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Published in:
BMC Medical Ethics

DOI (link to publication from Publisher):
[10.1186/s12910-018-0337-7](https://doi.org/10.1186/s12910-018-0337-7)

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Publication date:
2019

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Van Howe, R. S., Frisch, M., Adler, P. W., & Svoboda, J. S. (2019). Circumcision registry promotes precise research and fosters informed parental decisions. *BMC Medical Ethics*, 20(1), 1-7. Article 6.
<https://doi.org/10.1186/s12910-018-0337-7>

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Circumcision registry promotes precise research and fosters informed parental decisions

Robert S. Van Howe^{1*} , Morten Frisch², Peter W. Adler³ and J. Steven Svoboda⁴

Abstract

Background: In 2017 Ploug and Holm argued that anonymizing individuals in the Danish circumcision registry was insufficient to protect these individuals from what they regard as the potential harms of being in the registry (overreaching social pressure, stigmatization, medicalization of a religious practice, discrimination and promoting polarized research).

Discussion: We argue that Ploug and Holm's fears in each of the areas are misguided, not supported by the evidence, and could interfere with the gathering of accurate data. The extent of the risks and harms associated with ritual circumcision is not well known. The anonymized personal health data supplemented with the circumcision registry will enable more precise research into the medical consequences of ritual circumcision, and allow parents to make more fully informed decisions about circumcision with minimal, if any, adverse consequences.

We read with interest the recent publication by Ploug and Holm regarding the Danish circumcision registry [1]. As they note, the main purpose of the registry is to enable future research into the consequences of circumcision, and they concede that research into personal health data holds great potential for improved treatment. They argue, nonetheless, that anonymizing the males listed in the registry is insufficient to protect these individuals from the potential harms of being in the registry, and they ask whether informed consent should be obtained before inclusion in the registry. Even though they acknowledge that the potential for harm is speculative, the authors identify five sources of concern: 1) overreaching social pressure; 2) group stigmatization; 3) medicalization of a religious practice; 4) group discrimination; and 5) the potential bias in circumcision research as a polarized field of study. We argue that their fears are misguided and not supported by the evidence.

Overreaching social pressure

Ploug and Holm argue that a circumcision registry may be perceived by adults who favour circumcising boys for religious reasons as a form of social pressure that threatens their self-expression and self-development, and that the registry, “may infringe [their] self-determination and it may cause [them] harm.” The authors also argue that social pressure may denormalize the practice of male circumcision. These arguments are not convincing.

First, regarding the concern that social pressure may *denormalize*, the practice of male circumcision is already denormalized. That is, circumcision of male children has been practiced in some geographies and cultures for thousands of years, it has on a wider scale been the exception and not the norm. Second, it is improbable that anyone who has a genuine and deep religious commitment to circumcise his or her son and learns of the establishment of an anonymous circumcision registry will abandon the practice because of it [2].

Third, we all have an interest in accurate public health research and of knowing to what extent any medical procedure — in this case the removal of the foreskin of the penis — risks harming or does harm boys and the

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men they become. Whether performed in a sterile hospital setting or otherwise, non-therapeutic circumcision is an invasive surgical intervention. As such, it entails the risks of any invasive procedure, along with the specific risks associated with the removal of the foreskin, including a significant risk of meatal stenosis, [3] serious disfigurement, [4] hemorrhage, infection, [5] and on rare occasions, death [6]. Even when there are no “complications,” circumcision is itself a physical injury as it removes functional tissue with known erogenous, protective, and immunological properties; it can also cause psychological harm [7–9].

Insofar as parents choosing to circumcise their children risk significantly attenuating the health of their sons, it is important to gather accurate information regarding the harms of circumcision so that parents who make this decision on behalf of their children can do so in an informed fashion. In this sense, the gathering of health statistics increases the capacity for religious adults and/or communities to express their agency and autonomy: a fully-informed decision is more autonomous than one that is unexamined or based on wishful thinking. Whether information regarding the harms associated with the practice is seen by parents as grounds to abandon the practice is up to the parents; the registry is a vehicle for providing accurate information. What people do with this information is up to them. An incomplete registry would result in incomplete information, which can lead to uninformed decisions, and hence less autonomous decision-making.

Fourth, male genital cutting is usually performed for religious, cultural, and personal reasons, and not for medical reasons [10]. While Ploug and Holm do not take an overt position on the ethical permissibility of circumcision, the tenuous ethical position of the practice highlights the need to bring the most accurate empirical evidence possible into the debate to minimize the potential for polarization discussed below. While Ploug and Holm express concern regarding the social pressures surrounding circumcision, it must be noted that circumcision is itself an extreme form of social pressure that does not merely threaten the self-development of boys and the men they become — it irreversibly changes an intimate part of their bodies without their consent, removing a part of their genitals with which adult men rarely volunteer to part. In other words, Ploug and Holm appear to confuse the interests that society extends to the individual with the interests of the group. Pre-enlightenment thinking viewed children as a possession of their family and their community. Contemporary society considers the individual, even a child, to be of primary ethical importance [11]. Accordingly, legal scholars argue that children, including boys, are themselves entitled to protection from certain group-level

social pressures in virtue of their own right to freedom of religion, i.e., their right to choose to affiliate with any religion or no religion at an age of understanding. Such affiliation may be compromised by having previously been permanently and involuntarily marked as a member of their parents’ religion [12]. One must ask, then, whether the child in this example, who is powerless to resist a community-enforced encroachment upon his body, is at greater risk of harm from being circumcised than the community is by virtue of having health statistics recorded about its invasive rites. In order to answer this question — in addition to conceptual, moral, and legal analysis — the most accurate empirical evidence concerning the effects of the practice must also be brought to bear [13]. A circumcision registry does not interfere with that aim, but rather supports it.

Group stigmatization

The authors note that the specific religion of boys “can easily be deduced from the timing of circumcision, the name of the boy, and immigration status of the parents.” This demographic information, which is easily available, is already sufficient to ground stigmatization, if that is the worry. There is no evidence that a circumcision registry would contribute anything further. If one is aware that a Danish male is Jewish or Muslim, one can reasonably infer, to a certain extent, that he is circumcised. It is unfounded speculation to assume that the circumcision registry would add to any such stigmatization if it does exist.

Medicalization of a religious practice

In their discussion of the fear that religious circumcision will become medicalized, the authors repeatedly refer to “everyday activities.” Cutting the genitals of a minor is not an “everyday activity.” While babies are born every day, for an individual mother/baby pair, the birth of the baby is not an “everyday” event. If one is to consider circumcision to be a profoundly important religious/cultural event, one should not place it in the same category as mundane, everyday activities. It is a special event. There is no evidence that a circumcision registry would change this.

Circumcision has medical aspects to it, so some medicalization is inevitable. It involves cutting and removing tissue. As stated, it can result in complications such as bleeding, infection and, occasionally, death. Given the complications associated with the practice, one could argue on the basis of ensuring public safety that only licensed medical practitioners be allowed to perform circumcisions.

The authors express fear that the medical aspects of circumcision will replace the religious aspects as the primary focus of the event. Evidence from the United States

suggests that this is unlikely to occur. Circumcision was introduced there as a medical procedure in the Nineteenth Century, but today is performed primarily for cultural rather than medical reasons [10]. Consequently, the authors' fears of medicalization are overstated and unlikely to take place.

One of the duties that we expect of the medical establishment and of the state is to protect the most vulnerable from harm. The authors make a bare assertion that protecting a child from the harm of having his genitals cut without his permission is beyond the purview of the medical establishment or the state, Ploug and Holm do not even attempt to demonstrate why circumcision should be exempt from functions normally performed by medical and governmental authorities to protect children.

The medical aspects of circumcision are an important part of the decision-making process in religiously motivated circumcisions. The practice is not risk free. Certain sexual functions, including all those that involve manipulation of the foreskin itself, are of necessity lost; and others are placed at an increased risk of harm. In the end, the physical losses need to be assessed against the putative religious/cultural gains.

To summarize, it is inescapable that circumcision has a medical aspect to it. Nevertheless, it seems unlikely that medical concerns will replace religious/cultural enticements as the primary motivation to continue the practice.

Group discrimination

The authors are concerned that the circumcision registry singles out a minority cultural practice for monitoring. Potentially harmful practices are identified on a regular basis to determine their impact on health and fundamental well-being. The authors provide the example that sports activities are not monitored, but there are two problems with this example. First, sports are engaged in with the age-appropriate consent and involvement of the child: the nature of the activity and the type of risk to which he is exposed through his participation differ markedly from the nature and risks of circumcision. In the latter case, he is a passive participant, and has no ability to determine whether the risks are worth it to him because of the gains he expects to achieve through his involvement. Second, perhaps sports should be monitored with a registry. Football in the United States, for example, is coming under closer scrutiny to determine the level of exposure needed to result in chronic traumatic encephalopathy and it is likely that registries are on the horizon. Any discrimination from a circumcision registry would be incidental and the registry would only provide more precise information than is already available from the demographics associated with the genital cutting of minor males. Using the authors' logic, it would be discriminatory to have a registry of patients

with sickle cell anemia because the illness affects primarily people of relatively recent African heritage. If the object of interest happens to occur primarily within a demographic minority, is study of that object discriminatory? Without further premises added to the argument, the answer is no. In fact, insofar as society monitors the health of boys and men in various ways, it would discriminate against boys and men in groups practicing circumcision not to monitor the effect of circumcision on their health.

Polarized research

Male circumcision is an extremely divisive topic to the degree that it is difficult to determine whether an expert's views are based on the findings of legitimately performed research or whether the findings of research are driven by the researcher's pre-existing views. All researchers in all topics have an expectation bias. They would not have the energy to pursue an experiment or study if they did not have a specific outcome in mind. Hypothesis generation is an integral part of the scientific process. Eliminating or weakening the circumcision registry does not address this issue. It is up to the entity that controls the information in the registry to determine whether the data will be used in a scientific and ethical manner. In this instance, the data are kept by a national entity that does not have financial or other potential conflicts of interest. Moreover, to minimize the risk for unqualified or biased research, data will only be released for use by qualified researchers whose projects have been approved by the national Data Protection Board. If what the authors are arguing for were adopted, then no national registry could exist on any demographic or medical factor.

The answer to polarization is not to encourage incomplete data collection. The answer to polarization is to collect the most accurate and complete data possible. It is the very absence of high-quality data that often allows polarized researchers to veer off into their respective corners, as they "fill in the gaps" in evidence with their own preferred inferences and biases.

Anonymized data

Is using anonymized data enough protection? Contrary to what the authors claim, no one believes that using anonymized data provides complete protection. Still, the authors show very little trust in the ability of research ethics committees and data protection boards to protect the individual. They argue, without providing evidence in support, that these committees and boards may take on the "objective view" of the "equanimeous[sic] Danish citizen" rather than the "subjective view" of the young Muslim man.

The authors provide a special pleading for the case of circumcision in minors. Anonymizing data, in general, has worked well so far, and nothing the authors present indicates the need to change course. Without impeccable data, polarization will only increase. If, as the authors suggest, we need to analyze database-based research on a case-by-case basis, then there would be a roadblock to any research that uses a national database. Requiring informed consent, even meta-consent, presents enough of a barrier to prevent research from being undertaken [14]. Given the important findings extracted from national databases, such impediments would hold back important discoveries.

Conclusion

Ritual circumcision entails risks and harms, but the extent of the risks and harms is not well known. The anonymized personal health data supplemented with the circumcision registry will enable more precise research into the medical consequences of ritual circumcision, and allow parents to make more fully informed decisions about circumcision with minimal, if any, adverse sequelae. The concerns raised by Ploug and Holm are unfounded and spurious. Their recommendations are unnecessary to protect identifying information and would purposelessly interfere with data gathering that may help identify and eventually reduce the harms associated with circumcision.

Response to “Circumcision Registry Promotes Precise Research and Fosters Informed Parental Decisions”

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Response

We thank Howe et al. for the response to our paper. As prominent anti-circumcision activists and academics it is perhaps understandable that they seem to read our paper as an intervention in the debate about male circumcision, but that is a misreading, as we already state clearly in our paper. Their response ignores our stated arguments and instead argues against straw men. We will therefore commence with making it entirely clear what is argued.

We argued that anonymised registry-based research may be associated with types of harm that individuals may have an interest in avoiding, and for that reason individuals should be recognised as having a right to protect themselves against these harms through the provision or refusal of consent to participate in such research [1].

Essentially, we argued that registry-based research is similar to other kinds of research where there may be great benefits for society and individuals, but where there are also risks of harm. In all such cases the individual is recognised as having a right to weigh benefits and harms against each other and on this basis to provide or refuse consent. As we also point out, repeatedly, that right is not absolute. It can be outweighed by other considerations, but that does not diminish its status as a right.

We used the case of the Danish Circumcision Registry to illustrate the respective harms. However, our argument has nothing to do with the circumcision debate per se.

And, contrary to the authors of the response, we do not hold any particular views on the legitimacy of male circumcision in minors or adults. Their claim that “the authors provide a special pleading for the case of circumcision in minors” demonstrates an unwillingness to engage in the actual debate in our paper, namely the issue of informed consent for anonymous registry-based research.

In light of this it is perhaps not surprising how much effort is devoted to listing the harms of circumcision throughout the response. However, even if such harms are recognised they are at most reasons against circumcision. They are not reasons for coercing individuals into registry-based research any more than the prospect of a cure of prostate cancer is a reason for coercing individuals to participate in such research. Most other medical research is aimed at producing real and significant health care benefits for individuals, but such potential does not in itself negate the requirement of informed consent, and especially not in cases where the individual is at risk of suffering harm.

Hence, in order to counter our argument the authors must show both 1) that mandatory participation is necessary, and 2) that the suggested harms are not real.

We contend that van Howe et al's claims over-emphasise the importance of having accurate and precise information about circumcised boys and men, and especially over-emphasise a further claim that this implies having complete

information in the registries used for research. Thus participation in registry-based research such as the circumcision registry should be mandatory because otherwise information will be incomplete, and this will lead to biased results about the effects of circumcision. This argument is flawed for three reasons. First, it tacitly assumes that completeness cannot be achieved voluntarily. There is significant evidence to the contrary [15]. Second, there is no straightforward logical connection between completeness and accuracy. Accuracy may be achieved on the basis of incomplete data. Third, most registries are incomplete to some degree and this does not seem to have posed an obstacle to epidemiological research presently or in the past [16]. Hence, the authors fail to establish 1) above, namely that mandatory participation is necessary. But what about 2) – do the authors succeed in showing that he harms are not real?

The authors claim that social pressure cannot lead to the denormalization of circumcision because it is already denormalized. However, their conception of what it means that a social practice is denormalized is puzzling. They write:

“...the practice of male circumcision is already denormalized. That is, circumcision of male children has been practiced in some geographies and cultures for thousands of years, it has on a wider scale been the exception and not the norm.”

But that claim entails both that circumcision is not normal, but already denormalized in Saudi Arabia where more than 95% of the population are Muslims and circumcise their sons; and that social practices like strict respect for human rights are already denormalized in Denmark and the UK, because they are “on a wider scale the exception”. But that cannot be right. Male circumcision is normal in Saudi Arabia and respect for human rights normal in Denmark and the UK, whether or not it these practices are ‘normal’ world-wide. What is conceived as normal in a given society, and what can therefore be denormalized is influenced by what is seen as normal in other societies, but it is not definitionally or analytically tied to any conception of a global ‘normal’.

In terms of stigmatization and medicalization, the authors deny that a circumcision registry could add anything to stigmatization of religious minorities and the medicalisation of these practices, and they think that we should provide evidence to show that it does. However, the burden of proof in relation to the potential harms of conducting a certain type of research will always fall to the researchers. We have provided several reasons for believing that stigmatization and medicalisation is likely to follow; and there is evidence that stigmatization may have a number of negative effects including lowered self-esteem, anxiety and depression [17, 18]. The

account of medicalization the authors rely on is again quite odd, and differs markedly from the standard account in the literature. They write: “Circumcision has medical aspects to it, so some medicalization is inevitable.” However, all human activities have ‘medical aspects to them’, but they are not all medicalized. What the concept of medicalization points to is that it matters in a number of different ways whether a given practice or activity comes to be understood in medical terms and inscribed in a medical framework of meaning and value [19].

The response also has a number of problems in relation to our analysis of discrimination. First, our claim is misrepresented. They state:

“Let us define discrimination as involving acts and practices that confer harm upon a group of people by treating them differently from relevantly similar groups in society. The very existence of the circumcision registry may be claimed to be discriminatory in this sense because 1) it singles out a minority cultural practice for monitoring of and research into the associated risks among a number of practices associated with relevantly similar risks, and 2) the singling out of this practice may confer the harms of stigmatization and medicalization on group members.”

Let us first note, pace the implicit assertion in the response that incidental harm is also harm and should be taken as seriously as any other harm. Causing intentional harm may be more blameworthy than causing incidental harm, but the person who is harmed incidentally is harmed to the same extent as the person who is harmed intentionally. It is therefore irrelevant whether harm caused by discriminatory effects of a particular registry is caused incidentally or intentionally. But, perhaps more important is that the operative conception of discrimination here is *causing harm by differential treatment*. It therefore does not follow from our analysis that:

“... it would be discriminatory to have a registry of patients with sickle cell anemia because the illness affects primarily people of relatively recent African heritage.”

On our analysis, whether a sickle cell anemia registry will be discriminatory will depend on whether it causes harm, incidentally or intentionally to ‘people of relatively recent African heritage’. And the answer to that question will clearly depend on exactly in which society we envisage the establishment of such a register. Such a register may be innocuous in Denmark, but as the literature on sickle cell disease and racism in the USA shows it is

not obvious that it would be purely beneficial in that country [20, 21].

Second the response presents the point that “... perhaps sports should be monitored” as a criticism of our paper, but we explicitly raise this point ourselves:

“The inequitability point does, however, cut both ways because it can also be claimed that those participating in these other activities [sports] have a claim that their problems should be investigated.”

Second, let us turn to the argument that the use of data can be adequately regulated by data protection agencies and research ethics committees. As we have explained in our paper, the only relevant agency in Denmark is the Danish Data Protection Agency. In this context it is interesting to briefly look at the largest project using Danish registry data to study the effects of childhood male circumcision [22]. This study was approved by the Danish Data Protection Agency based on application 2009-41-4154, but the word circumcision does not occur anywhere in the application that was approved. The Agency therefore had no possibility to even consider whether the project was contentious or not before approving the use of data. Van Howe et al. do not recognise this. Its omission significantly weakens their claims about the adequacy of the protective functions of research ethics committees and data protection agencies.

We should perhaps note that there is a very fundamental agreement between us, and the authors of the response. They write:

“Contemporary society considers the individual, even a child, to be of primary ethical importance.”

We completely agree that the individual is of primary ethical importance. But, if that is the case it is not only an ethnic or religious group that cannot override that importance without sufficient justification, it also applies to medical researchers and society. As a matter of ethics it is not (as claimed by the authors) society that extends interests to the individual, it is the individual who has rights and interests that contemporary societies recognise.

Acknowledgements

None.

Funding

None.

Availability of data and materials

Not applicable.

Authors' contributions

RSVH wrote the initial draft, while the other authors contributed to subsequent drafts and approve the final draft.

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors have published articles and taken part in national and international debates concerning health-related, sexual, and ethical aspects of male and female circumcision. From a medical ethics perspective, we are generally skeptical about the advisability of performing non-therapeutic genital surgeries on minor children.

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Received: 29 November 2017 Accepted: 13 December 2018

Published online: 09 January 2019

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