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A Narrative Approach Using Epistemic Injustice**

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Published in:
Value in Health

DOI:
10.1016/j.jval.2023.05.004

Publication date:
2023

Document version:
Final published version

Document license:
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Citation for pulished version (APA):
Karlsson, A. W., Lundsgaard, H. H., & Janssens, A. (2023). Mothers' Views on the Storage and Usage of Their Children's Biological Material Under the Danish Biobanking Model: A Narrative Approach Using Epistemic Injustice. *Value in Health*, 26(9), 1308-1313. <https://doi.org/10.1016/j.jval.2023.05.004>

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Contents lists available at sciencedirect.com
Journal homepage: www.elsevier.com/locate/jval

Themed Section: Data, Privacy, and Health

Mothers' Views on the Storage and Usage of Their Children's Biological Material Under the Danish Biobanking Model: A Narrative Approach Using Epistemic Injustice



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ABSTRACT

Objectives: To investigate the knowledge and attitudes of mothers living in Denmark on the storage and usage of their children's biological material. The Danish Neonatal Screening Biobank contains blood from the Phenylketonuria-screening test. Legal, ethical, and moral concerns have been raised in several countries of how consent is obtained best in pediatric biobank governance. Research on knowledge and attitudes of Danish parents on the usage of their children's biological material is scarce.

Methods: A coproduced study between a mother and 2 researchers. We analyzed 5 online focus group interviews using Ricoeur's hermeneutical narrative analysis.

Results: Mothers have very little knowledge on the storage and usage of their children's biological material. They consider the Phenylketonuria-screening test to be part of a birth package, which leaves very little option of choice. They accept donating the material as a token of appreciation in an act of altruism toward the wider society but are only comfortable supporting Danish research.

Conclusions: An exploration of the communal narrative build in the interviews reveal an overall feeling of duty to help benefit society, an overwhelming trust toward the health system, and epistemic unjust storage information practices.

Keywords: biobanking policy, coproduction, focus group interviews, narrative analysis, patient perspectives.

VALUE HEALTH. 2023; 26(9):1308–1313

Introduction

Denmark has a tradition of a public welfare system ensuring equal healthcare to all citizens and of keeping health registries, both becoming highly digitalized.¹ Every contact with the public healthcare system is on record and is available for health research via linkage in the Danish civic registration system which allocates a unique number to all Danish residents.

The Danish National Biobank is the largest biobank in Denmark, storing over 25 million samples of blood and other biological material. Its goal is to strengthen opportunities for Danish health research and international research collaboration.² It contains the Danish Neonatal Screening Biobank, which contains 2.5 million blood samples from the Phenylketonuria heel bloodspot screening (PKU-test). The PKU-test screens infants for 18 rare innate diseases, which can cause severe disabilities.^{2,3} Almost all parents in Denmark accept having the test done 48 to 72 hours after delivery of a child.^{4,5} Parents receive pamphlets from healthcare professionals (HCPs) after delivery^{3,5} informing them of storage in Danish Neonatal Screening Biobank, the child's future treatment, and health research. The pamphlet also informs

on parental control of the sample and of the possibility to opt-out of storage and usage.⁶ Many research areas rely on children's biological material⁷ and the collection has been called a potential science goldmine.⁸ Classic consent for each study has been noted unviable in large-scale biobanking⁹ presenting issues such as monetary gains, trust in large-scale biobanking, and right to privacy.¹⁰ Pediatric biobanking raises special concerns, as most countries acknowledge that children have a right to be heard in matters that concern them.¹¹ A potential risk of using the stored material in undesirable contexts could potentially lead to future stigmatization and danger of limiting the "child's right to an open future." (page 30, Kranendonk et al⁷). Studies have found low knowledge on biobanking in the general population, but find that the majority is willing to donate biological material contributing to the common good and help generate new medical therapies.^{12–14} Focus group studies find parents broadly support using their children's PKU-test in research. Trust and distrust in authorities and concerns for individual interests were issues of concern among participants.^{15,16}

Danish governments have expressed focus on giving citizens more autonomy over their data.^{17,18} The Danish Health Act allows

registration in the “Use of Tissue Registry” (*Vævsanvendelsesregisteret*),¹⁹ which limits the use of tissue to the individual’s own treatment. Less than 500 people are registered.²⁰ In 2016, the Danish National Genomics Centre commissioned a survey on Danes attitudes to genetic investigation during treatment and found that 84% of Danes accepted that genetic research may be conducted as part of their treatment, and 48% had prior knowledge this.²¹ The survey does not question respondents on their genetic data being used solely for research. To our knowledge, no research investigates Danish public opinion on storage and usage of the residual material from the PKU-test. Hence, this study’s aim was to obtain a better understanding of mothers’ reasoning and thoughts on potential research and data linkage of their children’s biological material, and what socio-historic factors drive these thoughts.

Methods

Patient and Public Involvement

This study has been coproduced by HHL, a mother of the target population. Together, we developed the scope of the study, interview guide, data analysis, and discussion. We followed INVOLVE’s principles for patient involvement (as cited by Dewa): “Sharing of power, including all perspectives and skills, respecting and valuing the knowledge of all those working together, reciprocity, and building and maintaining relationships.” (page 2, Dewa et al²²). A GRIPP2 report²³ of our collaboration can be found in [Appendix A in Supplemental Materials](#) found at <https://doi.org/10.1016/j.jval.2023.05.004>.

Study Design

Because literature suggests low knowledge on the subject among participants, we anticipated the topic could benefit from pooled knowledge generation in a group discussion,²⁴ qualitative focus group interviews were chosen. Focus groups also uncover contemporary social and cultural structures as master narratives gain support.²⁵ A semi structured approach was chosen to progress discussion and ensure that participants related to regulatory topic facts.²⁴ The interview guide was adjusted and tested by HHL.

During interviews, participants were allowed to explore areas of particular interest.

Participants

Inclusion criteria for participation were: Mothers living in and had given birth in Denmark to at least 1 child, aged ≤ 5 . Ability to speak Danish (see [Table 1](#) for focus group overview).

Setting and Data Collection

Recruitment via public mother’s groups (commonly facilitated by Danish municipalities) was planned. Nevertheless, because of the Covid-19 situation in Denmark in 2020 and 2021, these services had been suspended. Participants were contacted via snowball sampling on social media, in which a few mothers acquainted to the researcher and local mother’s groups on Facebook facilitated contact to other mothers. All potential participants were contacted via social media by AWK and informed of study purpose and aim. All were sent the participant information sheet in prior, the contents of which were repeated verbally at interview commencement. All participants verbally consented. Five focus group interviews were conducted online via Zoom (Zoom Video Communications, Inc, San Jose, CA) between December 2020 and January 2021.

The participants all reported to be living in the Capital region and region of Seeland. Their birth experiences are unique, as are their world views and personal history²⁶; yet, they have a similar external reference frame,²⁷ as all of them followed Danish standard hospital procedures of midwife and doctor appointments, prenatal classes, and hospital delivery. No social demographic information was collected, because the analytical focus lay on the communal narrative that was generated. Background knowledge of participants may also lead to unconscious epistemic injustice during analysis. No participants had children affected by any of the screened diseases. Two mothers had traumatic birth experiences of premature deliveries and prolonged stays in pediatric units. All were employed/on maternity leave.

Interviews were conducted and transcribed verbatim by the first author.

Table 1. Focus group overview.

Brief statistics of participating mothers and their children				
Focus group 1	Mother 1	Mother 2	Mother 3	
	Children: 2	Children: 1	Children: 2	
	Age: 5, 8	Age: 2	Age: 4, 8	
Focus group 2	Mother 8	Mother 9	Mother 10	Mother 11
	Children: 3	Children: 1	Children: 1	Children: 1
	Age: 6 months, 4, 6	Age: 1	Age: 1	Age: 1
Focus group 3	Mother 4	Mother 5		
	Children: 1	Children: 2		
	Age: 10 months	Age: 6 months, 3		
Focus group 4	Mother 6	Mother 7		
	Children: 2	Children: 1		
	Age: 4 months, 2	Age: 5 months		
Focus group 5	Mother 12	Mother 13	Mother 14	
	Children: 2	Children: 2	Children: 1	
	Age: 1, 3	Age: 2, 6	Age: 9 months	

- Age of children = 4 months to 8 years.
- Number of children = 22

Ethical Issues

In Denmark, no ethical approvals are needed for interview-study designs.²⁸ the interviewer (AWK) voiced the right to withdraw at any time before the focus group interviews and reiterated upon completion of interviews that she was available via email or phone if any concerns arose.

The interviews lasted on average 48 minutes. Several of the mothers attended to their babies during the interview and because of their verbal cues of being tired or done, a decision of not prolonging the interviews was made.

Analytical Framework

Analysis was performed using Ricoeur’s narrative analysis. Ricoeur’s interpretation focuses on why people narrate the way they do: people are embedded in a world of traditions and meanings, which forms their actions.^{29,30} Analysis is a dynamic process going back and forth between 3 steps: (1) naive reading, (2) structural analysis, and (3) critical interpretation and discussion. The first step aims to obtain a naive understanding of the text. Further levels of understanding and insight are generated through oscillations of naive exploration and comprehension of the text,^{29,30} wherein lies an inherent validation of initial pre-conceptions and presumptions. The structural analysis aims to further the understanding of the process by dissecting/cutting the narrative into units of action or events (units of meaning), which leads to patterns or themes, which are then further contextualized during critical interpretation.^{30,31} Each interview was rewritten in an initial narrative, fitting in a thematic organization. After this initial step of decontextualizing the material, the stories proved quite homogenous, and it was decided to allow a joint structural analysis of the 5 narratives as a whole as suggested by Blom and Nygren.³² This was done to elicit one master narrative from the 5 texts to be able to work with this narrative in historical and cultural context²⁹ (see Fig. 1).

In the final step of critical interpretation and discussion, the aim is to reach a deeper and richer understanding of the text. Here, the structural analysis is discussed in a dialectical manner with references to relevant studies and theories further validating the findings.³⁰ This has been done in dialog between all authors.

Results

Naive reading showed that all participants had agreed to the PKU-test and had not considered declining the test. Nobody had heard about the Use-of-Tissue Registry until being informed about it during the interviews. 12 of the 14 mothers were not aware that the material was stored or available for research. The mothers had limited knowledge on the usage of their children’s biological material and the potential data linkage that the Danish health registries allow. They saw few potential negative uses of the material but set clear boundaries for local Danish research use because they only entrusted the Danish system to secure confidentiality and ethical use of their children’s data.

Structural Analysis

The structural analysis revealed the following dominant narratives: the role of information and a total trust in the Danish health system. The main events driving these narratives are the following: the mothers’ mental state around delivery, the influence of self-organized social media groups, and a lack of self-agency in the data-sharing debate.

Dominant narrative: The role of information

The mothers birth stories are full of expectations and preparations leading up to the birth. They worry about whether the child is healthy and whether labor will go well, etc. They partake in maternity communities on social media in which birth and babies are discussed passionately. These lay groups provide input for the mothers for what they should be concerned about and what decisions they need to make before delivery. The PKU-test is not discussed in these forums; therefore, mothers either do not know about the test until the HCP hands them the information pamphlet hours after birth, or they do not have an opinion on the PKU-test:

Maybe it is a bit overlooked.... I mean the talk about what we are exposing them to right after birth – there are very strong opinions about that. I made decisions about that because others were passionate about it... But nobody was talking about the PKU-test.

I think you try to make decisions about all these things around the birth before the birth. But what came after, we kind of never really made decisions about that, nor was it a subject we discussed with the [health care] staff – other than I just put my trust in them.

The mothers entrust society represented by social media communities and HCP to provide necessary information on the birth and perinatal period. The mothers do not experience discussion of the PKU-test with HCPs, and because the HCP pays little attention to it, the mothers consider it unimportant.

In the days around birth, mothers describe themselves in an altered mental state: they lack sleep and have a new overshadowing concern for their infant. A vast amount of information and pamphlets is given, which they are not capable of reading. One mother sums it up as follows: *“With the first child – you don’t know anything. You didn’t have anyone but the doctors and nurses to put your trust in. You think that all they recommend is the best.”*

Multiparous mothers emphasize extra calm and capability compared with their first birth experience. They were no more informed or attentive on the PKU-test than primiparous mothers, but their stories were less dominated by confusion and insecurity in the days around birth. No difference between primiparas and multiparas in their stance about information was seen.

The mothers had little knowledge on the potential uses of the material. When informed during the interview, they assumed it would be used for research purposes to benefit society. Not being

Figure 1. Schematic presentation of analytical approach. Moderated from Blom and Nygren.³²

Schematic presentation of analytical approach					
Naïve reading narrative 1	Naïve understanding of narrative 1 & 2 by coproducer and researcher	Naïve understanding of all narratives as one whole with construction of initial themes	Thematic organisation	Structural analysis of all narratives combined focusing on actions, actors, and narratives.	Critical interpretation and discussion of structural analysis.
Naïve reading, narrative 2			Thematic organisation		
Naïve reading, narrative 3	Naïve understanding of narrative 3, 4 & 5 by researcher		Thematic organisation		
Naïve reading, narrative 4			Thematic organisation		
Naïve reading, narrative 5			Thematic organisation		

Narratives = transcripts from each focus group interview.

informed about this by HCP installed a small distrust, which also allowed small doubts in the system elsewhere:

Yes, I want to say that of course, I trust it. But then something in me shows... A form of doubt, right? Like, if they can store something without people actually knowing about it and all this... Then there are probably some loopholes which makes it possible for them to use it for things without informing people... There are probably some loopholes.

The new information made some women doubt their decision; yet, it was not to the extent that they changed their view on the tissue usage being in the best interest of society.

The mothers consider cloning as an example of unsafe usage but push this aside as highly unlikely: *"It's not like they are going to build a new baby."* Ethical concerns discussed included the linkage of genetic data with other data and how this might evolve in the future: *"It's vulnerable. All the things they register on you... It's a form of stigma... The more we register, the more there is out there to define you."*

All 14 mothers agreed that the data should only be used in Denmark to the benefit of the Danish public healthcare system: *"I don't have a problem, as long as it is the state controlling it."* They were unwilling to share the data internationally or with pharmaceutical companies, understanding that potential financial gains can be made.

The mothers express a passive stance on the matter: *"What can we do about it, really? I can't say no, I'm not ok with that, can I?"* Giving themselves a lack of agency and free will in the data-sharing debate, because the system has already decided. Being realistic that the system is imperfect, they believe that the data is protected as well as possible. They settle for such a system because they trust governing bodies to avoid unwanted data uses and leaks from happening.

Dominant narrative: The trust in the Danish system

The transcending driver of the collective narrative is the trust the mothers put in the Danish healthcare system. The mothers trust the system to make decisions on their behalf; therefore, they do not have to seek more information themselves. This trust aids them in making decisions on behalf of their child—if the system recommends it, there is no question of acceptance:

I must admit, I find it easier [when making decisions on behalf of your child]. Because you feel you do things in the best interest of the child, so of course you accept. You also feel slightly controlled when it's part of the whole package... It's all scheduled: then this and that happens, and how about the child's reflexes, and the PKU-test and vaccinations... Some things are recommended, and my principles should not hurt my child.

It also reveals an authoritarian trust, as one mother puts it as follows: *"Well, I just think personally... If it's recommended by someone who knows what they are talking about, then I just trust it."* The mothers' narrative incorporates scarcity of time and resources in the healthcare system and accepts losing certain information to have time with the HCP to discuss other infant issues, such as lactation techniques. The urgency of the wellbeing of the child puts everything else in the background: *"In the labor unit, there are a lot more urgent things that health care staff needs to prioritize, so I think it is ok that this information is downgraded."*

The mothers explain that current information procedures leave out any decision on storage and usage. Saying yes to the test closes any further discussions. The mothers suggest obtaining a signature would ensure people are informed and actively decide on storage and usage. They believe that they would pay more attention if they were required to sign; it would present the option of saying no. The fact that it is not presented in such a way makes the mothers suspicious that their attention is not wanted on the matter: *"If you don't ask, or you ask in a bit of a sneaky way, of*

course you get everyone to accept. I'm thinking it's a bit... ehm... dishonest might be a strong word..."

Two opposing narratives take form during the interviews: some would like to be informed of the storage and usage because it instills further trust in the system, and they want autonomy to say yes or no on the matter: *"The more I'm informed and the more I have to sign and am told: Remember - you can always cancel your subscription, the more I trust that they take care of me and my data..."*

Others unquestionably put their trust in the HCP's choice of information and do not want more information: *"Is all this information going to do me any good? Or is it just more of worry and things I need to relate to?"*

Both narratives include the importance of a visible option for those who are interested in knowing more: *"I think the information is important, if you are a person who cares about that kind of thing."*

Critical Interpretation

In this section, the context of the two dominant narratives is explored. According to philosophers Fricker^{26,33} and Freeman,³⁴ individuals undergo ethical training that involves both social and individual input. The mothers have been born into a history and culture in which there is a tradition of high trust in the healthcare system and contribution of the individual to the public good is deemed necessary. For example, the head of the Danish National Science Ethical Committee, which appraises protocols on research involving biological material, wrote the following:

One could argue that research participants, who altruistically donated, should have more influence over the further use of samples than patients, who obtained free health care from the welfare state, and thus could be expected to contribute willingly to research and the collective good.³⁵

The Danish Council of Ethics shared the following in a statement about research using health data and biological material in Denmark:

If it is expected that health data and biobank research should benefit other patients and society as a whole, one could argue that the citizen at least should have a basic duty to let their tissues and data be included in research.³⁶

The above quotes are from stakeholders in public debate on biomedical research and are examples of entries making up a collective ethical training, as well as the development of guidelines and governance in Denmark. These social inputs are shaped by the individual mother²⁶; although part of the same historical and social context, they still have personal preferences about information. The mothers may have grown up with the notion that they should be contributing to advance society and do not feel they have sufficient knowledge on the subject to contribute to a debate on data usage and potential consequences of data linkage; resolving to display a proxy trust to all HCP involved in the future events of their children's samples. Medical knowledge and training are often seen as superior to patient experiences, which results in the epistemic superiority of the HCP.³⁷⁻³⁹ This creates power imbalances, and although birthing women are not patients, the mothers in this narrative express the same feelings of vulnerability and fragility as ill persons.⁴⁰

Fricker discusses how an epistemic unjust situation can occur when people are not recognized as knowers by themselves and others, as the mothers suggest themselves to be here.³³ Epistemic attention deficits are elaborations of this and they occur when we fail *"to pay someone the attention they are due in their role as an epistemic agent."*⁴¹ Neither HCPs nor the healthcare system make sure that mothers have received and understood information on

the PKU-test. The “birth package” does not allow consideration of mothers’ experiences of an altered mental state around birth. The agent is perhaps not the individual HCP, or the limited time resources experienced by the mothers, but a case of institutional structures not designed to give mothers attention or draw attention to the storage and usage of their children’s tissue. Those who are acknowledged knowers set the agenda of what knowledge is and what can be ignored in the political and social arenas of society.⁴¹ In this regard, when the information on the PKU-test is relayed as unimportant by the HCP and not discussed in mother’s communities on social media, mothers are socialized into not paying specific attention to the birth package that is offered or to the pamphlet given.

Discussion

The results found during the naive reading align with previous studies: mothers willingly donate their children’s material to help improve treatments and support the common good.^{15,16,42,43} Mothers have difficulty separating the PKU-test from the actual birth⁴⁴ and have limited knowledge on storage, usage, and linking possibilities.^{12–14} This study adds new understanding of how the Danish healthcare system may operate within the Danish collective context. Here, the system benefits from a trust and a gratitude build up in a national narrative. Through public and stakeholder input during ethical training, a moral demand of contributing to improve the Danish medical system by putting communal benevolence before our own beliefs is generated. In the matter of using children’s biological material for research, mothers fully accept epistemic inferiority. An added finding is how mothers may struggle making their birth experience to be understood by HCP and the healthcare system, both of which are not acknowledging the vulnerability and altered mental state around birth.

Sustainable pediatric biobanking governance should aim for public transparency and parental education.^{13,45} Several studies argue that parents should not have option for blanket consent on their children’s biological material, as children should be allowed to express their opinions on the matter when they reach legal age.^{11,46} Models suggest repeat information sent to parents and children when the child reaches legal age as a way to ensure ethically sound practices.⁴⁷ The increasing focus on a person-centered health system and political strategies for including patients and citizens in healthcare matters and data usage, as mentioned in current governance strategies,^{17,18,48} seem well intended to adopt this approach. Whether this solution is viable in a Danish context should be investigated in future studies. The findings of this study suggest that one way to reach current governance goals of transparency and insight into the usage of health data is to deliver information at a time other than a few hours after birth. It would be beneficial to give the information with the means of more than a pamphlet, perhaps in an active opt-in form, in which signatures must be obtained. We believe that sustainable biobanking governance should be realized by including parents, legal guardians, and children in the development of informational material, as well as how and when to deliver the information. An existing prenatal visit with the midwife was an idea generated by the mothers during the interviews in this study.

Limitations and Scope for Further Studies

Further studies on fathers’ and children’s opinions should be made. This smaller explorative study into biobanking practices in a Danish context did not collect information about participants’ life context as can be advocated in narrative analysis.⁴⁹ We wished to

avoid making presumptions as to why some mothers narrated certain opinions. Furthermore, because socio-economic status was not a part of the analysis, we considered it an unnecessary burden to participants, as well as unethical to collect unused data. Snowball sampling can result in homogenous selection of participants,⁵⁰ and a selection bias may exist because all mothers had given birth within the hospital. Further exploration into regional or cultural differences in opinions and trust, as have been found in other countries,^{51,52} could also be viable in a Danish context.

Conclusions

Mothers have very low knowledge on the PKU-test, the storage, and potential usage of their children’s biological material. The communal narrative infers Danes a moral duty to contribute to research and the communal good. Mothers trust Danish governance to ensuring safe local usage and accept epistemic inferiority on the subject, but they identify information as key in maintaining trust in the system and point to different practices as being necessary if true information and transparency is to be obtained. Governing policies should consider changing information practices on the usage of left-over genetic material from the PKU-test. This study points to 3 areas of change:

- Informing parents on the PKU-test, storage, usage, and opt-out during prenatal visits rather than a few hours after birth.
- Obtaining written consent from parents to ensure information on usage and opt-out options.
- Sending information to parents and children when the child reaches legal age and should be included in their own health decisions.

Supplemental Material

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.jval.2023.05.004>.

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Accepted for Publication: May 4, 2023

Published Online: May 31, 2023

doi: <https://doi.org/10.1016/j.jval.2023.05.004>

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Provision of study materials or patients: Karlsson

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Conflict of Interest Disclosures: The authors reported no conflicts of interest.

Funding/Support: The authors received no financial support for this research.

Acknowledgment: The authors would like to extend our genuine thanks to the participating mothers.

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