

10, leads to discussion of the development of this branch of ethics from the 1970s. A section of this chapter discusses stages of ethical transgressions in Nazi Germany, stemming from the new “opportunities” provided by the regime in power. Hildebrandt shows how Pernkopf was refused the bodies of Polish prisoners whilst Hirt successfully petitioned for those of Russian prisoners. Graphic descriptions of the consequences of the large numbers of executions and the glut of bodies make us shudder even today.

The very term “future dead” is horrifying. Anatomists (and physiologists) were provided advance information on executions and permitted to obtain medical histories from family members and medical records to enable them to plan removal of relevant tissues immediately after death.

After the end of World War II, anatomists were unwilling to dwell on events during the Nazi regime. When German anatomists did study the ethical implications of their acts, they attempted to rationalise. “70% of the executed were criminals anyway; they do not have to be pitied...” “Nobody cared, so why should we care?” Serious discussions and publications appear to have emerged only over the past 20 years.

Tables in the appendices provide a fund of data for researchers:

political affiliations of leading German anatomists 1933-1945 (11 pages); scholars of anatomy whose careers were disrupted by National Socialist policies (9 pages); body supply of anatomical departments of German universities; Professor Stieve’s list of bodies (7 pages) and so on. Each table is substantiated with references to the sources of entries.

I return to Dr. Hildebrandt’s introduction. The last paragraph is, at once, inspirational and demoralising. “After studying this history for several years now, I believe that it represents an example of the ethical dangers inherent to a medicine that believes itself on secure moral grounds and has ceased to reflect on...its methods of gaining knowledge. This lack of doubt... is not specific to the Third Reich... It can be seen in many other periods of the history of medicine and certainly in current medical research, education and practice.”

Each chapter starts with a relevant quotation (with its source specified) and is followed by Notes providing references to specified statements and an exhaustive bibliography. The book ends with a detailed index.

#### Reference

1. Pandya SK. Pernkopf’s Atlas: Should unethically obtained life-saving data be discarded? *Indian J Med Ethics*. Published online first on August 22, 2020. DOI: 10.20529/IJME.088.

## Rooting for Roona: Predicament of addressing birth defects and childhood disabilities in India

ANITA KAR

**Rooting for Roona, Producers: CurleyStreet Media, Directors: Pavitra Chalam, Akshay Shankar, 2020, 41 minutes, English.**

*Rooting for Roona* is a thought-provoking documentary on the unaddressed problem of congenital disorders and children who survive with severe disabilities in India. Released on Netflix, the documentary narrates the brief life of Roona from Jirania Khola village in Tripura. Roona is born with severe hydrocephalus, a disfiguring enlargement of the head due to fluid accumulation in the brain. She is non-verbal and visually impaired. Roona’s young father is a daily wage

labourer, employed at a brick kiln in the village. Her mother is a housewife. Even though the fluid build-up in the brain can be relieved through shunting, Roona’s mother tells us that government hospitals in Tripura lack the facility to treat children with hydrocephalus. When we are first introduced to her at eighteen months, Roona is untreated and severely disfigured.

Roona’s story begins with her discovery by a photo-journalist visiting the brick kiln. Villagers believed that a child with an unusually large head would be of interest to him. Although the documentary does not delve into it, one wonders whether Roona’s parents, like other parents of children with congenital disabilities, experienced the stigma and the social consequences of the “undesired differentness from what had been expected” (1). A child with a severe disability is a socially uncomfortable phenomenon, and Roona’s parents tell us that they were advised to send the baby away to an orphanage. This advice directs us to reflect on the vulnerability of children in public orphanages and institutions in the country. The inability of the country to protect its abandoned and orphaned children has not yet been corrected, despite the fact that India was an early signatory to the Convention on Rights of the Child,

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and the Convention on the Rights of People with Disabilities. Roona's parents are however steadfast in their determination to care for the child to the best of their knowledge and ability.

Paternal abandonment is a frequently reported phenomenon in cases where children are born with severe disabilities, making a disabled child the mothers' responsibility. Roona's father is however resolutely determined to stand by his family. The audience cannot but empathise with his forlorn longing for freedom from the unexpected change in his routine life, caused by a severely disabled child. One is also left to contemplate on the lack of a perinatal counselling service that can provide psychosocial support to parents, and dispel myths about congenital disorders (the parents were told by villagers that Roona's disability was caused by past sins).

The highlight of the documentary is the stark disparity between the public and private health care capabilities in India. The infrastructure and professionalism of the doctors in the private hospital is in marked contrast to the circuitous replies and lack of professionalism of the doctors at the government hospital. One wonders at the causes leading to the insensitivity of the doctor at the government hospital, as he sprawls in a nonchalant fashion in his chair, while providing no information at all to the distressed parents. The need for developing basic competency on management of congenital disorders in the public health systems is evident. The complex surgeries that restored Roona's quality of life to an extent also leads us to reflect on the fact that while Roona's surgeries were supported by a state-of-the-art private hospital in Delhi, for less fortunate parents across the country, the options of accessing care for congenital disorders are limited.

At the same time, the documentary cautions us on the realistic dilemma of public investment for correction of congenital malformations. Even as the early surgeries are filled with parental anticipation ("...you will get better, you will have to grow up and learn to cook and sweep..."), gradually, they are replaced by a slow realisation that surgeries do not cure; neither do they make the child "normal". The reluctance of parents to opt for the next round of surgeries frames the reality of investing in chronic care that requires multiple medical interventions.

*Rooting for Roona* underlines another reality. Over half of birth defects cannot be prevented, and nearly 70% of children with birth defects survive with disabilities or medical needs (2). Leaving children and their parents without the best available care is unethical. Low cost interventions, such as teaching parents to care for a child with a severe disability, regulation to ensure evidenced medical care and protecting families against exploitative and untested therapies, and ensuring a functional disability service that is connected to the medical service via a strong referral system is the need of the hour. A start has been made through the Rashtriya Bal Swasthya Karyakram (RBSK) and the services offered by the Department of Empowerment of Persons with Disabilities, but a lot more needs to be done (3). For example, disability sensitisation of

communities to understand and accept birth defects is an important public health function. It is also important to ensure that the community understands that early intervention and rehabilitation services (such as those established under the RBSK programme) nurture the potential that the child is born with.

One bright point in *Rooting for Roona* is when the mother tells us that the Auxiliary Nurse Midwife and ASHA had assured her that her second pregnancy was normal. We do not know how she was told this (hydrocephalus is most frequently detected late in pregnancy, and the documentary steers clear of prenatal ultrasonography), but it is heartening to see the value of community health workers in the public health system. Educating them on birth defects (as has been proposed under the RBSK) (3) would strengthen community level lay support for women who may be detected with a foetal anomaly during pregnancy. Drawing from the implications of the documentary, one more demand can be added to the wish-list for services for congenital disorders. Women have a right to know about teratogenic exposures, as well as have the freedom to opt for ultrasonography for detection of congenital anomalies. The rights of the woman, of the unborn foetus and the rights of prospective parents of a child with disability have to however be balanced through an appropriate dialogue.

As Roona's brief life comes to a sudden end, we can relate to the evident relief of the parents. We understand when the mother says that no parent should go through her experiences. This powerful documentary tells us that children with disabilities do not choose to be the way they are. Learning to empower them and putting in place social security measures are fundamental responsibilities of the welfare state. *Rooting for Roona* is a telling commentary on how the lack of health services and the disorganised social welfare services leave few options for parents, especially the indigent and those located in rural areas. This documentary can be used as a teaching case study for students and researchers in the field of maternal and child health, disability studies, public/global health and human genetics disciplines.

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