The miracle workers: obstacles and opportunities for restoring sight to children in KwaZulu-Natal

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The miracle workers: obstacles and opportunities for restoring sight to children in KwaZulu-Natal

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The case studies presented in this paper reflect on the experiences of parents and the caregivers of children from the province of KwaZulu-Natal who overcame multiple obstacles to prevent childhood blindness due to cataract. Borrowing Sarah Franklin’s metaphor of an “obstacle course,” the paper plots the challenges facing ordinary people as they navigate processes of diagnosis, care and treatment for children with cataract. The research, originally spearheaded by Orbis Africa, an NGO dedicated to restoring sight in children, signals a critical shift in collaborative forms of knowledge production whereby the consultant anthropologist was not merely an add-on to a development project, but acknowledged for her unanticipated and often ambiguous research findings.

Keywords: blindness; cataract; children; eyes; sight; South Africa

Introduction

Ejaj dug into her deep handbag and produced a bright yellow ear of corn, which she handed to Fikile. They sat together in an unremarkable consulting room in the Inkosi Albert Luthuli Central Hospital (IALCH) in Durban, where I conducted formal interviews with the caregivers of children who were undergoing, or who had recently undergone, eye surgery. Ejaj had escorted Fikile to his follow-up appointment after undergoing cataract surgery. Ejaj was 68 years old and Fikile was aged nine. He was a small-framed boy, withdrawn and coping with flu. His right knee was bandaged after a soccer injury, but beyond that Fikile appeared exceptionally tired. Formerly Fikile’s neighbour, Ejaj offered him a home after his mother died of an AIDS-related illness in 2011. They were both HIV-positive, but only Fikile was on antiretroviral treatment. Ejaj was unemployed and, self-reportedly, extremely poor. She received an old age pension and disability grant, yet it took her more than a month to save enough money to pay for the 52 minute taxi ride from her home in Ilembe to the eye clinic in Durban. Fikile’s father lived with his girlfriend in another village. He was also sick with an AIDS-related illness and unable to provide financial or interpersonal support for his son. Without extended family to care for him, Ejaj was determined that Fikile would not go blind from the cataract, a condition which would irrevocably entrench the myriad layers of obstacles already in his young path. Leading up to the eye surgery, Ejaj maintained a rotating eating schedule for the other six people in her care, namely her children and grandchildren. For more than six months, the children in her home ate only every other day. Such an unwelcome accommodation of poverty points to the social layering of disease and distress, to the inability to isolate medical conditions from the social and economic contexts in which they are lived, and the work that people undertake for one another (see Henderson 2012). Although eye disease is considered a “low impact” affliction in South Africa, for the afflicted who cannot see it is a significant gateway to the world that is closed.

What ties the stories in this paper together is the ultimate restoration of sight in children who would otherwise have lived with permanent poor vision or blindness. The “miracle,” or the miraculous, emerged in all of my discussions with parents whose children were unable to see one day, and
to see the next. Caregivers referred to the transformation in their children’s sight as a “miracle,” a “gift” and “a blessing,” and expressed their relief that their children would have one less obstacle to overcome in a country that remained so deeply divided along lines of race and class. Children struggling in school due to poor vision were suddenly learning to read and were participating in sports and other activities from which they had been excluded. Their stories reminded me of the enduring story of the miraculous moment when Helen Keller made the connection between the repetitive signs for water being traced on her hand by her teacher Annie Sullivan and the water running from an outdoor pump over her other hand. It’s a scene that has been rendered for the stage, for the silver screen, and published in biographical and autobiographical accounts of Keller’s life. Keller’s inability to see or hear was irreversible in her case, and yet she received an education that led her to become a professor at Radcliffe College. She became a committed activist for the disadvantaged disabled, and her politics led her to South Africa in 1951. That the biographical film of her teacher Annie Sullivan was called The Miracle Worker (1962) is not inconsequential here. The miracle workers in this paper are parents and caregivers who overcame a range of socio-economic obstacles, which too often prevent the application of biomedical solutions to remedy poor vision.

This paper draws on the stories of children who underwent surgery for cataract in Durban, and describes how their caregivers navigated the diagnosis and treatment in contexts of economic and educational marginality. The practice of disease recognition and treatment, including the consultation of traditional healers, diviners and allopathic doctors in a medically plural landscape, raises difficult questions for medical anthropology, exemplified by its paradoxical chime. Anthropologists often portray how structural inequality can underpin a reliance on folk or traditional modes of diagnosis through processes of biomedical exclusion (Chesselet and Levine 2004), and yet they also acknowledge the value of diverse knowledge forms that exist in a medically plural world (Macdonald 2012; Wreford, Esser and Hippler 2006). Merrill Singer (1995) argues, on the contrary, that early anthropologists who were seduced by exotic healing practices mistook poverty for culture, and unwittingly allowed the anthropological gaze to mask bare life. In this paper I tread lightly on the thorny issue of culture in medical anthropology by placing greater emphasis on the political economy of health care, but not so lightly that I erase the presence of the ancestors, the weight of generational hierarchy and power, and the structural forces of history that sustain uneven access to medical care. The issue of culture is thorny because of the ways in which aspects of cultural practice, including consultations with traditional healers and the use of traditional medicine, are typically cast as obstacles to health care within public health discourse (Levine 2012). The framing of culture as an obstacle to better public health outcomes tends to obscure other historical forces that shape the landscape of health care in South Africa, which is why I find Sarah Franklin’s (1997, 101) metaphor of an obstacle course so appealing. It provides a far more complex model for describing the range of over-determining forces that can lead to childhood blindness.

In 2012 I was hired as the primary investigator for Orbis, an international NGO that promotes public sector doctors in clinics and hospitals working in the field of eye care, in particular providing cataract surgery for children living in underdeveloped contexts. Lene Øverland, the CEO of Orbis Africa, had worked with me in her capacity as a media activist in 2002 on a series of documentary films called Steps for the Future, which told ordinary stories about people living with HIV/AIDS in Southern Africa (Levine 2007). We had stayed in touch over the years, and when she told me about her most recent work with Orbis, I expressed interest in the question of childhood blindness. I have long been interested in the dual purposes of anthropology, namely pure and applied research, which, I argue, need not be at odds. I informally suggested that should she need a researcher, I would be interested. The conversation lasted well over a year when Orbis offered me a consultancy position as a researcher on this particular project in Durban.
In South Africa, the absence of an adequate infrastructure to cope with eye disease underpins the need for Orbis. There are approximately 383,920 known blind people in the country, with a ratio of six ophthalmologists per million people. Since 2010, Orbis has worked to pilot, evaluate and determine the most appropriate model for comprehensive child eye health in South Africa. Orbis works closely with the National Department of Health on this model. Significantly, Orbis funded the research that led to this paper, and its research team of eye specialists framed the initial research questions around the causes of delayed presentation and the potential consequences of not attending follow-up consultations after eye surgery. In designing the methodological tools to answer their questions, I drew on a number of methods including a detailed questionnaire that probed the routes to care in relation to children’s health and more open-ended conversations relating directly to children’s eye health.

With the exception of an essay written by Helen Keller about her momentous 1951 trip to South Africa (Blaxall 1952), there are few analytic accounts of the social consequences of visual impairment in South African history. Keller’s socialist oriented essay describes the uneven distribution of care for blind and deaf “Coloured,” “Bantu” and “European” children and offers a critical account of the impact of racism and class oppression on the disabled at the inception of apartheid. She wrote:

All my life I had acted upon the conviction that humanity must be one. Each group is in a position to benefit the others by various means; supported by these thoughts I had had a measure of success in my work with the assistance of others, but how could I count with certainty on gratifying results in a country like South Africa, divided against itself? (cited in Blaxall 1952, 34)

More than 60 years have passed since Keller’s visit, and notwithstanding the massive changes in health care legislation, the roll-out of state subsidised medical facilities and the uprooting of the pillars of racial capitalism that underpinned apartheid policy, screening for eye disease and access to quality eye care for the poor remains inadequate. Rural clinics in particular are under-resourced, under-staffed and ill-equipped to cope with the number of children living with treatable conditions such as cataract, infectious and non-infectious illness (TAC and Section 27 2013). Keller’s political commentary, while by no means revelatory today, offers an historical anchor with which to connect poverty, the delayed presentation of children with cataract and childhood blindness. According to Orbis, “[t]here are 285 million people in the world who are blind or are visually impaired, yet 80% of visual impairment can be avoided or cured” (Orbis n.d., 1). These recent statistics both suggest a relationship between visual impairment, blindness and economic deprivation, and point to the fact that South Africa remains a country divided in itself, though not in the way that Keller had observed. At the time of her visit the NGO movement had hardly taken root. She was a maverick in her undertaking to raise public awareness about the impact of racism and class oppression on those whose seeing and hearing is impaired. She believed that, with adequate education and health care for people of all race groups, serious obstacles could be overcome. She used the concept of blindness as a strong metaphor to condemn apartheid. In what follows, blindness is no metaphor but continues to be a condition experienced in terms of inequalities rooted in apartheid. And, complicating Keller’s perception of how obstacles can be overcome, I present a situation where parents, medical caregivers and NGO staffers work away at obstacles that are reduced, rather than overcome.

The challenge of early detection

I came to this work through the ethnographic turn of Orbis Africa. In 2013 Øverland and its Director of Programme Development, Reshma Dabideen, attended a conference in Spain to learn more about the discipline of medical anthropology. Their engagement with anthropology, and their striking commitment to wrestling with unanticipated data, militates against, if you like, the common pitfalls of development work (Gardner and Lewis 1996). Our collaboration offers
a refreshing model where qualitative research took centre stage, rather than being miscast as a research formality, or worse, a rubber-stamping effort for funders.

The early detection of childhood cataract — best described as lens opacity that develops in children either from birth or due to systemic conditions or trauma — is critical for preventing childhood blindness. As Courtright, Hutchinson and Lewallen (2011, 1129) explain, cataract is the leading cause of surgically treatable blindness in children in poor settings. According to Sarkin, Øverland and Davideen (2012), the largest burden of childhood blindness is in Africa, with at least 300 000 thereof in sub-Saharan Africa (one out of every five of the globally estimated 1.4 million blind children). The emphasis on early presentation is based on the fact that, “without surgical intervention[.] the posterior pole of the eye will not receive the visual stimulation necessary to achieve normal visual development”. The timing of surgery for cataract removal is critical: amblyopia, which can occur with the presentation of cataract, can mean that normal vision will never develop, even if surgery is then performed (Bronsard et al. 2008, 383).

Borrowing Sarah Franklin’s (1997, 101) potent metaphor of the “obstacle course” from her analysis of IVF-assisted reproduction, I chart the routes, obstacles and barriers through and against which residents in rural and urban parts of KwaZulu-Natal (KZN) navigated processes of diagnosis and care for cataract. In Franklin’s ethnographic work, it is the potential “failure” of women to conceive despite using new reproductive technologies that makes up the obstacle course (1997, 108). These obstacles are built into the medical technology. In the words of Nicholas Fox, biomedical technologies “produce bodies” (1993). Franklin’s (1997, 110) emphasis is on the medicalised language of failure and the exhaustion and frustration that women feel when they “fail” to conceive. In the present case, the medical technology at hand, while never fool-proof as a treatment for removing cataract, is not the most serious obstacle. The obstacles presented here have more to do with accessing the required level of care, everyday setbacks of transportation, financial support, awareness of eye disease, and a range of politico-economic realities and intergenerational conflicts and fears, all of which are inextricably linked. Against the backdrop of a health care system marked by deep structural inequalities, the medley of stories about failed primary health care services, cultural models of affliction and beliefs about the relationship between disease and family strife suggests the interplay of the political economy and culture, and the body as a signifier of both.

**Socioeconomic obstacles**

On paper, everyone in South Africa has the right to access health care services, sufficient food and water, and social security. This much is detailed in Section 27 of South Africa’s Bill of Rights in words that reside in the everyday as an impossible horizon (Henderson 2012; Levine 2012; Ross 2010). Under-resourced primary health care services, unemployment, chronic underemployment, unstable households and a weighty referral system contribute to the statistically uneven distribution of eye disease. In short, the searing warnings about the post-apartheid state posed by Harold Wolpe (1988) and Bernard Magubane (1979) have come home to roost. Obscene inequalities deepen even as the dream of a vibrant and creative black bourgeoisie thrives, to such an extent that it might be fair to say that there are multiple twenty-first century versions of post-apartheid South Africa, or multiple interlocked worlds or entanglements.

Amidst all the politics, eye health has not figured as a matter of urgency at the level of primary health care. All doctors have to complete an eye module as part of their training, but it is such a small part of their many rotations, with not enough emphasis placed on detecting cataracts in children. It is the same with the nurses. Small modules about eye care form part of their normal training, but either it is not emphasised enough, or they do not receive adequate training, or competing conditions like HIV/AIDS and TB place different emphases on their training. Based on my research findings, it is clear that nurses are not adequately trained to recognise eye conditions. The respondents uniformly agreed that their primary health care practitioners misidentified
their children’s cataracts as eye infection in the first instance, or failed to recognise any optical abnormality. Only after repeated visits to their local clinics were they given referrals to one of the larger state hospitals.

In addition to the misrecognition of eye disease, the cost of transportation contributed in some cases to delays in presentation. The province covers the cost of transportation for people who live outside the eThekwini municipality (a region that spans 2,300 km² and includes more than three million people), but the province does not cover transport costs for people who live within the district. The benefit of this social service for the rural poor cannot be overstated. By contrast, people who live inside the municipality are incorrectly assumed to have the means to travel the shorter distance to medical facilities. Thus people who live closer to the IALCH find it more difficult to access care than people living further away in rural parts of the province. How to put such an inversion of common sense on the policy agenda is one of the practical outcomes of this study.

With two exceptions, research participants who lived within the municipality relied on loans from their neighbours, boyfriends, parents, siblings, and the old age pensions of their parents or grandparents for travel costs. Didiza, who lived 14 km from Durban’s Central Business District (CBD) in Yellowwood Park, said: “I never had enough money myself to get to the hospital. My boyfriend gave me the money. It would be a good idea if the hospital could provide transportation.” Didiza was unemployed, the mother of three children and pregnant at the time of our interview. She was now distressed as her former boyfriend had stopped paying for the transportation costs for their daughter Busiwe’s hospital visits since their relationship had ended. She needed R38 per trip from her home in Yellowwood Park to the hospital and back home.

Factors that contribute to the likelihood of Busiwe’s eventual blindness include the withdrawal of financial support from her father, her mother’s chronic unemployment and status as a single mother with limited family support, and the reality of poverty in a country with one of the highest Gini coefficients in the world. On an administrative level, the obstacle course also alludes to a costly referral system in terms of time and money, and the emotional distress of a prolonged diagnostic journey. Didiza’s work at securing a diagnosis for her daughter began at her local clinic in Yellowwood Park and ended more than a year later at the IALCH. In between these poles she was referred to King David Hospital, St. Aidan’s Hospital and then back to King David Hospital. Hurdles along the way included misdiagnosis, long waits to see clinicians, a distinct lack of adequate communication between patient and the examining doctors, and the delay between scheduled appointments. These obstacles suggest the structural setbacks that led to Busiwe’s delayed presentation.

Didiza’s perseverance led directly to Busiwe’s sight being restored. Her contribution does not diminish the “miracle of science,” but suggests the usefulness of positioning diagnosis and treatment as a social and interpersonal set of processes, or an obstacle course. While the superior medical expertise at the paediatric eye clinic at IALCH must ultimately be acknowledged for restoring sight, it is the invisible work of patients and their families in persevering despite the obstacles they face that provides for its success. Ordinary people do not simply land up at hospitals. They make it happen, and often through a great deal of personal effort (see Abney 2009; Henderson 2012).

Competing medical paradigms within families
The socioeconomic obstacles considered here were often folded into local disease idioms. Respondents frequently referenced “modern” and “traditional” approaches to illness in their families, which hinged strongly on their perceptions of “rational” and “irrational” medicine. Apart from the opening story of Ejaj, the cases considered here reflect generational points of tension where younger parents blamed their own parents for the delays in presentation. In a comparative
study I recently conducted in Kitwe, Zambia, a similar narrative emerged, where young parents described how hard it was to take control of their children’s medical options by way of challenging the authority of their elders. In Durban, Gugu, the mother of Anele, explained:

If the father was like this and ended up visually impaired, then when I give birth to a child like this, it is just the way it is. Some people think the ancestors will be angry if you intervene.

In cases where congenital eye disease was regarded as an ancestral inheritance, half of the 20 respondents faced conflict within their families over treatment intervention. Out of respect for their elders and their ancestors, the respondents explained that they felt compelled to weigh blindness against the other potential harms associated with disrespect. Gugu said: “Some people in my Zulu culture are afraid of treating a hereditary illness.” Gugu’s mother, in this case, took the position that intervening with an inherited affliction in the grandchild would cause greater harm than the affliction itself. “Treatment,” Gugu explained, “would go against the ancestors because it is in the family and they can kill the child.” She said, “you can’t go there … these people are suffering from ignorance.” It was only after her mother died that Gugu felt able to take her daughter for the surgery that restored her eyesight.

The presence of the ancestors in everyday decision-making processes in the corporeal realm lends itself to debates about “cultural barriers” to health care. The “cultural barrier” emerges as a powerful social category — especially in public health discourse — to explain why certain health-promoting interventions fail to take root. A cultural barrier might be the belief that optimum health is achieved by the interpersonal and social exchange of fluids (Taylor 1990). In the early years of the HIV/AIDS pandemic in Rwanda, Christopher Taylor considered the failure of condom campaigns as the result of local conceptions of the “fractal person,” whereby wholeness and, by extension, health depended on the carnal exchange of bodily fluids between lovers. Condoms, as barriers that trap bodily fluids, were thus imagined to invite disease. The work of anthropology here was to recognise the cultural belief and, by identifying the problem or barrier, suggest ways to overcome it. The political economy of belief, by contrast, remains relatively unmarked in these styles of ethnography.

The outcome of identifying culture — in its most reductionist sense — as a barrier to health care has allowed collaborations within the pluralistic field of South African medicine to emerge. The growing awareness at the height of the AIDS pandemic that traditional healers were filling the gap in the lives of people caught up in the national mismanagement of the pandemic (to put it mildly) alerted national health policy makers to the need to professionalise the sector, as well as to initiate training centres in the science of traditional medicine (Levine 2012). Joanne Wreford, a practicing sangoma and HIV activist, warned promoters that the nature of these projects was assuming a one-way flow of knowledge about the benefits of biomedicine, and in the eyes of traditional healers was emphasising the limitations of their knowledge for medical science (Wreford, Esser, and Hippler 2006). Qualitative research produced under the banner of medical anthropology has also found its unidirectional way into public health campaigns, radio broadcasts, documentary films and massive billboard campaigns (Levine 2007). Numerous ethnographic and social scientific research has followed this applied research trajectory, much of which points to the idea that the high incidence of, or risk for, disease in underdeveloped contexts can be attributed to the culture of the race groups (i.e. black) in which it appears (see Nattrass 2012).

While culture certainly shapes disease response in powerful ways within populations and among individuals, the “cultural barrier” model tends to understand culture as static. Delinked from the political, economic and historical forces that underpin the uneven distribution of health care, the cultural barrier model runs the risk of being lifted out of context, and sensationalised (Singer and Baer 1995). A recent article in The Star newspaper (6 September 2013), for example, grossly misinterpreted a set of my research findings. The bolded caption in the centre of the article...
read, “Blindness seen as an ancestral gift.” The message was that organisations like Orbis face an uphill battle extending their services among Zulu-speaking communities due to the latter’s cultural beliefs. Contrary to the newspapers headline, not a single caregiver I met framed cataracts as a gift, but rather as an inherited affliction to be endured. The distinction is highly significant. The latter conveys simultaneously something about the weariness of affliction, and the historical exclusion from medical services. The art of interpreting family dilemmas is a little bit like keeping tea in its cup while out in a raging sea. Indeed, balancing the considerable disagreements among family members about how to address childhood cataracts, which practitioners to consult, and how to interpret a child’s hazy sight required just the kind of analysis that is the hallmark of anthropology. As touched on above, if the condition of cataract was considered to be “in the family,” meaning that it was an illness that had been passed down from one generation to the next, then it was accepted by some as “the way things were.” To interfere with an inherited condition was regarded as a sign of disrespect to the elders, alive or transcendent, but certainly not as a gift.

By way of contrast, other families settled for consultations with traditional healers (herbalists) or spiritualists (mediums). Durban’s enormous and enormously popular “muti market” is filled with herbal remedies for cataracts, the combinations of which I was unable to establish. Given the recent legal battles over patents for medicinal plants such as *Sutherlandia frutescens* and *Hoodia gordonii* (“Struggle over Hoodia Patent” 2006), the healers and traders at the market expressed their concern that I would steal their remedies for profit (also see Green 2012). Several were generous with information about the generic treatment for cataracts, which include fresh squid and jellyfish which are placed directly onto the eye (the translation in Zulu for jellyfish is “faeces of the moon”), and dried cuttlefish which is ground into a paste and rubbed into the eye. There is no scientific evidence that any of these remedies, either herbal or marine, have any efficacy, which is why all the respondents in this study who had consulted with traditional healers eventually sought out biomedical care.

**What do nurses know?**

Nurse Bheka noticed when patients in the eye clinic at IALCH wore thin strips of goatskin around their wrists, which denote clan membership in general, but indicated to her that a traditional healer had been consulted. She said that while nurses were aware of their patients’ plural medical histories, parents hid information from their doctors. She said:

> They don’t want to tell the doctors that they have consulted traditional healers … They also don’t want to tell the doctor how afraid they feel about their children going to theatre. They tell me how afraid they are that their children won’t wake up. Parents are afraid, not the children.

While the nurses clearly had intimate knowledge regarding the plurality of patient practice, they were reticent about communicating their insights to doctors. Buhle, an ophthalmology ward nurse, confirmed that there are four etiological models that explain the delayed presentation in the research sample:

- Delay due to misdiagnosis by health care practitioners at local clinics, with the most common treatment for “infection” being eye drops.
- Delay due to fights between members in the family of the patient about how to treat cataracts.
- Delay due to the consultation of traditional healers.
- Delay due to the congenital nature of childhood cataracts.

Nurse Bheka offered similar explanations. She said, “people keep going to the clinics but they get eye drops and are misdiagnosed, and then the problem does not go away.” She continued:

> It’s a family thing. Cataracts run in the family so people think they need to slaughter a goat. Medication from traditional healers … is used. Herbs are crushed with a little water. They believe a lot of myths such as using breast milk on the eyes for cure. Biomedicine is the last resort for people struggling with illness.
Significantly, all of the children in this study had been immunised at clinics as babies, and all the children’s cataracts were congenital in nature and not due to an injury or other developmental causes. This means that if the immunisation nurse had been trained to recognise the early visible signs of cataract, and if there were an efficient infrastructure to deal with cataracts in poor medical settings, then the delays would have been dramatically reduced. Biomedicine was therefore not necessarily a last resort, but one option among many in the context of the non-recognition of cataracts, the failure of traditional remedies, and the failure of eye drops to solve the problem.

Nurse Bheka also noted that because “old people do not go to theatre” they are unlikely to send their grandchildren there. Reiterating the idea that older people were more comfortable consulting traditional healers, she said, “they want to talk to the ancestors first and the family second to get permission to take the child to hospital. The decision to take a child to hospital is a family decision and this can take time.”

While the nurse’s observations reflect the way things appeared, their analysis remained partial, and leaned heavily on the kinds of dichotomies that ultimately blur the complexities associated with ordinary and extraordinary forms of diagnostic practice (see Gibson and Oosthuysen 2012). In four cases it was the parents and grandparents of the primary caregivers who tempered their fears about surgery, and who allocated generous portions of their old age pensions to restore their grandchildren’s and great-grandchildren’s sight. They also encouraged and financially enabled follow-up visits after the surgery. Ejaj, like the others, had pushed back against the socioeconomic obstacles in her way to ensure that her ward received medical attention.

On another note, the nurses themselves expressed their desire to acquire enough medical knowledge to be able to alleviate patients’ fears and answer their questions, including medical questions. Nurse Bheka could not, for example, say exactly what a cataract was, nor identify the possible risks associated with their removal. When asked about the likelihood of children losing an eye during surgery, or about the potential of failing to recover vision after surgery, Nurse Bheka could only gesture towards answers. Sister Bhule emphasised, “we are desperate for training so that we can answer these questions.” She continued:

The role of the nurse is to be an interpreter. In this hospital the nurses are translators. We are professional nurses, but the doctors don’t want us to get involved. There is no need for a nurse aside from putting eye drops in for dilation.

Nurse Sibongile said, “[t]his is a very big problem,” while Nurse Bheka explained: “I take orders from the doctors. I dilate eyes, we help mothers sign consent forms, and we assist with translations.” Uwungwengwezi is the Zulu translation for cataract, meaning “something that covers the eye,” but beyond this description the nurses claimed to be uninformed about the medical explanation for cataracts.

Ordinary existential fears
Ordinary existential questions by patients and their relatives include those that have no clear answer and, accordingly, can cause tremendous anxiety. The questions posed by the respondents in this study were rather ordinary in that they touched the borders of their anxiety and fear about the well-being of their children. Among their questions were: “Will my child’s sight return if a family conflict is settled?”; “What if my child dies under anaesthesia?”; “What if my child loses an eye?”; “What if my child is left permanently blind?”; “What if the ancestors are angry?”; and “What if this child is meant to be like this?” Each question draws out a cosmology of care and worry. Each question signals very real concerns about the nature of affliction and power. Herbalists, diviners and biomedical health care specialists each offer different sorts of answers to these questions, with the first possibly best positioned to answer the existential aspects of the questions. The following abbreviated case studies highlight the interplay between socioeconomic, cultural and existential quandaries.
Delay I: Medical misinformation
Minenhle noticed that one of her daughter Zinhle’s eyes was “white” from the time of her birth. Minenhle took Zinhle to her local clinic when she observed that Zinhle was unable to see with her “lazy eye.” The doctor on call prescribed eye drops, but when the white spot in Zinhle’s eye did not clear, she returned to the clinic. She was then referred to St. Aidan’s Hospital in November 2012. By this stage the situation was urgent. Minenhle explained, “I was so worried because the lady at the creche said she can’t see. Before the operation she could not see.” When Zinhle was five months old an ophthalmologist at King Edward Hospital told Minenhle that “it was too risky to operate.” By way of contradiction, he also explained that cataract could cause permanent blindness. After the consultation, Minenhle waited to see if the condition got better. The critical aspect of this story is that, irrespective of the fact that Minenhle observed and drew attention to Zinhle’s cataracts at birth and drew on evidence that Zinhle could not see, at least three delays within the first five months of Zinhle’s life deferred her final diagnosis and treatment.

In December 2012 an attending doctor at St. Aidan’s referred Minenhle to IALCH where she was told that surgery was required immediately. The diagnosis produced both intense anxiety about the anaesthesia and relief that a cure was possible. She prayed and cried during this difficult period, while her father supported her wholeheartedly. She said, “I made the decision. I said yes. I didn’t have a choice.” Before IALCH, not one health care provider informed her that cataracts could be successfully removed, and with limited risk. At the time of our interview, both of Zinhle’s eyes had been operated on and her vision restored.

Delay II: Social layering of forces
When he was three months old, Busisa stayed with a neighbour while his mother Nkululeko worked long hours at a pharmacy. After regularly finding her son in tears at the end of the day, she decided it would be better for him to stay with his father Kwanele. As he was working as a taxi driver, he was rarely home and so Kwanele’s mother became Busisa’s primary caretaker. Though Busisa was born with congenital cataracts, it took more than three years for Kwanele to identify them or, perhaps, to identify them as a problem. Nkululeko said that Kwanele noticed “white dots on the black part of the eye when Busisa was three. His father also noticed that he was blind…He tried to show him things in front of his eyes, and he could not see them.” Like other cases in the study, Busisa’s condition was not detected at the immunisation clinic, and it was only when he began “bumping into things and acting the same way as his older brother” that his father notified Nkululeko about the problem. Perplexing in this case is that Busisa’s father, uncle, and brother had all been surgically treated for cataract, and yet his family’s medical history was allegedly not taken into consideration during his early medical appointments.

Nkululeko understood that Busisa’s cataract “came from his father.” Taking the cataract as a metaphor, there was something else blinding or disabling this family from recognizing Busisa’s visual impairment. It appears that his condition fell through the cracks of his care arrangements. I was not able to interview Busisa’s paternal grandmother about her involvement with the case, and Nkululeko had little to say about her role in decision-making processes. Busisa was eventually taken to a clinic by his mother where a nurse wrote a letter for them to consult with an eye specialist at Prince Mshiyeni Memorial Hospital. The doctor on call explained to Nkululeko that Busisa would be permanently blind if he did not have surgery. They were referred to St. Aidan’s Hospital where the eye specialist referred them to the eye clinic at IALCH.

Notwithstanding these systemic delays, Nkululeko said that “problems within the family” also contributed to the delay. There were differences of opinion about what should be done for Busisa in spite of his older brother’s case. These conflicts were compounded further by Nkululeko’s anxiety about having missed some of Busisa’s early immunisation appointments, as she felt responsible
for the cataract. She worried that she had contributed to the condition by missing his early medical appointments.

Though Yellow Park was relatively close to the IALCH, Nkululeko needed to borrow R36 from her sister or boyfriend for each visit. Busisa’s father was unable to accompany him to the clinic due to his work, and so Nkululeko, who had lost her job at the pharmacy, took him to the hospital for his appointments. After the surgery Busisa went to Nkululeko’s sister for two weeks in a rural area where she placed him in a crèche. Nobody at the crèche was informed about the surgery and there was some confusion about post-operative care. Nkululeko said, “I must put drops in his eyes four times an hour. They say it will help the healing, but nobody showed me how to put the drops in. His father said he will take care of him.” In fact, drops should have been administered four times in a day, but not one of Busisa’s primary caregivers — his father, grandmother, or aunt — had any interaction with the eye clinic or were sent pamphlets about post-operative care. Information was communicated with the biological mother only, rather than taking into consideration the people who gave the everyday care. In the end, thank goodness, Nkululeko could say, “Busisa can see perfectly now.”

Delay III: “It was in the family”

Lindiwe recognised opacity in her son’s eyes, but as this was a condition he shared with his cousin, she did not intervene. Her explanation, “It was in the family,” served as an entry point to my investigating the reasons why a congenital inheritance, as opposed to an infectious illness or developmental disease, might be left untreated. When her son Luthando “looked down” and failed to “take things from the table,” Lindiwe explained, “I did not see it as a problem as it was familiar.” When Luthando turned two and could not open his eyes, she began to worry. He complained about the sun and said, “they are paining.” Luthando walked into bushes and fell often; by this time he was blind in both eyes. Lindiwe said, “I could clearly see white spots on one eye when he was two.” When Luthando was three and struggled with blindness, Lindiwe took him to the Ndwedwe clinic where an eye specialist saw patients only two days a month. The nurse on duty prescribed eye drops, but when the drops failed to help, Lindiwe returned to the clinic with Luthando.

Rajeshree, an optometrist at IALCH, explained that “parents can pick up that their child has cataracts if they are observant. But when they are observant and see that there is a problem they are often not listened to by doctors at clinics.” Lindiwe waited for over a month to see the eye specialist, a consultation which finally yielded a proper diagnosis. He referred her to Stanger Hospital where she was given eye drops to dilate her son’s eyes, a procedure repeated at St. Aidan’s Hospital to which she had then been referred. She took her son to St. Aidan’s twice at a two week interval, and was eventually referred to IALCH. Luthando was nearly four years old when he reached this hospital’s eye clinic. At no time until her visit to St. Aidan’s did Lindiwe know that there were eye treatment centres she could afford. Once the diagnosis was made, and surgery offered as the only option, Lindiwe became afraid. She said, “There is talk in the community about theatre … most people say you are going to die if you go to surgery.” Lindiwe’s mother comforted her and encouraged her to go ahead with the surgery, and said that everything would be okay. At the time of our interview, Luthando was five years old and able to see.

Delay IV: Names, naming, and the named

Amahle’s parents were alerted to her condition when they took her to a paediatrician for flu symptoms when she was six months of age. “The doctor,” said her father Kubu, “noticed that her eyes were moving slowly. He prescribed some eye drops, which we bought. The problem persisted. After two weeks of anxiety, we took her to a different clinic.” A second doctor also observed that Amahle’s eyes were “slow.” They were referred to Addington Hospital where a third doctor confirmed that something was wrong, and he identified the white spots associated
with cataract. The diagnosis helped Amahle’s parents to recognise the cataracts. Naming a disease is a critical step for shaping what people recognise as pathology, with language and visual images playing a significant role in how people identify an affliction. Amahle’s father said that Amahle had shown signs of discomfort, but he read these signs as a game. For instance, when Amahle was a baby she put her thumbs in her eyes and “pressed and rubbed them. I thought it was a funny game.” From the age of two to three months, she was unable to open her eyes in the sunlight, but her parents thought she was just sensitive to the bright light. She was also being treated for TB, and her father thought there might be a connection between the TB illness and the sensitivity of her eyes. Her mother Khanya was studying to be a nurse, but said that she was not taught to consider the eyes as an integral part of the body. Her insight was instructive.

Kubu had been unaware of the possible treatment for cataracts, and when he found out that surgery would remedy Amahle’s condition, he was initially excited. Closer to the time of surgery however, he felt fearful. He said, “two other kids came here and their eyes were badly damaged … I was worried about the surgery and was afraid of artificial eyes.” Pre-circulated stories of mishap, whether real or imagined, had the potential to delay Amahle’s treatment, but Kubu and Khanya decided to go ahead. Amahle had surgery on one of her eyes in January 2012, when she was 10 months old. The surgery went well, and at the time of the research Amahle was seeing well out of her operated eye, with surgery for the other eye being planned. Kubu and Khanya emphasise the need for public health campaigns through radio or television, especially on the relationship between childhood cataract and childhood blindness. The relatively early detection of Amahle’s condition by a doctor, notwithstanding the numerous referrals, led to a swifter cycle of intervention than in the previous cases. The absence of family conflict, the absence of financial concerns due to both parents being employed, and the presence of trust in the medical system also contributed to the shorter delay in presentation. The class variable in this case is significant.

**Conclusion**

Julie Livingston (2012, 175) reminds us that “global health … occurs on the ground through the work of specific individuals labouring in particular circumstances.” This paper considered the labour of ordinary people in rural and urban parts of KwaZulu-Natal seeking relief for their children in a field marked by radical medical pluralism, where patients move between advanced biomedical institutions, such as IALCH, primary health care facilities, traditional forms of healing, and the context of the family where all forms of diagnosis and disease recognition begin. The state, and the state of the country, becomes irrelevant for organisations invested in offering practical solutions. The fact that South Africa continues to be a country divided against itself, continues to be a country where schools for the blind remain largely segregated by race, and where resources for these schools are unevenly distributed according to race and class, emerge as the most significant obstacles for universal eye health in the country.

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**Notes**

1. Orbis works in partnership with stakeholders from government to civil society and aligns all its work with national policy. Orbis is using the findings from this research for policy advocacy. The goal is to ensure the integration of child eye health within the Early Childhood Development Framework that is currently being designed in South Africa.

2. Amblyopia means that visual stimulation is transmitted to the brain only partially or not at all.
References