

On Community Epistemic Capacity

Itai Bavli and Daniel Steel, University of British Columbia

Ian Werkheiser's (2015) article "Community Epistemic Capacity" investigates the relationship between citizens' consent and the idea that they should be sufficiently informed in order to participate meaningfully. He argues that citizens should be informed enough to give free informed consent, and that only a community with sufficient epistemic capacity can participate meaningfully. Werkheiser concludes, "Therefore, it is within the remit of many organizations to increase epistemic capacities in the communities from which they are trying to obtain consent" (2015, 18).

While epistemic capacity varies from community to community, four conditions are necessary for community epistemic capacity: gain, maintain, adapt, and continue knowledge (Werkheiser 2015, 8-9). By gaining knowledge he means that there are "accepted methodologies within the community" for generating knowledge on the topic in question. Maintaining community knowledge is said to require cohesion and trust within the community as well as the ability to legitimize community knowledge to outsiders. Adaptation means the ability of the community to adapt to new problems or challenges it has never faced before: knowledge that already exist with the community should be periodically revised against new experiences to see if it still relevant. Lastly, continuing the knowledge refers to the inter-generational transition of knowledge and methodologies.

To apply Werkheiser's recommendations in practice, policy makers would need to have an idea when community is exists and when not. He provides interesting examples of building epistemic capacity of specific communities such as by the Anishinabek/Ontario Fisheries Resource Centre and the Walpole Island Heritage Centre. Both cases show how these centers worked to increase the epistemic capacity of the communities (Werkheiser 2015, 17). Werkheiser, however, does not tell us what a community is or how a community should be defined. As a result, it is unclear whether a community exists in a given case and hence whether an obligation to foster community epistemic capacity is present. Consequently, it is unclear just what obligations Werkheiser's proposal places upon policy makers, such as representatives of public health agencies.

In this essay, we suggest that for present purposes a community can be understood as a group of people capable of developing epistemic capacity in the manner Werkheiser describes (i.e., to gain, maintain, adapt and continue knowledge). Some features of a group of people make it more likely to be able to do these things. Shared history and culture, for example, are likely to make it easier for groups members to better coordinate, trust each other, distribute new knowledge and maintain it.

Consider a group of people who share a culture and history and now are facing a severe problem (e.g., water pollution). They can better understand and trust each other, work together to distribute the knowledge about the problem within the community, to agree upon strategies for legitimizing community knowledge to influential outsiders, and even adapt to new findings about the problem. Another factor that is likely to increase community epistemic capacity is geographical proximity. The capability of a specific

group in society to communicate and coordinate and build community epistemic capacity is likely to be related and affected by geographical proximity of the group, that enables members of a community to better communicate. Face to face meetings, formal and informal gathering, public debates, group deliberation – all are more likely to occur when people live closer to each other. Having the opportunity to meet and discuss variety of issues that are related to the group is likely to increase the capability of gaining and distributing knowledge with the community, maintaining this knowledge, to adapt that knowledge to changing circumstances, and continue the knowledge to the next generations.

Shared history and culture along with geographical proximity, then, could be considered as two rough indicators of the potential for epistemic capacity in the sense Werkheiser describes. Populations that lack both of these features, such as all people suffering from cardiovascular disease, are less likely to succeed in epistemic capacity building than groups that possess both of them, such as a cohesive neighborhood populated by people belonging to the same ethnic group (cf. Checker 2005).

Let us consider these suggestions in relation to the case of the long-term adverse effects of radiation treatment both in Israel and the United-States. The practice of using X-rays for medical treatment of benign diseases began in the 1920s, peaked in the 1940s and 1950s, and then slowly became less frequent by the 1960s. Radiation therapy was considered to be good medical practice and very effective treatment for benign illnesses such as, cervical adenitis, hemangiomas of the head and neck, birthmarks, infertility, pertussis, hypertrophy of tonsils and adenoids, deafness, enlargement of the thymus gland (which was incorrectly believed to cause crib death), tinea capitis (ringworm) and acne (Simpson et al. 1955; Crossland 1955; Shvarts 2010; 2012). In the early 1970s, medical research confirmed the long-standing suspicion that children and young adults treated with radiation for benign diseases, during the 1940s and 1950s, showed an alarming tendency to develop thyroid cancer and other ailments as adults (DeGroot and Paloyan 1973; Modan et al. 1974).

Let us consider how Werkheiser’s proposal would apply to these two cases.

The Israeli Case: Mizrahi-Ashkenazi cleavage

After War world 2 Israel witnessed waves of immigration of Jews from around the world. New immigrants underwent series of medical checkups for TB, Trachoma, STD’s, and ringworm. As in other parts of the world, ringworm, a highly contagious fungal infection of the scalp that is particularly common in childhood, was treated with radiation therapy to remove the hair of the affected area before treating the affected area (see: Shvarts et al. 2010; 2013). Most of the patients who underwent radiation treatment were from the Mizrahi ethnic group: Middle Eastern, Asian, and North African Jewish immigrants, most of them from the Arab and Islamic countries (also known as “Sephardim”), most of whom were from the lower socio-economic class (see: Smootha 1978; Chetrit 2000), and believed that they had been singled out for this treatment (Bar Oz, under review). The Mizrahi were viewed as inferior to the Ashkenazi ethnic group (Jewish from Europe America and Australia) in all aspects of social life (Bar Oz 2012). For example, *Ha’aretz*

daily newspaper published an article in 1949 describing the Mizrahi group in the following way: "... people whose primitiveness is unprecedented, the level of their education borders on absolute ignorance, and what is worse is their lack of talent to learn anything intellectual ..." (Gelblum, 22 April 1949). In 1974, a new large study was published on the 10,834 Mizrahi children treated with radiation for ringworm of the scalp in Israel (Modan et al. 1974). The findings showed that the group that had received radiation was at significantly greater risk for developing both malignant and benign head and neck tumors, especially in the brain, and thyroid.

This case seems to be a clear example in which Werkheiser's proposal would be applicable. Mizrahi community has its own unique Mizrahi culture, and share a similar history (i.e. immigrating to Israel from Arab countries). Thus, the level of trust among the group's members is expected to be higher since they share so much in common (history, culture). Moreover, as Israel is a small country, geographical proximity is also present. The Mizrahi, then, would appear to be a group with a strong potential for community epistemic capacity building, and health authorities should have fostered this capacity. This would have involved communicating timely warnings to former patients about the adverse effects of radiation, as well as providing the Mizrahi community with the available scientific information, and providing resources for them to maintain this knowledge and develop it further as they saw fit. Unfortunately, authorities failed to do so. Mizrahi groups started to pressure parliament members to act on their cause in the late 1980s, and in 1994, the Knesset passed the Ringworm Irradiation Compensation Law that took effect in 1995. For many, this was too late. Early detection could have saved the lives of many, and the failure of authorities to engage with the Mizrahi in a transparent and respectful manner also lead to broken trust, suspicion, and conspiracy theories that continue to poison this issue and Mizrahi/Ashkenazi political discourse in Israel more generally.

The American Case: Radiation Treatment for Those Who Could Afford It

In the United States, over two million people are estimated to have been treated with radiation for benign conditions (Rosenthal 2002). Unlike the Israeli case, those who underwent radiation treatment in the US, with the private nature of its healthcare system, were those who could afford it. Thus, in contrast to Israel, patients who had received radiation treatment in the U.S. were from the middle or upper middle classes and, almost all were white (see: Murphy, et al., 1977; Roudebush and DeGroot 1977). In July 1973, a study at the University of Chicago confirmed suspicions that linked radiation treatment in childhood to a variety of diseases, including thyroid cancer. A few months later, a worker at Michael Reese hospital in Chicago found a registry of 5,266 former patients who had been treated with radiation during the 1950s-1960s. After much deliberation, hospital officials decided to contact these patients and arrange for follow-up medical examinations. Media coverage led more medical institutions to follow suit and to a nationwide campaign (July 1977), launched by the National Institute of Health (NIH) and the National Cancer Institute (NCI), to warn the medical community and public about the late effects of ionizing radiation (Bavli and Shvarts, under review).

It is unclear how Werkheiser's proposal would apply to this case because it is not clear that a community is present. Middle to upper income Americans in the 1950s and 60s appear to be a rather disparate collection of people. Patients received the treatment in different medical institutions across the country, and thus were geographically dispersed. Nor did they share strong bonds of culture or history, aside from being (mostly) middle to upper income white US citizens. Thus, unlike the Israeli case, health authorities in the US would have probably found it hard to follow Werkheiser's advice, as there appears little potential for building community epistemic capacity.

Werkheiser might reply that in the US case, the patients and medical establishment were from the same community—namely, mid to upper income American whites. Thus, he might argue, community epistemic capacity was already present in the form of medical schools, hospitals, public health agencies, associations of medical doctors, and so on. But again this raises difficult questions about what constitutes a community. Is a professional society of experts (e.g., the American Medical Association) a separate community from the lay public, or part of a community that includes of some segment of the public, and if the latter, which segment of the lay public exactly? Would the medical establishment and mid to low income whites also constitute a community, for example? Moreover, there are reasons to question the assumption that “mid to upper income American whites” constitute a community in the relevant sense. After all, people in this category differ in many respects that create challenges for community epistemic capacity building: geographical location, regional culture, social class, politics, religion, and so forth.

The two examples discussed above also raise the question of whether informed consent is best way to motivate the importance of community epistemic capacity. The radiation therapy case discussed above is not an instance of a community consenting to some further act, but a case in which authorities bear some responsibility to inform the public of a past mistake. Furthermore, no attempt to foster community epistemic capacity occurs in either example, but this seems only to have been a problem in the Israeli case. This suggests that community epistemic capacity may be important as a potential antidote to mistrust between marginalized groups and representatives of a scientific establishment. For example, if the people given radiation treatment in the US were predominantly African American, then controversies like those that arose in the Israeli case may have been more likely.

In sum, we find much to admire in Werkheiser's article, but we think that, to be applicable in practice, his proposal must address the question of what a community is. Otherwise, it is unclear when an obligation to foster community epistemic capacity exists. In addition, we are skeptical whether the medical ethics model of informed consent is the best way to motivate Werkheiser's approach. Another motivation, illustrated by the cases above, would emphasize the potential for social inequalities to undermine trust in representatives of a scientific establishment.

Contact details: itai.bavli@alumni.ubc.ca, daniel.steel@ubc.ca

References

- Bar Oz, Aya. “It’s All in the Head: Ethnic Identity Formation Among Patients Treated for Ringworm in Israel,” MA Thesis, The Hebrew University of Jerusalem, 2012. [in Hebrew].
- Bar Oz, Aya. “The Unintended Consequences of Social Movements’ Framing Processes.” under review.
- Bavli, Itai and Shifra Shvarts. “‘Deadly Medicine’—Michael Reese’s Pandora’s Box and the Campaign to Warn the Public of the Late Health Effects of Ionizing Radiation in The United States.” under review.
- Checker, Melissa. *Polluted Promises: Environmental Racism and the Search for Social Justice in a Southern Town*. New York, NY: NYU Press, 2005.
- Chetrit, Sami Shalom. “Mizrahi Politics in Israel: Between Integration and Alternative.” *Journal of Palestine Studies* 29, no. 4 (2000): 51-65.
- Crossland, Paul M. “Therapy of Tinea Capitis—The Value of X-ray Epilation.” *California Medicine* 84, no. 5 (1956): 351-353
- DeGroot, Leslie and Edward Paloyan. “Thyroid Carcinoma and Radiation. A Chicago Endemic,” *JAMA* 225, no. 5 (1973): 487-491.
- Gelblum, Arie. *Ha’arets*. 22 April 1949.
- Modan, Baruch, Hannah Mart, Dikla Baidatz, Ruth Steinitz, and Sheldon G. Levin. “Radiation-Induced Head And Neck Tumours.” *The Lancet* 303, no. 7852 (1974): 277-279.
- Murphy, E. Dennis et al. “A Community Hospital Thyroid Recall Clinic for Irradiated Patients.” In *Radiation-Associated Thyroid Carcinoma*, edited by Leslie DeGroot, 35-40. New York: Grune & Stratton, Inc., 1977.
- Rosenthal, M. Sara. *The Thyroid Cancer Book*. Canada: Your Health Press, 2002.
- Roudebush, Carbin P. and Leslie J. DeGroot. “The Natural History of Radiation—Associated Thyroid Cancer,” In *Radiation-Associated Thyroid Carcinoma*, edited by Leslie DeGroot, 97-118. New York: Grune & Stratton, Inc., 1977.
- Shvarts, Shifra, Goran Sevo, Marija Tasic, Mordechai Shani, and Siegal Sadetzki. “The Tinea Capitis Campaign in Serbia in the 1950s.” *The Lancet Infectious Diseases* 10, no. 8 (2010): 571-576.
- Shvarts, Shifra, Pnina Romem, Yitzhak Romem, and Mordechai Shani. 2013. “The Mass Campaign to Eradicate Ringworm among the Jewish Community in Eastern Europe, 1921–1938.” *American Journal of Public Health* 103, no. 4 (2013): e56-e66.
- Simpson, C. Lenore, L. H. Hempelmann, and L. M. Fuller. “Neoplasia in Children Treated with X-Rays in Infancy for Thymic Enlargement.” *Radiology* 64, no. 6 (1955): 840-845.
- Werkheiser, Ian. “Community Epistemic Capacity.” *Social Epistemology* (2015): 1-20. doi: 10.1080/02691728.2014.971911.