# Telling a child he is HIV positive

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## ABSTRACT

Telling a child he is HIV positive can create a number of difficulties. An example is given of a consultation where an 8 year old HIV positive child accidentally learnt of his diagnosis, while his mother continually denied this result to her child. The doctor tried to pressurise the mother into telling the child the truth and reflects on whether this was the best course of action. The issue of whether HIV positive children should be told the truth is discussed in the light of contrasting ethical issues: the autonomy of the mother versus the autonomy of the child; the autonomy of the mother versus the doctor's duty to tell the truth; the beneficence versus the maleficence of knowing the result; and family and cultural issues. From the lessons learnt, some recommendations are made regarding how to handle such difficult situations. ***(SA Fam Pract 2004;46(9): 35-40)***

## The story

**T** was an 8 year old boy with tuberculosis who was well known to me. He had been admitted several times to Manguzi Hospital, in rural northern KwaZulu Natal. This time he and his mother were in my consulting room with the results of the HIV test that I had earlier requested. After looking down at the out patients card and seeing that the HIV test result was positive, I asked the mother if she had been told the results by the AIDS counselor, and if she knew that the "iciwane" were present? ('Iciwane' is the Zulu word commonly used for germs, but nowadays has the additional unspoken connotation of HIV). After she said yes, I asked her whether the counselors had explained how the child had got these "iciwane". I was quite used to this line of approach and thus was totally unprepared for what happened next.

**T** suddenly burst into tears and cried out aloud in Zulu, "this doctor says that I have AIDS, this doctor says that I have AIDS". He was crying, screaming and pointing to me. The mother turned away from me, held **T** tightly and spoke forcefully to him, saying that he did not have HIV but that he had TB "iciwane" which were now cured. Both continued to cry and speak loudly.

Feeling fairly strongly that patients with a terminal illness should know the truth about their disease, I told the mother that it was not good to lie to **T** and that he should know the truth. At this stage the mother turned briefly back to face me and snapped, "he is too small to understand". She then reassured **T** that he did not have AIDS. **T** continued to cry, his mother continued to deny loudly that he had AIDS, and I continued to feel terrible.

Desperately looking for an excuse to get out, I told the mother I wanted to discuss this with someone else. I left the room to phone the AIDS counselor who had done the post-test counseling with this mother, and I shared my dilemma with her. She told me that the child had waited outside the door while the counseling was going on and so did not hear the diagnosis first hand.

Still shaken, I returned to the consulting room and asked the nurse assisting me to take **T** outside while I spoke to the mother alone. Still crying and fighting, he left with the nurse. Not really knowing what I was going to say, I started to explain to the mother why I felt it was not helpful to hide this diagnosis from the child. She replied that this would hurt him too much, that he may even commit suicide if he knew, and that he was too small to know. She was also scared of what might happen if Themba's aunt found out that he was HIV positive. Only at that stage did I learn that he was staying with this aunt, along with 8 other children, because his mother worked about 300km away, cutting grass for R500 per month. The aunt had already seen from the outpatient card that an HIV test had been done and had started to ask the mother awkward questions. **T's** mother was afraid that if the aunt found out the full story, she might ostracize him and stop him from attending school.

I had heard too many stories of children rejected by their families, once they were known to be HIV positive, to think that this was an idle threat. With that pressure, and **T** still wailing outside, I gave in and accepted the status quo – no more discussion about HIV.

When **T** came back into the room, he was still crying and pointing

at me, and even tried to snatch the outpatient card out of my hand in order to tear it up. I concluded the consultation as quickly as possible, telling the mother that the tuberculosis treatment was completed and **T** now cured. They left, with **T** still crying, while I escaped to my lunch break.

The whole event left me feeling deeply disturbed.

**Should a child be told the truth about his HIV status?**

Whether or not **T** should have been told the truth about his HIV status was one of the most disturbing questions of the consultation and one to which I could find no ready answer. I felt deeply that an 8 year old child was old enough to know and that to lie to such a child was not helpful.

Should we tell young children their HIV status? If so, do we do so against their parents will? These questions involve several complicated ethical issues.

*Issue 1: The autonomy of the mother versus the autonomy of the child*

The principle of autonomy is that every person has the right to make his own decisions about his health. But these principles may "not apply to children because they lack the capacity to make rational decisions. …Children are not accredited moral autonomy…. because they lack psychological maturity".[1] It is accepted that a parent will make decisions for a child, including what treatment is given and even what information is shared. However, this right is not absolute and may be overridden if it is seen that the parent is not acting in the best interest of the child.[2]

As the child matures, he/she is able to think and make decisions more independently. Thus "a parent's request to shield a young child from specific knowledge is less morally objectionable than such a request for an older child or an adolescent".[2] A shift then occurs, from a parent deciding what is best for a child to a child being old enough to decide for himself. But when does this shift occur? What of an 8 year old child? Was **T** old enough to know? I think this age is a transition point and the mother's argument to withold information does have some validity, but will have less and less validity as the child grows older.

The American Academy of Pediatrics "strongly encourages disclosure of HIV infection to school age children"[3], but states that this process of disclosure needs to be discussed and planned, and may require a number of visits.

*Issue 2: The autonomy of the mother versus the obligation to tell the truth*

Physicians do have an obligation to tell the truth to their patients. However, even in the case of adults with terminal disease, doctors are advised not simply to tell the patient everything to do with the disease and prognosis, but instead to let the patient control the flow of information.[1] Just as it is paternalistic for a parent or family member to withhold information from a patient for fear of how it will affect them, so too it is paternalistic for a doctor to assume that the child or patient must know the whole truth.[1]

Many people similarly feel that it is wrong for family members to decide on behalf of their sick relatives how much truth they should know about a terminal disease. It is difficult to deceive someone for long and little is gained by this deception, whereas much can be lost through damage to a relationship of trust. Adults who are terminally ill have usually already thought about dying and are often not afraid to face it.

One of the main reasons that both adults and children may not be told the truth is the reluctance of the doctors and the family to confront death. This may particularly be the case with HIV/AIDS where infection in the child (or partner) implies infection in the mother (or other partner). This reluctance to deal with death, or with HIV in general, was certainly part of the reason for this mother's reluctance to tell her child the truth.

Doctors differ in their views on the importance of telling the truth to patients. Some may see deception as therapeutic, others that any deception at all is wrong in any circumstance.[2] These views may arise from the family or religious backgrounds of the doctors. There is also external pressure from the profession and broader society, which now emphasise individuals' rights to full knowledge about their disease.

*Issue 3: The beneficence of knowing vs non maleficence*

A strong argument for telling a child about his/her disease is if that knowledge will affect the disease course or prognosis.[2] Not telling the child would deny access to support from other children suffering from the same disease and thus to participation in a care group. While this may be relevant for many childhood illnesses where compliance or self care is important, it was not relevant in this context because **T** could not access anti-retroviral treatment and no support group was available.

Studies in the USA seem to suggest that children who knew their HIV status had a higher self esteem than children who did not know their status.[3] Parents who had disclosed the HIV status to their children experienced less depression than those who did not.[3] These studies are important but one must take into account the cultural and family context in which they took place, which is vastly different to ours.

An argument for not telling the

child is the powerful stigma that HIV/AIDS carries in our soicety and thus the harm the knowledge of this diagnosis may cause for the child. There are few modern day diseases that carry such a weight of societal rejection.

Another reason given by **T's** mother for not telling him, was that he was too young, it would hurt him and he might commit suicide. Many parents fear that the truth may cause depression, distress and anxiety.[4] Suicide has been reported amongst adolescents who were told they had a fatal disease, but it is rare.[2] It is a myth to think that children do not have the ability to grieve and so should be spared bad news.[5]

An advantage of telling a child is that it can be done in a supportive way before he finds out accidentaly. If, as in this case, a child accidentaly finds out his HIV status, it may be difficult for him to discuss this with a parent, adding to the conspiracy of silence. As it is highly likely that hospitalized children will find out their status from overhearing remarks and results, the American Academy of Pediatrics recommends that symptomatic or frequently hospitalised children should be told of their diagnosis.[3]

Finally, if **T** reached adolescence, and became sexually active, the potential risk to others may well be a reason to tell him his HIV status, even against the parents' wishes.

## Considering family and cultural factors

Family issues were clearly of vital importance in this consultation. The family, and particularly the mother, has to accept the disease before the issue of how to tell the child can be worked through. This disclosure should be planned with the parents and may have to be done in stages.[3] If a mother is still in denial, very little can be gained from telling her child.

Disclosing HIV status to children can also raise questions such as "am I going to die?" or "why me?", which parents may not be able to deal with. It may bring up issues of death or sex which might be taboo subjects for families to discuss.[4] It may also provoke feelings of guilt in a parent that she has passed this disease on to her child, or may provoke anger in the child towards a parent for the same reason.[3]

It is also important to take into account the authority of parents in the culture concerned. In certain cultures the authority of a parent is held unquestioningly. In such families children may not be upset with parents for withholding this information from them.[2] Doctors with Western cultural values must be careful not to impose their individualism on the family of a group orientated culture. Western health workers are often tempted to focus on the individual patient, but work with Latino families with children who have HIV, has shown that care is best when the family is seen as a vital aspect of disease treatment and education. [4] A family centered approach is thus the ideal approach to the problem of children with HIV infection, especially in the practice context of a rural African community.

The issues of disjointed families are also important to consider. This family was broken up because Themba's mother was a migrant worker in a town about 300 km away. She therefore was not his primary caregiver, yet she was the one to whom the diagnosis was disclosed. Families separated by migrant labour are common in rural communities. It is important for the primary caregiver to be involved in any discussion about telling the child if a supportive home environment is to be achieved.

## What have I learnt?

In considering all the above I think it was wrong to insist that the mother tell the truth to the child. The mother does have autonomy over the child, at least at this age. The harm caused by the child knowing seems greater than the benefits of the child knowing. I was influenced by my values of telling the truth no matter what the circumstances. I was also influenced by my individualism (the child has a right to know) and not adequately aware of the mother's values of family and group decision making..

The mother had good reasons for not telling the child, centered around the stigma of the disease and how the family may react. I now think that the mother did have the right to withhold the information from the child at that time, but this would be untenable as the child grew older, or came to hospital more often. Telling the child would then need to be worked through to ensure that he did not find out inadvertently. This disclosure should be planned with the parents. As it was, the inadvertent disclosure to the child made a mess of everything and should be avoided in any future situation.

## How would I handle a similar consultation in the future?

I would aim to implement the following principles in the future.

1. Try at all costs to avoid the child discovering his diagnosis accidentally. This would include being careful of what one says in front of an older child, and making a child wait outside the room during consultations and pre and post test counselling.
2. Work for parental acceptance first. There is no point in trying to tell the child, if the parent is in denial.
3. Discuss issues of disclosure with the mother. There are many people in the family who may need to know the diagnosis of HIV, not just the child, so I would look at the issue of disclosing to the child, in the broader context of who else in the family needs to be told. These may include sexual partners as well as other

caregivers of the child. I would then discuss with the mother whether she thinks it is a good idea to tell the child. It may be particularly influenced by factors such as whether the child suspects the diagnosis already, is asking questions, or is becoming an adolescent.

4. Plan with the mother how to tell the child. The mother has the choice as to whether to tell the child herself or involve a health care worker. She should find out how much the child already knows and how likely the child would be able to cope with knowledge of the diagnosis. This will determine if, and how much the child should be told. This may be done over several sessions and would be well discussed with the mother first. The mother will need to be able to give much emotional support to the child at this stage, showing love and trying to be positive.

In practice, there are probably very few mothers who will complete all of the above steps, but striving for this ideal should prevent some of the difficulties faced in this consultation.

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**References**

1. Christie RJ, Hoffmeyer CB. Ethical issues in Family Medicine. New York: Oxford Univ Press,1986.
2. Sigman GS, Kraul J, La Purna J. Disclosure of a diagnosis to children and adolescents when parents object. Am J Dis Child 1993;147:764-8
3. American Academy of Pediatrics, Committee on pediatric AIDS. Disclosure of illness status to children and adolescents with HIV infection. Pediatrics 1999;103:164-5.
4. Brown LK, Lourie KJ, Maryland P. Children and adolescents living with HIV and AIDS – a review. J Child Psychol Psychiatry 2000;41:81-96
5. Doka KJ. Eight myths about children, adolescents and loss. http://www.hospicefoundation.org



# ANNOUNCEMENTS

*Prof. Bruce Sparks* was recently elected the *WONCA President* for the next triennum (2004 - 7) at the Orlando, USA conference.

*Prof. Gboyega Ogunbanjo* was elected President of the *College of Family Practitioners of CMSA* on the 1st of Oct 2004. Initial term of office is to the end of the current triennum i.e. Oct 2005.

**CONGRATULATIONS!**