Maintaining Distance and Staying Immersed: Practical Ethics in an Underresourced New Born Unit

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situated ethics, neonatal, LMIC, practical ethics, positionality

Case Study

Country Context (Including Health Features)

Within sub-Saharan Africa, Kenya is ranked relatively highly for access to health care services, but its public health system is under considerable stress due to increased demand, high patient to staff ratios, and the complete devolution of health services to largely autonomous County health teams (Wakaba et al., 2014; World Health Organization [WHO], 2006). New Born Units (NBUs) dealing with sick infants are particularly under strain, with inadequate availability of basic drugs and equipment and a ratio of 15:1 patients to nurses, while in high-income countries such as the United Kingdom, the recommended ratios are 4:1 (Aluvaala et al., 2015; British Association of Perinatal Medicine, 2001; Murphy et al., 2018). The lack of effective care can be directly linked to significant neonatal mortality in Kenya (Gathara et al., 2011). In 2014, the neonatal mortality was at 22 deaths per 1,000 live births (Kenya National Bureau of Statistics, Ministry of Health/Kenya, National AIDS Control Council/Kenya, Kenya Medical Research Institute, National Council for Population and Development/Kenya, and ICF International, 2015), which indicates a need for significant progress before Kenya achieves the Every Newborn action plan target of 10 or less neonatal mortality per 1,000 live births by 2035 (WHO & UNICEF, 2014).

Description of the Study/Research/Situation in Which the Ethical Issues Arose

The Health Services that Deliver for Newborns (HSD-N) project is supported by a multidisciplinary team with experience in ethnographic work, epidemiology, and health systems. The project aims to investigate the projected need for neonatal inpatient services; what existing infrastructure and human resource capacity is available supporting access for this population; utilization of these services; and the quality of existing nursing care services. The latter aim is supported by an ethnography of neonatal nursing. This research was undertaken at three of Nairobi’s NBUs over a period of 18 months, beginning early in 2015. Two of the three researchers were based in Kenya, while one was primarily based in the United Kingdom. All three researchers are social scientists, they were involved in the data collection, and all research was coordinated through the KEMRI-Wellcome offices in Nairobi.

Case Vignette

The ethical implications of this setting are significant: The infants in the NBUs were extremely vulnerable as were their mothers who were frequently overwhelmed by feelings of despair and anxiety. Furthermore, this work took place during a period of nationwide health worker strikes which strained relationships between health workers and their employers. Consequently, nurses were unhappy and stressed and further were potentially at risk of losing their jobs if they were seen to complain too much. Under these conditions, our aim with regard to ethics was to be as prepared as possible while also treading carefully and remaining reactive. Unfortunately, we still encountered two major ethical dilemmas: the first concerned our respondents’ apparent willingness to delay work to speak to us, thus creating a fundamental ethical issue in putting infants at increased risk (World Medical Association, 2013); and the second, the potential harm resulting from being asked to help in medical tasks having quickly been accepted as “one of the team” (Department of Health, Education, and Welfare; National...
Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 2014). Both issues were made more difficult to manage by the emotional toll posed by ethnographic immersion into such a resource-limited, high-stress environment.

The application passed through three ethics review committees prior to the start with significant feedback and editing of the protocol. One of the two ethics committees that reviewed the study was formed of senior researchers with great experience in research ethics. Upon receiving approval, the first phase of interviewing began. We determined that it would be best to speak to senior nursing trainers, and leaders of nursing organizations first, because in addition to providing us with a managerial and policy-level view, they also helped us secure access.

Following the interviews with the senior managers and leaders, we managed to gain access to the hospitals. After gaining verbal permission from each hospital manager or CEO, we began interviewing senior members of the nursing staff. Interviews with nursing “in-charges” (matrons) were conducted in the nursing station or a private office, and this did not seem to interrupt the flow of work, because they were not involved in direct clinical work. We were then allowed to speak to more junior members of staff and began interviewing frontline nurses.

One of the first topics to be raised in these interviews was the ratios of nurses to babies—very much lower than international or even national standards. Our ethnographic interviewing methods generally demanded that we spoke to our interviewees for 40 to 60 min, and we soon realized that we were taking active nurses away from the wards to interview them. The nurses seemed willing to do this, but we felt uncomfortable and so asked if we could interview them after the shift. It seemed clear that this would not be possible given nurses’ other responsibilities, and so we tried to ensure that our interviews were conducted during well-staffed morning shifts, or during very quiet moments. We had not anticipated such challenges in finding appropriate slots for interview. It would have been easier to agree with the nurses and accede to interviewing them during the shift, but this felt wrong. It was difficult to explain our concern to the nurses while avoiding the suggestion that they were being negligent in their willingness to be interviewed during the shift. Our concerns were based on one of the most basic ethical principles—to protect those involved in the research from harm (Department of Health, Education, and Welfare; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 2014)—but our challenge was to also manage the relationship with the subjects of our research while doing this. Such difficulties have been encountered by researchers elsewhere and it is important that we stay alert to the challenge of situated ethics issues such as these (Molyneux & Geissler, 2008). In our case, we shared our experience in the larger research team and our experience led to the adoption of a policy that offers financial compensation for out-of-hours interviews.

After gaining a level of trust from the nurses, and understanding of their work, we began observation of the shift work. This was critically important, as it provided a great deal of context and ethnographic detail to what we had learned from interviews. Unfortunately, it also put a great deal of strain on one team member, who found it difficult to navigate this particularly stressful environment. First, the strains and emotions of the NBUs we studied wore heavily on the observer, and witnessing the death of infants and failed resuscitations was distressing. Of course, this was helpful for the research, as we began to witness if not directly feel, the “emotional labour” of nurses. However, we were ill prepared for the stress of the NBU and had not considered how hard the research would be.

A further problem was encountered in being asked by nurses for help. At first, this was easy—It was not ethically problematic to be asked to fetch certain members of staff or folders. However, it became harder to manage when we were asked to help with medical care. During one emergency, a nurse asked one of us to turn the dial on the oxygen machine. The researcher felt this was beyond their ethical mandate and was able to find help on this occasion, but in other pressing situations, we felt that providing some assistance was ethically reasonable. For example, one of our researchers helped cup-feed the abandoned babies who did not have a mother to do it for them. In hindsight, we should have perhaps predicted where our immersion into the ward may lead, but we did not react quickly enough to prevent a particularly problematic event. The nurses we worked with were often overwhelmed—not only by the high patient to nurse ratios in this setting but also with the difficulties of commuting and managing responsibilities at home. This was evidenced by the fact that nurses frequently arrived late to work and would “rest” (sleep) when the pressure eased. Unfortunately, on one relatively quiet night, a nurse who was meant to relieve an afternoon shift nurse, phoned to inform them that they were running late. The afternoon shift nurse cited major demands at home and announced they could not wait, and so left only our non-medically trained researcher to watch the ward. We were unprepared to deal with this event and feel very fortunate that no harm seemed to result. Striking the correct balance between ethnographic immersion into the culture of nursing and maintaining sufficient barriers to protect infants was thus very challenging. The challenges posed by the use of ethnography in similar contexts has been noted by researchers, for example, Lichtner (2014) shares her experience of fieldwork with vulnerable patients; she highlights the constant presence of situated ethics such as “calls for assistance” by patients or staff. It is therefore important that we reflect on our findings and continually improve our ethical approach to account for this.
Ethical Issues Arising

Frontline interviewing as obstructive to care. We had presumed that nurses would never put patients at risk to participate in the research, but this was not a simple matter. The nurses’ understanding of “busy” was quite different to our own, and we soon realized that nurses were willing to leave the ward at times where we felt patients might be at risk. Avoiding harm, especially to vulnerable patients, is a key tenet of ethical research practice (Department of Health, Education, and Welfare; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 2014) and so we needed to develop our own systems for ensuring the interviews did not result in a reduction in the quality of care.

Medical responsibility and liability. Our medically unqualified researchers were asked to help with simple administrative tasks such as fetching people or things, and this was fairly unproblematic. But being asked to help with emergencies and direct infant care raises important issues around accountability and duty of care. As described above, on one occasion, a nurse who had clearly come to see our researcher as one of the team left the shift entirely, leaving only our researcher on the ward with 12 sick infants. Thus, while we were driven to reduce barriers as part of our ethnographic approach, this presented challenges to our ethical practice in this environment (Hoeyer, Dahlager, & Lynoe, 2005).

Conclusion

The questions raised above were not addressed in the ethical review and we failed to identify them as concerns quickly enough. However, in response to the ethical challenges we encountered, we did conduct debrief meetings within the research team where we shared our experiences and agreed on possible actions. Through this mechanism, we were able to address some of the issues. Two of the researchers also attended an emotional management course aimed at helping researchers deal with emotional distress.

Throughout the study, we provided feedback to each of the study hospitals, where we also discussed some of the ethical challenges that arose during data collection. We hope to learn from our experience and are working with our ethics team to ensure future reviews cover these topics. We also recognize the need for reflexivity. However, while a generic sense of “keeping distance” was a consideration, how it applied to the specifics of the research only became apparent through the “doing” of the research.

In addition, our experiences highlight the fact that the ethics of conducting health policy and systems research are relatively underexplored in low-and-middle income countries (Molyneux et al., 2016). While there is an emerging understanding of the need for a more “situated ethics,” guidance specific to context and particular environments is lacking, and it seems important to both to share and learn from our experiences and also to create systems that allow researchers to react more quickly.

Suggestions for Commentary Topics 1 and 2

Fairness toward co-researchers or participants
Research integrity and responsible conduct of research

Author Biographies

Joyline Jepkosgei is a junior researcher at KEMRI-Wellcome in Nairobi, with interests in ethnography. Her research interests are in health systems, research ethics and HIV. She conducted the greatest share of field research, including night shifts and weekends—Her struggles were the basis for the Case Study.

Jacinta Nzinga is a senior researcher at KEMRI-Wellcome in Nairobi. Her research interests focus on health care management, and in particular, hybridity among midlevel managers. She managed much of the day-to-day research and interactions with staff and management.

Jacob McKnight is a senior researcher at the Oxford Health System Collaboration (OHSCAR). His research covers health system reform, new public management, health seeking behavior, consumer culture theory, and managerial change. He designed and initiated the research, and wrote the body of the Case Study.

Commentary 1

Sassy Molyneux and Vicki Marsh

Sharing and Responding to Day-to-Day Ethics Challenges in Health Research

We thank the authors of this case for giving us the opportunity to comment. We recognize that many researchers conducting scientifically and ethically approved health research in a range of settings globally are faced with daily dilemmas about what “the right thing” to do is. In this commentary, we would like to (a) support the need for us all, including social scientists, to share more of the day-to-day ethics dilemmas that arise over the course of our health research work; (b) highlight how potentially important the key intersecting issues of positionality and collaborations can be in shaping the nature of the ethical dilemmas faced and how they might be responded to; and (c) share some examples of strategies and approaches we have used in similar contexts in responding to day-to-day ethics dilemmas. In so doing,
We hope to contribute to continued discussion on day-to-day ethics and prompt input and ideas from others.

**We Should Share Our Day-to-Day Ethics Dilemmas and Responses**

The authors of this case share a range of important day-to-day ethics dilemmas they have faced over the course of their work, and some of their responses. This is important in itself: All too often, the day-to-day ethics dilemmas we face in our studies are quietly dealt with by individual researchers or within the research team. There may be many reasons for this: It could be part of what we consider to be the normal work of being a professional researcher, or there might be a concern that sharing our issues may lead to our professionalism or morals being questioned. The ethical dilemmas that we encounter can be particularly acute when our research involves apparently vulnerable participants (whether patients, parents, community members or staff) and where we have responsibilities not only to research participants but also to research team members. We can feel torn: We are often conducting research in contexts of vulnerability and inequity precisely because we think there is an important gap or need that research can address (a social value), but what if we are inadvertently contributing to that vulnerability and causing harm? For social scientists, where positive transformation is often a key driver of conducting research, this may be a particular tension.

The suggestion to share more of our day-to-day ethics dilemmas is far from new. Over 10 years ago, participants in a large international, interdisciplinary meeting held in Kenya highlighted the importance of giving more emphasis in ethics guidance and practice to issues of justice, and to ethics issues associated with complex power relationships between different research stakeholders (Molyneux & Geissler, 2008). Meeting participants highlighted that the frontline researchers and field staff who often play a crucial and unsupported role in “doing ethics” in the field should be given greater voice and visibility. In “doing ethics,” Guillemin and Gillam’s (2004) work provides invaluable advice. They highlight that giving credence to those moments in the everyday practice of research where researchers are “not feeling quite right” is ethically important; a crucial part of building up our “ethical mindfulness.”

Appropriate ethical guidance and review processes should carefully consider the ethics issues and dilemmas expected to emerge in a specific context, how these issues and dilemmas will be identified and handled, and the implications for science. In some cases, anticipation of ethics dilemmas may necessitate the selection of an alternative study design, given that good science requires good ethics. Nevertheless, as researchers and reviewers, we need to be careful not to shy away from potentially transformative, ethically challenging, studies. Conducting such research, where there are no alternative approaches to gather the knowledge and achieve the associated social value, could be argued to be an ethical responsibility (Council for International Organizations of Medical Sciences, 2016). Furthermore, we must recognize that even after selecting an appropriate study design, ethics issues will almost inevitably emerge over time; sometimes in dramatic events, but more often in feelings of discomfort that reflect ethical tensions. Below we suggest some mechanisms to build into studies (and into protocols for review) that might support the identification, sharing, and discussion of ethical issues as they emerge over time, “in real time.”

**How Positionality and Collaborations May Influence the Nature of the Ethical Dilemmas Faced and How We Might Respond**

Key issues in the science and ethics of important but potentially sensitive studies like the one shared in this case are positionality and collaborations: who’s involved in the research, what are our various identities, backgrounds and experience, and what are our interests and perspectives? These factors interact with what can be complex sociopolitical contexts and team dynamics to influence the ethical issues encountered and the responses.

In this case, in our view, key strengths to support the quality of the science and appropriate handling of ethics issues are the social science team including a senior Kenyan social scientist with long experience of working collaboratively with mid-level health system managers in the country, and the social scientists being part of a broader research collaboration involving experienced clinical researchers as well as senior hospital and wider Ministry of health staff and policy makers. The team are uncovering major and diverse challenges for nurses with potentially important implications for patient care, and the findings are likely to point to actions and interventions to support positive transformation of the health system. The social scientists’ debriefs and regular feedback meetings with their research colleagues and hospital collaborators have the potential to further strengthen the science and ethics through:

- Reminding everybody about the roles of the research team and seeking advice on the appropriate distance to maintain (strengthening understanding of the research and demonstrating respect);
- Supporting learning about any challenges or burdens being imposed on the staff and more widely by the research team (facilitating agreements on less burdensome research practices);
- Allowing careful sharing of what is being learned and seeking additional information from those with tacit knowledge of the system (supporting the social value of the work); and
• Building interest in and support for the quality and relevance of the work, in turn hopefully promoting positive action in response to research findings (supporting individual-, community-, and system-level benefits from the work).

Our own experience elsewhere in Kenya suggests that such mechanisms are important to establish, but will face their own practical and ethical dilemmas. They require—and are an approach to building—strong and productive relationships between collaborators. However, researchers will need to operate within what are often complex health systems imbued with unequal and shifting power relations. There may well be other researchers working in the setting with different approaches and institutional requirements. Developing close and trusting relationships is difficult in these situations and, as relationships develop, researchers will inevitably become part of those contexts, potentially influencing power dynamics in both intended and unintended or unexpected ways. Dilemmas can result. For example, in this case the identity of the nurse who left her post might be inadvertently revealed to her managers, adding to her challenges. Or—as a result of sharing findings that are considered to be inappropriately accusatory of poor practice—there may be a distancing between hospital managers and researchers, with a negative impact on further learning and positive action. The longer and stronger the links and relationships between researchers and health managers, with the positive gains mentioned above, the greater the potential risk that “Researchers come to see questionable practices as normal and acceptable, possibly because they become so acclimated to study settings, or because they feel uncomfortable about ‘betraying’ the staff who allowed them access, p. 267” (Dixon-Woods & Bosk, 2011). Fundamentally, there could be a dilemma that in trying to build and maintain relationships, a transformative agenda to raise awareness about and reduce damaging power imbalances is undermined.

Despite such concerns, our experience suggests that such feedback mechanisms are valuable in building mutual understanding and trust, and are central to good quality science; that careful reflection of the positionality of different members of the research team, and of the evolving relationships and their implications, can help to mitigate some of the biggest potential challenges and dilemmas.

Some Examples of Strategies and Approaches to Raise and Respond to Day-to-Day Ethics Dilemmas

Recognizing that it is usually the frontline researchers and field staff who are placed in and face the most challenging issues in “doing ethics” in the field, and that there may be pressures and power dynamics within a research team and with collaborators that discourage those frontline staff from sharing their dilemmas with others, we would like to share some examples of strategies and approaches we have begun to develop for similar studies in Kenya.

One strategy is building in specific ethics reflection meetings into studies. We initiated such approaches in our health systems studies (Molyneux et al., 2016; Molyneux & Geissler, 2008) and have continued to evolve them over time. In brief, special sessions lasting 2 to 4 hr each and involving all social science team members are organized, with the specific aim of creating a relaxed and judgment-free setting to share experiences of feeling “not quite right” about professional and personal roles, where the right thing to do is unclear. These sessions allow team members with different experiences and expertise to share worries, carefully identify and explore any related ethical issues and researcher responsibilities, and agree upon any appropriate action. For studies where social science teams are part of wider collaborations, we have found these sessions invaluable in reflecting upon which issues need to be shared with the wider team/collaborators, and how. These sessions might well be valuable for the social scientists working on this case, essentially as expanded versions of their regular debriefs. We recognize that clinical research team members and non-research clinical staff in this and other similar interdisciplinary studies may themselves face numerous day-to-day ethical dilemmas. In one such study, we ran ethics reflection sessions for both the social science team and the wider research team. Across both sets of ethics reflection sessions, we valued access to diverse forms of expertise: local field assistants with deep local knowledge, social scientists, clinicians, and ethicists. Accordingly, we recognize that for the NBU case we are discussing, and for other similar research teams, it is key to carefully consider the range of expertise and experience needed and available to support the science and ethics of research in practice.

Although ethics reflection sessions, including acting on agreements made, can help to alleviate the huge moral distress that so many research staff face at the frontline, it is only one strategy. Two complementary strategies are participatory training in communication and emotional management, and facilitating access, where necessary, to professional individual counseling. We have supported the development of a series of participatory courses in communication and emotional management—for researchers, health workers and managers—to build awareness and skills of our own communication styles and emotions, and those of others, and their impacts (Mwangi, 2015). Our experience is that these courses can assist us to better understand our own and others’ needs and challenges, even in the context of structural difficulties and complex power relations. Such courses can therefore inspire and support stronger relationships with other team members, collaborators,
Commentary 2

Bobbie Farsides

Always Be Prepared: Anticipating and Confronting Ethical Challenges in the Research Setting

Presenting this honest account of conducting qualitative research in an ethically challenging environment is a generous act on the part of the authors because it reminds us of the potential cost to researchers when entering their research participants’ pressured work environment. The pressures they experience are twofold at the very least. On one hand, the researchers’ job is to try to understand and then report on what happens in a space where challenges and problems can be anticipated. This can be difficult when a relationship has been built between the researchers and workers such that criticism or negative revelations might be experienced as personally hurtful. On the other hand, being present in such a space, particularly when there is pressure on resources—human and otherwise—can lead to the researcher having to make difficult choices around their role and the boundaries they operate within.

Having studied the experience of health care professionals and scientists navigating complex ethical environments for nearly 20 years, some of the issues discussed here are familiar to me (Farsides, Williams, & Alderson, 2004). However, the sense of time and place evoked by this case study makes the particular encounters discussed both poignant and troubling. The researchers are at one in the same time a cause and a perceived solution for a problem which they are in real terms powerless to address. People who are expert in their own fields find themselves uncomfortable with their inability to make things better and indeed their propensity to make things worse. Added to this must be a sense of pessimism around whether understanding and reporting the situation will be an effective lever to making things better for staff or patients.

As the authors state, our growing experience in the field of ethnographic research and our increased awareness of the ethical issues it raises mean that we can often enter a new research setting having done our best to prepare for what we may find and the tasks we need to perform. (Alderson, Farsides, & Williams, 2002). The authors set themselves the laudable aim of being “as prepared as possible while also treading carefully and remaining reactive.” These were not naive or reckless individuals, and as such their experience is a warning to us all. We may feel prepared but our embeddedness may reveal what we could not be expected to anticipate let alone prepare for. Hence my claim that reporting our experience of unpreparedness is a generous and helpful act.
to other researchers: adding foreseeable risks to our understanding but also preparing us to be unprepared.

When seeking to be prepared we can think on one hand about what we might call the procedural ethical issues—gaining approval of protocols, preparation of informational materials, negotiating access, recruiting participants, and gaining consent. We know how to do this and systems are in place to regulate and govern our processes to ensure that they meet acceptable ethical standards. At a practical level, experienced researchers demonstrate a great deal of tacit skills in establishing themselves in a new setting—not to circumvent rules, but rather to help things to go easier. They know how to get a quick sense of organizational structures; how to navigate hierarchies and secure permissions; whom to get on side; how to ensure that people do not feel forced by pressures outside the project to agree or refuse to take part; and the sensitivities around critiquing one’s own or another’s workplace, particularly when the setting is seen as socially valuable and driven by a laudable set of values. A locally based governance process should also assist the incoming researcher in understanding more about the culture, personalities, socioeconomic, and political context within which they will be working. If the researcher does not know what they are coming into, a locally based ethics committee should have a much better idea.

However, even with the best governance systems in place an experienced research team may not be fully prepared for the particulars of a new setting—Indeed, that is what they wish at some level to reveal. Even if they have visited several places “of this type,” this is a new space inhabited by a new set of people working in their own way albeit it in light of organizational, national, or international guidelines. There is a tension then between the procedural ethics of permissions and access and the need to explore the unknown, which necessarily involves a risk of being unprepared. A workplace may not present in the way such settings are reflected in the existing literature; it may challenge our preconceptions and thereby undermine our sense of preparedness. Those involved in formal ethical review of the proposed work may be unaware of or unwilling to acknowledge and share certain realities. What we can rarely identify let alone define in advance is the moral labor that takes place alongside or embedded within the everyday tasks of a particular health care setting. Only when you get inside do you really discover what is troubling a workforce at a particular time, what people care most about or, as in this case, what people appear not to care enough about. The particular is only apparent once we observe and understand the details of this laboratory, ward, or clinic and how this team’s way of doing things fits within our broader understanding of the field. And, importantly, what we find most challenging morally is more likely to reside in the particular features of a case. This suggests to me once again that the work of ethnographic observation in challenging spaces is important even if it can be difficult in predictable and unpredictable ways.

The need to acquire ethical permissions should not be seen as a barrier or hurdle to be surmounted ahead of conducting research. In fact, addressing the demands of procedural ethics processes can be helpful in developing an ethically robust and scientifically valid research protocol. However, the “situated” or “practical” ethics to which the case refers are also a necessity; it is important for those involved in the procedural side of ethical governance to understand the challenges of conducting research in particular ethically sensitive settings or indeed the unexpected successes where potential issues are successfully avoided or dealt with. This is why the sharing of this case is important—not simply to highlight the particular issues observed in this setting but to demonstrate the possibility that moral principles laid down in general guidance cannot always capture what is really important in a particular case. This being so, the researcher cannot and should not rely on the approval of an ethics committee as a once and for all rubber stamp to do what they said they would do; rather, they need to remain live to the need to amend, adjust, and in some cases even abandon their project.

In the study reported here, the researchers entered an environment known to very few. In any setting, the self-contained nature of neonatal care units can be easily explained and defended in terms of concerns about infection and contagion, the containment of the worst types of fear and grief, the need for expertise and technology, and in some settings the fear of abduction. In an affluent well-resourced hospital, all of this makes the place where we care for the smallest sickest babies a place apart, a place where miracles and tragedies occur side by side on a daily basis, a place where the phenomenal pressures of caring are relieved as far as possible by healthy staff patient ratios and high levels of training and commitment. In the well-resourced unit, tiny babies are kept alive against the odds, and once this basic task has been fulfilled, time can be given to strengthening parental bonds, securing attachments, and eradicating the sense of tentativeness caused by the timing and manner of the baby’s birth and the trauma of its early weeks. When a baby dies, the full tragedy of this loss can be acknowledged and steps can be taken to assist families in the grieving process and beyond. No one expects babies to die in the well-resourced affluent hospital, so when they do the full enormity of this event will be acknowledged. None of this is easy, and conducting research within the setting where people are delivering and receiving such a complex package of care will always be challenging. There must be room for criticism, but when the system works well it is seen as an example of medicine operating at its limits and therefore criticism bites particularly hard.

This is to suggest that research within neonatal units will always be challenging, but the unit described here will
clearly pose particular challenges. Staff ratios are well above the recommended level and technological assistance is presumably well below. Babies die in alarming numbers compared with the affluent hospital. Parents are possibly forced to prepare for loss in a way that would be inconceivable in a different setting. We learn that babies have sometimes been abandoned by their parents and families, and in the limited information before us there is little suggestion of parents being an ongoing and potentially supportive presence in the unit. Staff are stretched to the limit at work and may well lead complicated and demanding lives which force them to leave when their hours are fulfilled rather than their tasks completed. Yet at the same time they are prepared to leave their work (which essentially means leaving the babies) to talk about their experience of working in this particular setting.

And so, the researchers find themselves in a very difficult situation. In this case, it was important for the researchers to halt the research until a practical adjustment could be made, that is, paying the nurses to be interviewed after hours. However, one could suggest that this does not get rid of the really difficult issue which is causing distress to the researchers, that is, their concern at what they see as the prevalent attitude to caring, which in their eyes is lacking. Through their own actions they have revealed a situation where nurses appear prepared to prioritize other activities over offering appropriate care to their charges, be that participating in an interview or rushing home at the end of a shift irrespective of cover. Though the researchers have a responsibility to the nurses who trusted them, they must also consider the risk to vulnerable patients, especially when the closed nature of the working environment might otherwise mean such discoveries remain unreported. One can see the difficulties the researchers faced in deciding how to report their findings.

But the issue will go deeper than this and the distress may be thereby compounded, because as stated at the beginning of this commentary these researchers are neither naive or judgmental. One of the things they will understand is that behind what appear to be flawed moral choices made by individual nurses are systemic problems which make their behavior more understandable if not completely defensible. Stories are powerful things we know, and health care professionals are rarely invited to offer theirs so let us not be too quick to condemn those who rush to speak even if we fear the consequences for their patients. Their stories will no doubt reveal in turn why for some individuals “staying on for a while” at the end of a day is just not possible and may also reveal that a broken system has placed pressure on people to go over and above for far too long. While a researcher will quite rightly feel terrified and overburdened by being pulled into caring for babies in a situation where what one can realistically do is already limited any extra pair of hands will be seen to make some sort of morally relevant difference.

So, to conclude. We should have sympathy for the researchers in this case because they were predictably unprepared for what their task would consist in given the working realities of the people they were observing. While their study revealed structural issues which were to some degree predictable, they were possibly unprepared for the feelings of personal disappointment at how this translated into individual choices and actions. Nor perhaps were they prepared for the way in which the nurses’ experiences would shape their view of the researcher as “an extra pair of hands” with all that this entailed.

Author Biographies

Bobbie Farsides is a professor of clinical and biomedical ethics. Her research has concentrated on ethical issues relating to health care, especially ante-natal screening and testing, reproductive technologies, palliative care, and issues around death and dying.

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