the media but we also have a responsibility to them. So there's a balance.”

The support provided by a range of institutions included explicit media training for patient-families. This aimed to help make them feel comfortable and prepared for media exposure in order to minimise any potential risk to the patient-families who participated. However, it also looked to calibrate the patient-families' messaging, to ensure the content and delivery of their stories remained compelling within the broader argument of the for-legalisation campaign. One patient-family told us that their media trainers intimated that their tone was too positive, suggesting a desire from the media trainers for vulnerability and struggle to be emphasised.

The curation extended beyond media support. Letters were pre-written and posted by the national clinic to patient-families for them to sign and give to their MPs. As Turnbull told us, “we circulated [to our patient-families] all our information to provide to their MPs, asked them to go and see their MPs and give their views. It was quite a large effort that went on.” Another interviewee, from the Wellcome Trust policy team, highlighted the impact of this engagement, saying, “I think the majority of the MPs that spoke in that backbencher debate were people who'd had families with mitochondrial disease come and speak to them”. The power of these personal stories was noted by one participant, a key contributor to the Nuffield Council on Bioethics mitochondrial donation report, in their interview:

What was very clear to me in talking to MPs was they'd all been contacted by families about personal stories in their constituencies. So the Lily Foundation had clearly done a very crafty campaign to stop this being seen as about an abstract moral question and making it being seen as a question of concrete decisions that families were trying to make. That feels to me like a really important reframing.

These ‘backstage’ activities of key institutions, such as deciding how and when to direct patient-family activities, posting information packs

and preparing pre-written letters, and selecting individuals for media engagement and coaching, are a key element of the success of the for-legalisation campaign, and are essential to our understanding of patient-family activism, its power, and how it relates to, and reinforced, the existing power structures of UK biomedical science.

Finally, curation extended to considering who should not be included as the idealised policy patient. Mitochondrial donation was initially developed as a technique for improving fertility treatments, particularly in older women, and could also allow lesbian couples the opportunity for both to contribute biological material, and thus a biological connection, to a child (Cavaliere and Palacios-González, 2018). However, these uses were not taken forward by the Department of Health as permissible uses in the proposed legislation, and as such these stories were neither curated nor enacted, and these actors effectively excluded from shaping the idealised policy patient. The very character of proposed beneficiaries is itself politically negotiated.

8. Enacting the idealised policy patient

Once the idealised policy patient had been curated, it needed to be enacted. The UK policy process of reviewing safety, ethicality, and public acceptability produced many different avenues of engagement. Some people responded to calls for evidence in public consultations, while others responded to calls for research participants, even offering to donate their eggs for mitochondrial research. Patient-families attended and sometimes spoke at meetings and joined fundraising campaigns. They followed the debates on television, radio and in newspapers, and as we have seen, some patient-families spoke to media. As Luce (2018 p382) argues, patients were aware of the necessity, and power, in presenting as a “well-defined patient body in order to effectively lobby for healthcare resources and research attention”.

As noted above, patient-families were encouraged to engage with their local MPs. For some this meant not just sending the preprinted letter to their MP, but also meeting up with them and persuading them of the importance of supporting legalisation. In their interviews, participants described how they pushed for these meetings to happen, as one stated, “I called [the MP's office] Monday morning and I said, ‘Look, there's no point in us meeting later in the week if the vote is tomorrow, can she call me today?’”. Patient-families also told of how successful their interventions could be, with one interviewee explaining that “[My MP] said she was inclining to vote for it, but after talking to me she was determined to vote for it.” Across our interviews, patient-families reported their considerable willingness to invest their emotional and physical labour in delivering a positive vote.

However, enacting the idealised policy patient involved a set of tensions between the curated narrative and the lived experiences of patient-families themselves. One example is the patient-family noted above who received feedback from their media training team that their tone in practice interviews was too positive. These tensions are in part because mitochondrial disease captures a wide variety of causal mechanisms, symptoms, and life outcomes. While the idealised policy patient in the mitochondrial donation debates was curated around extreme child suffering, for many patient-families, this kind of suffering is simply not part of their personal experience, particularly for those living with a mild or adult-onset condition (see for example, Dimond, 2013; Featherstone et al., 2006; Herbrand, 2017). Another area of tension can be found in the focus on mitochondrial donation as a ubiquitous and essential technology for patients, as this did not match the experience of those who were at a stage of their lives where they had no need or desire for reproductive assistance. Distinctively and importantly, mitochondrial donation is also only suitable for a subset of patient-families with maternally inherited mitochondrial disease. This means that many patient-families, including some who have spoken publicly about the benefits of mitochondrial donation, could never be a future beneficiary of these particular techniques. This is because these families have a different pattern of genetic inheritance which mitochondrial donation

techniques are not designed to address. Finally, as others have noted, accounts such as Bernardi's blur boundaries between medical treatment and the right to reproductive technologies (Turkmenoglu et al., 2019; Rulli, 2016), a distinction which was not well articulated during the debates.

These tensions given, it was clear from our interviews that patient-families did not need to see themselves as future beneficiaries of the technologies to support legalisation. Whereas some patient-family participants expressed hope in their interviews that their daughters might benefit in future (Herbrand and Dimond, 2018), support for legalisation was mostly expressed in terms of the benefit for others, that is, for those who were more seriously affected and where the desire to use the technology might be more pressing or relevant. Patient-family interview participants made explicit links to legalisation, by imagining and demonstrating respect for the wishes of others. As one participant stated, "I just think if you can [stop] parents going through losing children or children having this disease, then I'm all for it", and for another participant, "I can get by—but to have a baby that was severely damaged, you know what I mean, I think if they can prevent that, then go ahead. I have no objections to that". Thus, while patient-families recognised the discrepancy between the dominant narrative of child suffering and their own more varied experience, the idealised policy patient still retained significant persuasive appeal.

9. Navigating the idealised policy patient

The power of the dominant narrative associated with mitochondrial donation, particularly around the prevention of child suffering, is rooted in its shared cultural resonance and broad human appeal which transcends political persuasions. In this final section we consider how those against legalisation were required to acknowledge patient-family accounts, and ultimately struggled against their persuasive power. Those against legalisation navigated both a powerful narrative of suffering and strong and seemingly unwavering support by the patient community, all of which pointed to the rightness of legalisation. Opposition therefore required a particular kind of labour. This involved a careful articulation of the reasons against legalisation, aligned with an explicit expression of empathy and respect for patient-families. The accounts of some of those who had campaigned against legalisation recognised the burden of navigating both the vulnerability of patients and the emotive and persuasive power of their experiences. When interviewed for one of our projects, a founding member of Campaign on Reproductive Ethics (CORE) acknowledged how this would require courage as well as compassion:

[I]t does make it quite hard for our side when we're trying to talk about [this issue] and all the public is going to see is a tragic mother who's had a very sad experience, which one obviously has huge sympathy for ... But you have to have courage to stand up and say 'no' to that, knowing that everybody is going to think what a nasty person ... You just simply have to say 'there's a reality here and I have to make it very clear this is not a cure' ... But one's got to be utterly compassionate when you're with a woman who has lost three pregnancies from mitochondrial disease, it's not an easy thing to do.

Similar concerns were raised by other campaigners against legalisation. The Director of Research at the Scottish Council on Human Bioethics explained in an interview, "the only way to have a balanced debate is to have two sets of patients, one set who is welcoming these procedures and another who is opposed". Representations of patient-family experiences, support for legalising mitochondrial donation, and the benefits of mitochondrial donation as a reproductive choice, were rarely criticised or questioned by those against legalisation. Indeed, many of those opposing drew on the rhetoric of hope to explicitly express their support for preventing patient suffering, as Parliamentarians against legalisation acknowledged the suffering of patient-families. Fiona Bruce MP, for example, in the House of Commons debate (3

February 2015) opened with "Human mitochondrial disease is a dreadful condition and, as a caring society, we must do all we can to address it" and Lord Deben in the House of Lords debate (24 February 2015), who called the debate explicitly to express concern about legalisation, stated "We have a huge responsibility to these mothers who cannot bear a well baby". Throughout the debates, the experiences of patient-families, their current, future, and potential suffering, and their support for legalisation, were all treated with compassion, sensitivity and respect. This is a recurrent theme in biomedical politics, and each of these aspects have previously been observed in media coverage of patient stories and the benefits of other new medical technologies (Petersen et al., 2005). In our case, ultimately the power of the idealised policy patient was such that those opposing legalisation were unable to garner sufficient support for their position to deliver the Parliamentary vote they desired.

10. Discussion

This article contributes to the growing body of sociological and bioethical literature exploring mitochondrial donation and its legalisation, including recognising the persuasive role of patients (Martin and Turkmenoglu, 2021) and questioning the representation of future benefit (Baylis, 2017; Haines and Taylor, 2017). Through our research tracking the mitochondrial donation debates in the UK, we identified the recurring use of a singular narrative of suffering and patient-family experience which persuasively evoked the benefits of legalising mitochondrial donation. We developed the concept of the 'idealised policy patient' to capture this narrative alongside the work performed by different actors in harnessing and directing its persuasive capacity. The idealised policy patient describes a dominant narrative of patient-family experience that exists in public, media, and policy spaces, presenting a morally deserving individual or group of individuals who experience suffering due to health issues. Context is an important consideration for understanding the productive power of patient narratives (Petersen and Wilkinson, 2015). The legal and policy process, of reviewing safety, ethicality and public acceptance provided a particular kind of engagement space in which concern for, and action warranted by patient suffering was directed towards support for the legalisation of mitochondrial donation. Overall the concept of the idealised policy patient adds a new and important dimension for understanding contemporary mechanisms which support and shape patient-family voices and engagement in political and policy arenas.

The four dimensions of the idealised policy patient – narrating, curating, enacting and navigating – provide a framework for identifying and understanding a particular type of patient activism. Narrating highlights the circulation of culturally meaningful narratives of patient suffering. It maps closely to the first dimension of Buchbinder and Timmermans (2014) 'affective economies', where activists and allies draw on their emotional experiences to elicit an urgent, compassionate response. We saw this through the telling of Sharon Bernardi's and other parental experiences, which were then amplified by others. At times the patient-family role was akin to that of an 'advocate', or as a witness, explaining the daily implications of their experiences of being affected by mitochondrial disease, and providing personal testimony as to why they considered legalisation essential. Patient-family experiences, representing a specific kind of suffering, were noted as tragic, emotive and factual, and where mitochondrial donation was presented as the most desirable and urgent solution. The second element of curating was seen in the strategic way in which those supporting the legalisation of mitochondrial donation directed and supported patient-family activities towards a particular purpose. It highlights how narration required multiple forms of facilitation, including identifying who might speak to the media as representative of the patient community, providing training, and encouraging patient-families to make contact with their MPs. As we have seen, this also required careful thought about the capacity of patient-families to undertake this work and recognition of

patient vulnerability and duty of care. The third element of enacting focuses on the work that patient-families do themselves in performing the idealised policy patient in public and policy forums. Who speaks on behalf of a community, and with what expertise is increasingly recognised as a political issue (Maguire and Britten, 2017) and a core concern for some patient communities (McCoy et al., 2020). And as DePalma et al. (2023) and Herbrand and Dimond (2018) have suggested, we need to acknowledge and better understand the complexity of hope and affect which engenders such significant investment. In our example, part of this work involves aligning with a narrative that does not necessarily represent their own experiences, and reconciling the differences in a way that does not problematise the dominant narrative of patient suffering. Our final element highlights the strength of the idealised policy patient, where we focus on the navigational work of those contesting legalisation. Here we identified how a particular kind of labour was required in articulating reasons for opposition. Respect was expressed towards patient-families, suffering was more likely to be acknowledged rather than challenged, and the difficulties of pursuing a campaign without vocal patient support were noted.

The concept of the idealised policy patient is an acknowledgement of the role of patient power in securing change, but it also helps us to question where power lies, particularly within policy contexts. In the case of mitochondrial donation, the path to legalisation was supported through a combination of strong narratives of patient-family suffering, strategies of engagement which were not necessarily directed by patient-families themselves, and a cultural propensity towards the rightness of alleviating suffering. Here we reflect on the significance of *alignment* between patient-family activities, mainstream medical institutions, and social norms. It is the nature of this alignment that contrasts the idealised policy patient with patient activists typically described as fighting against the system (see for example, Epstein, 1996; Gibbon and Novas, 2008) or the engaged and digitally empowered patients described in relation to the clinical consultation (see for example, Petrakaki et al., 2018; Timmermans, 2020). In our example of mitochondrial donation, patient-families and their accounts were already aligned to a powerful mainstream position, and therefore did not have to fight to be heard, nor need to challenge authority. Further, in our example, institutions supporting the legalisation of mitochondrial donation had powerful tools at their disposal and resources were invested to support the patient-family voice, thus explicitly removing the barriers which might normally prevent patient engagement (Slattery et al., 2020). Thus the mitochondrial donation debates were an 'invited space' for patient-families, with a kind of activism more commonly associated with Public and Patient Involvement (PPI) initiatives (Galasso and Geiger, 2021). The concept of the idealised policy patient responds to the problem of our limited language when articulating the increasingly complex role of public and patient participation in biomedical advances (Kelty and Panofsky, 2014).

Whereas our focus on the legalisation of mitochondrial donation in the UK is a specific case, we believe that the concept of the idealised policy patient will have more broader resonance. Mitochondrial donation as a new reproductive technology continues to be debated across the world (Bowman et al., 2023), with the first babies born through a Mexico/US collaboration (González-Santos and Saldaña-Tejeda, 2023; González Santos et al., 2018). We have yet to witness how the character and power of the idealised policy patient manifests in these different contexts, as national debates unfold. It is also likely that we will soon begin to witness how patient-families engage in debates about CRISPR gene editing. With such diverse uses for gene editing, it will be important to question what kind of patient representation will emerge in future as the most sympathetic, with broad public resonance and which can unite patient-families with different stories to tell, and how that voice will be facilitated. The analysis need not be limited to reproductive technologies, as a wider variety of biomedical interventions, drugs, and care pathways, or even new disease classifications or public health measures, are all suitable for inspection. We might question how or whether the

idealised policy patient is invoked in relation to technologies or processes as diverse as womb transplantation, access to high-cost treatment for patients with rare disease, assisted dying or abortion policies. In each case we can now ask 'what is the idealised policy patient'? This is not just to ask who a future beneficiary might be, but to identify and acknowledge how a particular kind of patient voice will be mobilised as a persuasive tool about the rightness or wrongness of supporting a process of change around patient care and experience.

We develop the concept of the idealised policy patient to help us recognise how actors, including at times, patient-families themselves, are users and producers of powerful narratives and movements that shape practice, and this requires an analysis of accountability and form. In focusing on mobilisation and orchestration, our work poses a significant challenge to future researchers. Social scientists have a proud history of working to bolster patient perspectives, but there are discrepancies and inconsistencies, particularly in terms of how patients are constructed as both powerless yet powerful. Here we recognise the inherent difficulties for researchers, in challenging the discourse of patient engagement, without undermining the valuable work of patient-family communities in advocating for change. Those who work to improve the experiences of vulnerable groups are often seen as "above suspicion" (Fassin, 2011 p37 cited in Buchbinder and Timmermans, 2014). Patient-families are of course too often marginalised and silenced, but their participation, engagement and activism still demand critical social science engagement, particularly in terms of which futures are rendered desirable and which are not, how patient-families and their activities are mobilised within political worlds, and what remains unseen and dismissed through the dissemination of each particular narrative. We encourage future researchers to develop the concept of idealised policy patient within different contexts, in order to gain a deeper understanding of the political power and engagement of patient-families.

Author statement

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Data availability

The data that has been used is confidential.

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