Age and high risk pregnancies

To what extent is knowing a contributor to medicalisation and suffering?

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Introduction: a discourse on risk

In Uganda pregnancy and the process of giving birth is viewed as a special health interlude by the medical system and the community. Hospitals have various units for regular surveillance of pregnant women with the objective of minimizing the occurrence of any preventable complications. Various messages exist for women to report to the nearest health centre, clinic or hospital as soon as they realize they are pregnant. This is because, for instance, as early as eight weeks gestation, they need to ascertain their HIV/AIDS status so that women who are HIV/AIDS positive can be enrolled in the Prevention of Mother to Child Transmission of HIV/AIDS programme. Pregnant women also need to be vaccinated against tetanus and begin taking anti-malarials on weekly basis to prevent infection with malaria. They are required to report to the health centre on a regular basis for monitoring and evaluation of the gestation process.

All these steps are supported by policies at national and hospital levels. For example, whereas testing for one’s HIV/AIDS status is voluntary, when a pregnant woman is enrolling for antenatal services, the policy changes to routine testing for HIV/AIDS thereby making it mandatory for such women to find out their serostatus. Some information may be given to the women client, but mostly every procedure they are subjected to including prescription for iron, monitoring their blood pressure, blood sugar and urine is done as a routine process. In the recent past, I was surprised to find out that pregnant women also need to take Fansidar every week as a prophylaxis for malaria.

There is another discourse about pregnancies in women above 35 years of age. These are characterized as high risk, advanced or delayed pregnancies. Vast literature (mostly statistical) supports this. For example (Loke & Poon, 2011; Salem Yaniv et al., 2011; Usta & Nasar, 2008) suggest that delayed childbearing has an increased risk of adverse pregnancy outcomes and advanced age (above 35 years) pregnant women may have more health concerns than younger ones, are more likely to be concerned about their
recovery after childbirth’ (63.8% vs. 42.7%), down’s syndrome (70.2% vs. 37.8%) and structural defects of their foetus (78.7% vs. 54.1%). Other complications include (Berkowitz et al., 1990) women who were 35 or older were significantly more likely to have specific antepartum and intrapartum complications and those who were 30 or older were significantly more likely to have both caesarean sections and infants who were admitted to the newborn intensive care unit. Older women were likely to have intra uterine growth restriction, low birth weight, congenital malformations, and perinatal mortality (Salem Yaniv et al., 2011).1

I would like to introduce this essay by sharing one woman’s experiences in a for-profit hospital in Uganda to suggest how a lay person with access to ‘insider knowledge’ or knowing coloured her experiences over a nine-month period during her pregnancy.2 I will argue that her knowing or not knowing influenced her health seeking behaviours, decisions made and outcome. Underlying the different processes in healthcare however, was the idea that ‘knowing’ made the otherwise normal process more challenging and caused unnecessary distress.

Case – Patience, a knowing client

Patience is a thirty six year old woman, expecting her third child.3 She is highly educated and can access any information she needs in the university library, internet and she regularly discusses her medical condition with different doctors she works with. She follows her pregnancy online week-by-week, both in photographic illustrations and notes about what could be happening. This information is confirmed by frequent ultrasound scans she can request free of charge to examine her own pregnancy since she has a health insurance with the for-profit hospital.

With her health insurance, she can report for regular examination and monitoring of her pregnancy in a prestigious hospital. Whereas she had already ascertained her negative serostatus in another hospital, when she visited this hospital, she was advised to go through all the routine procedures required of its clients. The routine procedures involve assessing different risk factors she could have. These risk factors include the her age (if it is above 35 years), number of children, whether there are illnesses within her or her husbands lineage such as sickle cell, diabetes, serostatus, blood smear(if there are malaria parasites in her blood), blood pressure and mental illnesses. The questions are asked and medical tests done with minimal
feedback to the client – apart from an explanation as to why the hospital
needed to know her serostatus.

After going through a battery of tests to ascertain her blood pressure,
her HIV/AIDS serology, the condition of her baby, whether she has malaria
and any sexually transmitted infections and all tests showed she was nor-
mal, Patience engages herself in a discussion. She asks herself what these fig-
ures and tests mean in relation to her health and that of the baby. She reads
the medical tests and results – and compares the information with what
is available in medical publications for normalcy and risk conditions. She
tries to examine how the general risk could apply to her individual risk. In
the process she also seeks to know what she/medical system could be done
to minimize such risks (if any). In the early stages of medical surveillance,
what fascinated her were results from the ultrasound scans and report from
the sonographer.

Patience is dismayed when she compares what happened to her six years
earlier when she was expecting her son and what is now regarded as routine
tests. She notices that at the time, the questions and medical tests she had
to go through during each hospital visit were fewer. Could it be because she
was now a high-risk client or is it because she goes to a for-profit hospital?
She decides that she would inquire about this difference during her next
visit. Upon inquiry, the doctor took time to explain how their policy is to
ensure a 99% positive outcome for the pregnancy. That is why it is manda-
tory for all pregnant women to test for their HIV/AIDS status so that they
can access free antiretroviral medication. In addition, there is a prescription
for antimalarials on a weekly basis, tetanus vaccine is administered regard-
less of how many times the expectant mother has received it-mostly to pro-
tect the unborn child-and a quarterly ultrasound scan to assess the baby
milestones. What is more, the client may request for an ultrasound scan at
any other time during the nine months if she needs it.

As will be discussed, Patience adhered with all the above tests and med-
ications partly due to her anxiety caused by knowing why these procedures
are done. Patience has also seen two family friends who lost their children
due to – as it was reported ‘negligence on their part and age-related com-
plications during pregnancy’. In one of her discussions with her bereaving
friend called Esther, Esther disclosed how she was so embarrassed that after
nine months of carrying her pregnancy, she had nothing to show for it. In
fact, one of the most difficult questions she had to answer was about her
baby; from people who did not know she had still birth’. Esther says: ‘For
instance, who would risk to transmit HIV/AIDS to an unborn child when
there are medicines to prevent this? Who would like to have a child severely
affected by malaria parasites which could easily be treated (and even prevented)? And in the era of high technology, to what extent can a disability in unborn children be minimized simply through medical surveillance and subsequent intervention?’

There is something unique about Patience. Perhaps it was because of the questions she always asked. Perhaps it was because of the information in her health insurance, it is not immediately clear. One doctor mentioned how he was surprised by the technicality of the questions she always asked. He concluded that Patience seemed to know much about her condition. Confronted with a multifaceted scenario where she knows about her pregnancies’ riskiness; the experiences of her two friends who experienced easily preventable deaths of their children; medical workers who were reserved or did not want to discuss much with their inquisitive clients, Patience is mostly anxious, and resorts to frequent requests for ultrasound scans and reading about them. She also adheres to any medication and sometimes makes requests for some like, iron. In one ultrasound scan, she is told about the knotted umbilical cord. Not much information is discussed thereafter. So she takes to reading and searching different people’s experiences. Whereas many publications show that the knotted umbilical cord is self-limiting, others show that there is a 50% risk that the unborn child (especially in twin pregnancies) could suffocate itself. The difficulty in determining the extent to which such a statistical analysis applies to her individual experience propelled her even further into discussions and reading about knotted cords. In a discussion with a colleague, Patience was told her about a recent case of a knotted cord pregnancy who was referred for a caesarean operation, but by that point the cord had strangled the baby already. Here then is a dilemma in knowing about a risk and the extent it can result in an adverse effect. How can one minimize the adversity and uncertainty after conceptualizing/individualizing the extent to which this discourse about general risk applies to them? I will come back to this issue below.

Discrimination in the healthcare system

As mentioned above, there are indirect consequences resulting from knowing and one of them is linked to the nature of interactions with medical workers. In particular, when a medical worker notices that a lay person has insider information. For Patience, the impression that she had insider information made it difficult for her to acquire much needed care and close monitoring. She was believed to be too engaged with her pregnancy and
that it was possible she would pose major difficulties and be too demanding to her personal doctor. Influenced by the information reviewed concerning such a pregnancy after 35 years, she visited a gynaecologist as early as eight weeks in gestation to request for an ultrasound scan. While the gynaecologist’s request was to establish whether Patience was pregnant, she at this time needed to confirm if there are any defects on the foetus. She was keen to read several times the sonographer’s report that ‘there were no major defects detected’. In an attempt to explore what the latter means, she got the following response: ‘A sonographer cannot talk about the health of the foetus, but the abnormalities. When these reports are made, unless there is a very clear defect, we always indicate and state our findings in the language that gives some element of doubt and risk.’ Whereas Gifford (1986, p. 220) states that there is always an element of intrinsic uncertainty in the practice of clinical medicine because the practitioner is required to translate generalized knowledge to the treatment of a particular individual: in our case, this intrinsic uncertainty was increased by the fact that Patience was to some extent the one who poses the different questions about her condition and to find answers to them. She believed that knowing, whether through reading widely or through biomedical technologies would minimize her uncertainty. However, instead of her quests for knowledge having an effect of minimizing her uncertainty, the effect of knowing was mostly increased uncertainty and stress. In effect, she was then propelled to seek for more knowledge, engage in many medical procedures, including scans and blood smears which were unnecessary. As a consequence, she ended up medicalizing an otherwise normal biological process.

Up to the time of writing this essay, I do not know if she could have done otherwise or if there is another way of going about this process which seemed subjective and highly ambiguous due to both the biomedical, epidemiologic and experienced risk. It could be said that the self-imposed surveillance and subsequent medicalisation of her condition was partly due to ‘knowing’ and partly due to the need to ascertain the extent to which the epidemiologic and clinical risk applied to her subjective experience. In effect she was in a situation which Gifford (1986, 234) describes as caught in a bind of being healthy and of needing medical surveillance until her condition is certain or goes away.

In other words, it was amazing that the very technology in which Patience was attempting to control uncertainty through exploring and viewing the unknown, instead increased or reinforced her uncertainty. As seen above, she received reports coloured in uncertainty. She interacted with colleagues and professional workers who also clearly stated how it was very
difficult to translate the statistical risk into a case-specific risk. In addition, her friends shared their experiences of adhering to all biomedical procedures, but ended with unfavourable outcomes. In short, if Patience needed an assurance-through the technology and knowing, she presently faced with more ambiguity and statements suggesting riskiness instead of ruling it out.

As Patience’s pregnancy progressed to 22 weeks—a process which she closely monitored the status on the internet week-by-week, perhaps to minimize the associated uncertainty and risk, available information suggested that her baby was now out of the dangerous stage when most miscarriages occurred. It was a relief, but the advice then was that it was time to register with a gynaecologist for regular monitoring. During one discussion a gynaecologist, Patience disclosed how at 22 weeks of pregnancy, she had undergone two ultrasound scans to monitor her pregnancy. In addition, she had decided to have an elective Caesarean Section because of many associated complications reported during normal birth—especially linked to a pregnancy six years since her last delivery. The gynaecologist disagreed with this point of view and insisted that biomedicine preferred that all women will first be given an opportunity to go through a natural labour; and it is only when this fails, that they are taken for an emergency caesarean section. ‘Besides, there are many complications which could arise due to the surgical procedure—not mentioning the high costs for the doctor, medicines and hospital bed. Of course many things could go wrong if the client was to first go through natural labour and later an emergency Caesarean Section surgery,’ she argued.

By this stage, it should be clear to the reader that, to Patience, the different scenarios are interpreted more in relation to what could happen to her and her child as compared to what would happen to many pregnant women. While many healthcare providers would like to generalize and give different statistics concerning an illness (see Gifford, 1986), such information may not be useful when an individual personalizes it and fails to see oneself as one of the general cases. At this point Patience expressed her fears openly concerning all the likely scenarios and I believe that it is this openness which prompted the gynaecologist to share the following experience.

... Hmmm, I have so many clients already and I do not think I would like to take on another client. Perhaps I will first consult with another colleague and let you know if he has fewer women this year. See, last year, I accepted to be a doctor to another lady gynaecologist expecting her third child. After the nine months and the caesarean operation we were no longer friends. She would argue about many things and dur-
ing the surgery, she screamed and shouted throughout the entire pro-
cess. For instance, she kept on ordering the anaesthetist to apply more
anaesthesia and complained that she felt a lot of pain. Since she was
watching the surgery on screen, she also advised me on a few occasions
how to handle some instruments. When I noticed that she also counted
the number of minutes as they passed, I instructed the anaesthetist to
do complete sedation before she would become a big problem patient.
From that day, I prefer having clients who know less about what we do.

The point I would like to stress here is that adhering with medicines and
suggesting that various medical procedures be carried out were not in any
way guided by a need to perform selective abortion in case it was discovered
that the foetus had any complications. Patience had a resolve to carry her
pregnancy to term but she needed to minimize the risks and negative out-
come based on available information and technology. However, as noted
before, the high technology and easy access to information – referred to
in this essay as ‘knowing’ – mostly contributed to more uncertainty and
stress. Whereas to some extent ‘knowing’ was beneficial, it was at the same
time dangerous, leading to unnecessary distress and what (Purdy, 2001;
Richters, 2003) calls medicalisation of normal biological processes. Purdy
(2001) reports that medicalisation has a purpose of transforming people
into patients and creates new markets for specialty clinics, diagnostic tests,
-pills, shots, self-help books, diet plans and the ultimate cash cow for regular
medical monitoring. I would like to add, knowing contributed to reserva-
tions on the behalf of medical workers in offering the healthcare in the best
possible way. Not-knowing in this case could be advantageous and even
beneficial to health since the medical worker is confident to perform any
procedure s/he thinks is appropriate.

**Adhering with various medical procedures**

Up to this stage we see that Patience requested various medical procedures
including an elective caesarean section and many ultra sound scans due to
her knowing and attempts to protect her child. In addition, she adhered
to many unnecessary procedures like weekly prophylaxis for malaria, regu-
lar checkups for changes in blood pressure and sugar level. To some extent
this adherence was propelled by her fears stemming from knowing and
her attempts to minimize uncertainty and the adverse outcome(s) which
are quite common in Uganda. Even when a caesarean section (CS) was
requested after learning about the presence of a knotted cord, it was with partial sedation because of the need to protect her baby from the various side effects of anaesthesia. The latter request was also guided by the need to be aware, to observe the entire procedure, to learn about CS, and yet not knowing other hidden effects such as the pain associated with any major surgical procedure. In fact many other complications could have arisen and complete knowing about them could have been a hindrance to making any decision in support of surgery. Patience was able to compare her experience after surgery with that of normal delivery as follows.

... it is true that the elective caesarean section helped to protect my baby and I. But if I had to go through the same process again while knowing all these other surgical procedures over a one-week period, I would have opted for a normal delivery. A caesarean section proved to have more risks and unforeseen consequences which could only be realized after I had gone through the surgical process.

In short, knowing had associated stress and anxiety, and helplessness that came with it, since it did not achieve its goal in helping to control uncertainty; I believe that not knowing would have caused more suffering. This is especially in connection with adverse outcome(s) which are otherwise preventable if such condition is detected early. Such conditions include likelihood of transmitting HIV/AIDS from the mother to her unborn child, a child developing defects due to malaria-related infections and still-birth due to the knotted cord. It would have been deemed negligence on her part to know much about her pregnancy or even to be able to know about her medical condition and yet not to make the right choices. The latter needs to be understood while bearing in mind that we are not really sure whether or not it is the decisions including those bordering to medicalisation of normal processes which helped to protect Patience and her baby. Life and achieving desirable health outcomes is more complicated than merely knowing and making the right decisions.

Conclusion

In sum, this essay has attempted to explore one pregnant woman’s health-seeking behaviour when she was aware of being a biomedical high-risk case. The argument is that whereas knowing led to distress, anxiety and medicalisation of an otherwise normal biological process, it is probable that some
of the informed decisions contributed to protecting the lives of both the mother and her baby. However, while Patience believed that knowing and even subsequent medicalisation would minimize uncertainty and riskiness, instead she found in medical technology and vast information an embodiment of uncertainty. ‘An embodiment of uncertainty because it resulted in extreme caution whereby an assessment was made of the extent to which a case is abnormal instead of assessing normalcy or the extent in which the case is normal. The clients are in most cases interested in the extent to which a case is normal.’ In addition, whereas medical personnel frequently quoted generalized statistical information including high risk of pregnancies carried by older women, they again preferred to view individuals on a case-by-case basis. The purpose of this essay was to pay tribute to Professor Annemiek Richters’ preference that her students think introspectively and analyze the meaning of phenomena basing on their experiences. Introspection in this essay means an attempt to analyze the extent to which medical information was relevant to Patience’s experiences and to what extent interventions promoted her health or distress.

Notes
1 Whereas it is widely documented that women with many closely spaced children are yet another high risk group; the senior gynecologist was again reluctant to attribute the idea that they are at high risk only because they are older or have had more children. Instead he preferred to analyze the extent to which a hospital has necessary equipment and how presence/absence of medical personnel affects a pregnancy outcome. In his view, it is mainly the lack of proper health services and the fact that fewer women in Uganda have ready access to professional care and that is why many of them (whether younger or older) can be regarded as high risk pregnancies.
2 In Uganda, middle or upper class patients and those who are literate attend for-profit hospitals since they have better equipment, more biomedical staff and mostly high technology. Similar reports are in (Finkler, 2008; Courtwright, 2008). For example Finkler (2008) contrasts between patients’ autonomies in two hospitals in Mexico. It is argued that middle to upper class patients and the highly educated are more autonomous than other patients.
3 Patience is a pseudonym. She agreed to make all the information written here public not only because the experiences are not specific to her; but perhaps – she imagined – that such information could be useful in future, if there is a need to improve reproductive health services to both younger and older pregnant women. Patience frequently discussed her experience(s) with the author. On various occasions she invited her to observe and listen to what doctors or nurses told her. She also shared report(s) from the sonographers and radiologists and she consented that information in this essay would be made public.
References

Berkowitz, G.S., Skovron, M.L., Lapinski, R.H. & Berkowitz, R.L.  

Courtwright, A.  

Ernester, V.  

Finkler, K.  
2008  Can bioethics be global and local, or must it be both? *Journal of Contemporary Ethnography*, 37(2), 155-179.

Gifford S.M.  

Loke, A.Y. & Poon, C.F.  

Pellegrino, E.D. & Thomasma, D.C.  

Purdy, L.  

Richters, A.  


Usta, I.M. & Nassar, A.H.  

Verkerk, M  