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ආචාර්ය එස්. රසුරාමි

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රජයේ ප්‍රවෘත්ති දෙපාර්තමේන්තුව

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සම්බන්ධීකරණ සභාය

ඩී. එන්. පී. ඩයස් - ප්‍රවෘත්ති නිලධාරී, රජයේ ප්‍රවෘත්ති දෙපාර්තමේන්තුව.

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මෙම ලිපි සරණයෙහි අන්තර්ගතය පිළිබඳ වගකීම ඒ ඒ රචකයන් සතු ය. තව ද මෙහි අක්ෂර වින්‍යාස යොදා ඇත්තේ ද ඔවුන්ගේ පිළිගත් සම්ප්‍රදාය ගැනු කොටගෙන ය. මෙහි අන්තර්ගත අදහස් සහ කරුණු පිළිබඳව සංස්කාරකවරුන්ගේ හෝ ප්‍රකාශකයන්ගේ හෝ කිසිදු වගකීමක් නොමැති බව සඳහන් කරමි.

විමර්ශිත මණ්ඩලය

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ජනසන්නිවේදන අධ්‍යයනාංශය, කැලණිය විශ්වවිද්‍යාලය.

මහාචාර්ය රෝහණ ලක්ෂ්මන් පියදාය

විශ්‍රාමික

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මහාචාර්ය ආරියරත්න ඇතුගල

විශ්‍රාමික

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මහාචාර්ය චන්ද්‍රසිරි රාජපක්ෂ

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මහාචාර්ය සමන්ත හේරත්

ජනසන්නිවේදන ඒකකය - කොළඹ විශ්වවිද්‍යාලය.

මහාචාර්ය ටියුඩර් විරසිංහ

ජනමාධ්‍ය අධ්‍යයනාංශය, ශ්‍රීපාලි මණ්ඩපය, කොළඹ විශ්වවිද්‍යාලය.

මහාචාර්ය සේන නානායක්කාර

මානව ශාස්ත්‍ර අධ්‍යයනාංශය, ශ්‍රී ලංකා රජරට විශ්වවිද්‍යාලය.

මහාචාර්ය රන්ජන් හෙට්ටිආරච්චි

ජනමාධ්‍ය අධ්‍යයනාංශය, ශ්‍රීපාලි මණ්ඩපය, කොළඹ විශ්වවිද්‍යාලය.

The Importance of Informed Consent in Mass Media

Amila Lokumannage

Introduction

Informed consent is one of the cornerstones of ethical principles in research and praxis, especially in work that involves vulnerable subjects (List, 2008). Informed consent requires that research participants have a "full grasp of the potential dangers involved" (Babie, 2007). Derived from Kantian principles of morality, which view "human beings as autonomous beings having intrinsic worth and dignity" (Kettle, 2002), informed consent is necessary to allow individuals self-determination. Although these days informed consent is almost universally expected (albeit with great debate about its modalities and efficacy), it is a relatively new development in human history. The journalist community, on the other hand, has opted to eschew informed consent in their sphere of work, arguing that 'public interest' trumps the drawbacks of not taking informed consent from their subjects. Development communication especially the part that deals with government and non-government outreach activity on behalf of the vulnerable in society poses a unique challenge. Its nature straddles both the vulnerability the medical community deals with and the public interest facet that journalists deal with.

History of Informed Consent

Compelled by law in the United States, the informed concept was first formally adopted by the medical profession post World War II (Katz, 1994). For centuries, doctors had comfortably practiced a paternalistic model of medicine, which believed 'doctor knows best, but beginning in the seventeenth century, the English Common Law recognized that the concept of assault and battery applied to surgeons who operate without patients' consent (Murray, 1990). Against a backdrop of the inhuman experiments Nazi scientists conducted on human subjects, the law increasingly had to deal with radically new technologies that "promised significant benefits but also exposed patients to serious and unpredictable damage" (Katz, 1994). Thus, in 1960,

a Kansas court in a landmark decision in the “Natanson v. Kline” case noted, that a man is the master of his own body and he may expressly prohibit the performance of life-saving surgery or other treatment. Informed consent had well and truly been born. Soon these ideas crossed into disciplines beyond the medical profession and were embraced by the research community as a whole, including anthropologists and sociologists (Birch et al., 2012).

Formalization of Informed consent

Over the decade’s informed consent has morphed into an “ethical panacea” for all involved (Corrigan, 2003), with regulatory bodies formally ensuring ethical considerations are adhered to in every authorized research activity. It is accepted that proper informed consent must consider “capacity, disclosure, understanding, voluntariness, and permission” (Joffe et al., 2001). In the US, regulations governing informed consent in research with human subjects have eight defined domains (*ibid*, p. 140).

Domain Description

1. A statement that the study involves research an explanation of the purposes of the research, Expected duration of the subject’s participation.
2. A description of the procedures to be followed identification of any procedures that are experimental.
3. A description of any hazards or discomforts to the subject that is reasonably foreseeable.
4. A description of any potential benefits to the subject that could be expected as a result of the research.
5. A description of any potential benefits to others that could be expected as a result of the research.
6. A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject.
7. A statement explaining the extent to which documents identifying the subject would be kept confidential if any.
8. For research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of or where further information may be obtained.
9. An explanation of whom to contact for answers to pertinent questions about the research and research subjects’ rights and of whom to contact in the event of a research-related injury to the subject.

10. A statement that participation is optional, that refusal to participate will result in no penalty or loss of benefits to which the subject is otherwise entitled, and that the subject may stop participating at any time without penalty or loss of benefits.

The doctrine of Informed Consent

The very origin of informed consent points to its most pervasive flaw. Born within the jurisdiction of law, informed consent typically remains a tool for those in positions of authority (physicians, researchers, etc.) to avoid legal liabilities, as opposed to facilitating man to truly become the 'master of his own body' (Katz, 1994). This is not due to any conscious malice on the part of those in authority, but an inherent limitation of the doctrine itself.

Several authors have discussed in detail what they call the 'ritual' of informed consent. O'Neill, (2003) notes that informed consent is particularly difficult: a) to obtain from those who are unable to give consent; b) in formulating public health policies which affect everyone in a population irrespective of consent; and c) in medicine, by recording and taking into consideration, patients' family history (whose informed consent is impossible to obtain), we are automatically violating the family members' right to consent. Katz, (2004) also writes at length about the "barriers to joint decision making", which lie at the heart of informed consent. There is medical uncertainty about procedures that doctors themselves may not be fully aware of, or may fear loss of their credibility and authority if shared with the patient. There is the allegation of patient incompetence in understanding key issues, although even that is complicated by questions about how far the blame falls on the doctors' mode of communication as opposed to the patients' comprehension. Finally, there is the issue of respecting patient autonomy versus actively steering them towards decisions that are more beneficial, in the doctor's informed opinion.

Administration of Informed Consent

Besides the philosophical and ethical conundrums, at the very practical level as well, informed consent procedures are rife with complications. Due to the overwhelming practice of taking informed consent to escape legal liability, consent forms frequently morph into thick and long documents, riddled with jargon and legalese. How much the 'consenter' actually understands remains highly disputed but studies indicate the number may be as low as 30% (Isles, 2013). So, in medical research, for example, many subjects who consent to participate actually believe the research to be a part of the treatment package itself (Lynöe et al., 2001). Too short forms do not have enough information; too long forms have too much information. The elusive balance is to convey key information in simple words (Bhutta, 2004). The complexity of the language is a key problem, although it is a natural extension of legalese. A study indicates a reading level of 12 years or below is appropriate, although this does not take into consideration illiterate participants (Isles, 2013). Attempting to get the staff to explain the

consent forms can become a very time-consuming exercise, which is often unfeasible (Isles, 2013). This has raised questions about how much a participant truly needs to know for it to be termed 'informed' consent (O'Neill, 2003).

Informed consent for Developing Countries

Although the challenge with the illiterate population is not confined to just the developing world, it remains a problem predominantly of the developing world. Bhutta, (2004) complains: Current procedures for obtaining and recording consent in developing countries are lengthy and frequently out of synch with local cultural norms and realities. The procedures are largely derived from developed countries that focus on the legal protection of researchers.

This has led to calls for reform of the doctrine, specifically with suggestions of replacing 'informed consent' with 'understood consent' (Cash, 2006). Researchers should gauge not only what the participants were told, but also what the participants understood. To accommodate this, there is obviously a need to present information differently (Bhutta, 2004). Posters, videos, making the participants recount what they have understood, recorded or witnessed consent, accessing community leaders, etc. are all possible alternatives that have been discussed in the literature (Bhutta, 2004).

Informed Consent in Mass Media

Whenever informed consent faces problems in implementation, such as in developing countries as discussed above, the response is to encourage innovation in the method of obtaining consent. There is however a notable exception: journalism, which simply bypasses informed consent in favor of 'public interest' (Levine et al., 2014).

As they rightfully pointed out, this is a paradox. The debate within the communications and journalism community on whether informed consent is necessary in journalism when the Ethics Advisory Committee of the Canadian Association of Journalists published a report on it outlining both sides of the debate (Levine et al., 2014). The tension is between 'public interest' and 'minimizing harm'. The split is often most visible between practitioners practicing journalism who insist on the public's right to know and communications researchers who, due to their research indoctrination, are more inclined to consider the impact on the vulnerable populace. The community also seems to differentiate between seasoned media savvy people (such as politicians) to whom they give no quarter and a more inexperienced, marginalized, powerless populace (such as the poor and minorities) who are treated more carefully.

This is not just an academic debate; the real-life consequences of powerless people appearing on media are frequently on record. Just two months ago, Washington Post reported the plight of a minimum wage worker who lost her job for talking to a reporter (Harlan, 2015). Some journalists have chosen to find a balance between the two in their own way.

Chicago Sun-Times columnist Neil Steinberg, for example, had a speech he gave to potential interviewees.

"You understand I write for a newspaper. That I'm speaking with you because I'm going to write an article based on what you say, which will be published in a newspaper and read by the public. Once this has been discussed, the journalists feel 'source remorse', where a source belatedly feels uncomfortable with what he has shared on record with a reporter, can be ignored" (Levine et al., 2014). However, even this strategy does not take into account the people who do not understand the consequences of going on record and having their words put in print.

This issue is further compounded when photographs, which are frequently a novelty in some communities, enter the discussion. During the period of destructive political violence that gripped India at the beginning of 2015, several vehicles were torched, leading to severe injuries, and even deaths, of many burn victims. While the country was reeling from the violence, a huge controversy arose on social media (later spilling onto print media) about the role of photojournalists in covering such victims. One photographer went to the burn unit of the hospital where the victims were being treated and asked them to pose in front of a black background, to make his photos vivid. He faced immediate criticism from all strata of society, despite his protestations that the burnt victims had willingly posed for him, and since there were other photographers there already, he was not particularly responsible for the potential health risks. What was interesting here was not so much the journalist's interest in taking these photos, but the victims' willingness to forego their physical discomfort and make them available to pose for him? As one victim has declared, What would I do? You journalists come and ask us to perform such acts and we are just cooperating with you people.

When the photographer or videographer requested people to pose for shots, they usually consented without hesitation. The adolescents' recurrent refrain was, "No one declined to have their photo taken" and "No one said no." They believed the subjects cooperated because they recognized the teenagers as neighbours who were representing a Non-Governmental Organization (NGO). Sometimes, going as a team, instead of individually, tipped the balance in their favor, with some of the adolescents priming their subjects beforehand to ensure a smooth discussion. In many cases, the subjects assumed that by cooperating with the Photographer, they would get financial support from the NGO, as other project beneficiaries had before.

This stems from a culture where powerless people automatically accept any voice of authority, as well as the novelty of being photographed, and therefore feeling important, and paradoxically less voiceless. While it is incredibly important to uphold public interest the stories of the arson victims are certainly of public interest the question of how far it is allowed to infringe upon an individual's interest, even with their nominal consent, remains in the hands of individual journalists. The unfounded suspicions that photographs may be used in

pornography, to evict people, and so on highlight the need for better communication between photographers and subjects. The teams had obviously stated that they were not engaged in any nefarious activities, but these assurances were not enough for the subjects. This shows a need for methods of communication beyond the usual norm, including even relying on community leaders as gatekeepers (Bhutta, 2004).

It is with contexts such as these in mind that Levine (2014) stated an obligation to inform inexperienced subjects about possible consequences should not be viewed as in opposition to the public interest, or more specifically to truth, it should be viewed as serving the same purposes of accuracy and justice. Failure to reveal to a potential subject the potential implications of which a journalist is aware is a violation of the truth, accuracy, fairness, and the public good. Withholding information, foreclosing choice, undermining autonomy, and so on in the name of serving the public well is logically and ethically inconsequential (not to mention hypocritical).

Tracing its history back to Kantian philosophies, and compelled by law, the medical community has robustly embraced informed consent for decades and was instrumental in social science researchers adopting it afterward. The journalist community, on the other hand, has opted to eschew informed consent in their sphere of work, arguing that 'public interest' trumps the drawbacks of not taking informed consent from their subjects.

Although it is easy to merely lay the blame on inadequate staff training, the truth is more nuanced than that. The staff operates under enormous time pressure, which hampers their ability to truly consider every case as deeply as they ought to be considered. Thus they need to be given adequate time to carry out their activities. A seemingly innocent logistical and planning failure meant that the girl who had dropped out of school was allowed to proceed with having her photo taken, despite obviously visible indications that she was not aware of the possible consequences. Informing subjects, especially inexperienced subjects, about possible consequences is viewed as an "obligation" within the doctrine of informed consent (Levine et al., 2014). As must be obvious, unless staff training on informed consent, photography ethics, and creative photography techniques are rolled out, these options merely create an illusion of anonymity. As they are being practiced now, anonymity is impossible to maintain in the photos.

Development communication, especially the part that deals with government and non government outreach activity on behalf of the vulnerable in society poses a unique challenge. Its nature straddles both the vulnerability the medical community deals with and the public interest facet that journalists deal with. More studies in this area will be able to test innovative, more contextually suitable approaches for obtaining understandable permission. It can also untangle the power dynamics that obstruct the gathering of fully informed consent. Finally, it

can investigate how individuals who have previously granted consent have been publicized, as well as the repercussions of this.

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