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'Too much for one day': a case study of disclosure in the paediatric HIV/AIDS clinic

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Abstract

Background Despite acknowledgement of the complexity and challenges of the process of disclosure of HIV status to adolescents, little work has been carried out on the communication features which facilitate or hinder the process. This qualitative case study reflects the interactional dynamics of an interaction between caregiver, physician and counsellor around the topic of disclosure in a South African clinic.

Methods A 40-minute encounter between a doctor, the grandmother of an adolescent with HIV/AIDS and a counsellor around the process of disclosure was transcribed and examined in detail in relation to its structure, topics, timing and sequence as well as its movement towards a collaborative ending. Analysis was based on elements of conversational and thematic analysis.

Results The session was characterized by distinct stages and the emergence of multiple voices and perspectives from the participants. The negotiated management of the session sheds light on multiple barriers to care as well as the influence of contextual factors on the process. The important mediating role of the counsellor in the triad emerges. The analysis highlights both unique features of the consultation and common challenges to clinicians when disclosing.

Discussion and Conclusions The task of disclosure is complex and intricate. Results suggest team processes are critical, as are temporal and contextual factors and the need for an understanding of communication. Implications for the clinic team are discussed and suggestions made for the development of collaborative partnership based on an understanding of roles and responsibilities, time factors and enhancement of features such as trust and communication.

Introduction

The topic of disclosure has received considerable emphasis in recent writings about HIV/AIDS yet remains a great challenge to practitioners. This is particularly the case (as Watermeyer's[1] paper suggests) in childhood and adolescent HIV/AIDS. Little has been written about the optimal process of disclosure and the impact that barriers to disclosure have on the process. In general, current studies suggest that the process is best managed by a team, and that the process should be careful, finely tuned to the child's age, language ability and emotional level of development and reflect deep sensitivity to issues such as stigma.[2,3] There appear to remain uncertainties, however, about whose role and responsibility the process relies on, the timing and way it should be carried out. As Watermeyer's paper implies, many factors influence the process, including the availability of the caregiver, the structure of the health-care team, the setting as well as prevalent (and often changing) guidelines and policies.

In this paper, I will report on a case that illustrates such complexities of disclosure in the case of an adolescent girl. While these data were collected some years ago, in the context of a paediatric HIV/AIDS clinic, it provides a rich example of so many of the issues that remain relevant and hopefully therefore serve as an opportunity for reflection and a springboard for pointers for practice.

The session described here is one of 21 interactions between doctors and caregivers of children attending a paediatric site at a large government hospital in South Africa which were studied in detail.[4] Over a 3-week period, a series of consultations between doctors and their patients were recorded in the context of the HIV AIDS clinic in a large children's hospital in South Africa, where the language of the majority of the patients seeking care is Xhosa and where language barriers often exist between health practitioners and patients.[5–8] Some of these interviews were mediated by a by a counsellor, an NGO trained and employed individual, herself HIV positive, whose role was to assist the medical staff with their role in the clinic. The powerful role of this third person in intercultural health settings has been recognized as being central to the success of interactions between the doctors and the patients and typically extends beyond that of interpreter to that of mediator or 'cultural broker'[9,10] or 'community navigator'.[10,11] However, the success of this triad is also clearly related to factors such as trust between participants in the triad[12,13] which may not always be easy to achieve in the context of a public health setting with limited resources and in the context of a disease with its mantle of stigma.

While many interactions in the South African context involve such a third party, little is known about the role of such individuals in the complex issue of disclosure and whether or how their presence facilitates or enhances the process. As seen from Watermeyer's paper, very often the complex task of disclosure is delegated to others and the whole process of locus of authority is both unclear and uncertain to those working in a clinic. It seems important to document the process in depth and to gain greater insight into what resources are brought to bear on the process by all those involved, which can facilitate understanding of this complex task. An illustrative case study on the process of disclosure between a doctor, counsellor and a caregiver will now be presented.

Methods

In the larger study, qualitative methods were used, including ethnographic descriptions of the health-care sites, recording of interactions between health professionals and patients and interviews with the participants in these interactions. Ethical clearance was obtained from the university IRB. Informed consent was sought from all participants, and data were anonymized. Sessions were video–recorded, and all components of the interactions were transcribed and translated where necessary. The primary qualitative methods of analysis were hybrid and qualitative in nature following research principles of interactional sociolinguistics. The organization of these encounters was examined through aspects of conversation and thematic analysis.[14,15] Interactional aspects such as openings and introductions, turn-taking, repair and the presence of collaborative moments (moments in the interviews where participants and observers endorse mutual understanding) were examined, as well as the unfolding of topics and segments.

In this case study, the analysis will focus on the text and the phases of the session, drawing liberally on the actual transcript and illustrating the turns, discourse markers, its organization its sequences and the transitions, the vocabulary, the repairs, the topics and the emerging narratives.[15]

This is an interview between a doctor and a grandmother of a 12-year-old girl (whom we shall call Anna) whose mother died the year previously from AIDS. Shortly before her death the mother asked her own mother to care for her children and not to disclose to them the cause of her own death. She also reassured her mother that her children were in good health. This was despite a visit of her younger daughter, Anna, to the hospital 2 years earlier to have lumps removed from her neck, which was attributed to TB.

On this return visit to the hospital, the grandmother (who is an unemployed teacher) brings Anna and learns during this interview that her granddaughter is HIV positive. As the interview with the doctor unfolds, we have an opportunity to see the agonizing implications of this diagnosis and observe an interaction around disclosure which in many ways serves as a microcosm of complexities facing many clinics.[16] The differing agendas and experiences of the two participants emerge and interface, and there is a move towards a resolution through the mediation of a third person (the counsellor) who is later brought in to assist and who helps frame the interaction in a particular way and produce a resolution and a decision.

Description of session

The interview has several phases illustrated in Table 1 which also indicates relative proportion of each phase based on word count. The major part of the consultation involves a dialogue between the doctor and the child's grandmother around the issues of disclosure to the girl.

Each of these phases is clearly discernible in the transcript and is marked by verbal as well as non-verbal aspects.

(In the ensuing discussion, direct transcript is represented in bold italics, line numbers indicate sequence in the interview and participants are identified thus: D = doctor, G = grandmother, C = counsellor, A = child; unintelligible utterances are in brackets; overlap is indicated [, latched utterances by =, hesitancies by, missing extract by …….)

Table 1 Phases of the medical interaction

1. Opening and introduction (18% of the interview)
    - referral to case file
    - brief history
    - interaction with child
    - establishing socio economic status
    - questioning mother's cause of death
2. Child leaves room
3. Doctor and grandmother dialogue (57% of interview)
    - Discussion of child's status
    - Doctor's reasons for disclosure to child
    - Grandmother's arguments against disclosure
    - How infectious is HIV?
    - Difficulty of decision acknowledged
4. Introduction of counsellor (12%)
    - Introductions
    - 'Who will tell?'
    - 'Maybe it's too, much for 1 day'
5. Final plea 'Contain the consequences' (8%)
6. Closure and the way forward (3%)

In the **opening and introduction** phase, the participants include the doctor and grandmother (who in this case is fluent in English) and the 12-year-old Anna. There is some discussion as to the language of the interview and the doctor enquires as to whether this is the first visit. The doctor notes from the file, a prior visit and says:

> **27 D 'And they recommended that they were concerned about TB and those things'.**

He guides the interview and is asking about the family circumstances, who lives at home, what school Anna attends and sources of income. He then moves to the circumstances of the mother's death:

> **93 D Do you know why she died and what was the problem?**

The grandmother answers:

94 I think it is a ritual there (at the hospital) that it is private and confidential

This serves as a trigger to the doctor and in the very next turn he says:

95 D I see. I think I would like to do – would it be OK with you if I speak to Anna first then I speak to you on your own and I speak to you both together at the end?

The grandmother says:

97 G No
98 D Is there something that you (unintelligible) = ?
99 G = No
100 D Alright. What I would like to do then is speak to you both together.
101 G I think I can just listen to you. She must report outside.

The doctor checks that this is all right with Anna, and she exits marking the next phase of dialogue between doctor and grandmother.

Then the grandmother says:

106 G She is going to shout at me. Why do I want to talk private?
107 D Don't worry she can shout when she comes back. Now alright. What is your understanding of what happened to Anna's mother?[What-
109 G [She had AIDS
110 D She had AIDS and died of that?
111 G Yes
112 D OK
113 G And I understand she did not want the children to know.

I consider this to be a critical interchange. The doctor was sensitive to the grandmother's message and had carefully avoided the term at the beginning substituting instead a vague 'and those things' (line 27). After the girl has left the room, the term 'AIDS' is used. The avoidance of the term has been documented in some other work and underlines the impact of the diagnosis.[17]

The grandmother's use of the word 'listen' in line 101 and '*I think I can just listen to you and she can go outside*' implies a passive role, either because that is her expectation in her role as a patient, or possibly because she is deliberately making an attempt to reassure her granddaughter that she will not be active in betraying confidences. She is also probably indicating that she is reluctant to take an active part in this difficult discussion.

The consultation moves to a discussion of Anna's previous visit to the clinic and the glands in her neck.

120 D: The doctor there was a bit concerned about HIV and one of the tests they did was an HIV test on Anna and that test was positive.
122 G Positive meaning?
123 D Positive.
124 G Because the mother said it was negative.
125 D OK.
126 G She did not want for me to know.

The full import of this diagnosis and her daughter's omission takes time to sink in.

I find it interesting that G seeks clarification on the term 'positive' – a recognition of the baffling ambiguity of the term in some contexts.[18]

The doctor points out from the file that there had been referral to counselling and follow-up appointments and they discuss again that the mother had kept the diagnosis from her daughter and from her mother.

138 D So in fact your daughter kept a secret from you your whole life until she died.
139 G Yes.
140 D How do you feel about that?
141 G Bad. Bad. Cause I was looking forward to her. I thought she was a child which I was going to look after you know.

She demonstrates real sadness at the prognosis that comes with this label for the remaining child in her care.

There is then a discussion about the child's 18-year-old sister who is left home and her whereabouts is not known.

147 G I understand she is pregnant somewhere.

The grandmother expresses distress and reports her efforts to find her:

153 G I try the social worker everything.
155 I wanted to give them the best.

The doctor is sympathetic to her plight and in the next explanation discloses his experience and frustration with the system and his understanding and daily engagement with the social and political context of the disease:

> **158 D You don't know where she is. Shoo. Umm You know then one thing that has happened with this HIV epidemic in South Africa you know it's that it's been kept a big secret. Whether it's at the top government level or whether it's at the family level. And from our point of view we can understand it's because of the stigma that's attached to HIV. But at the same time stigma and secrecy is one of the reasons why there's been such a mess you know with this disease.**

At the time of the study, this level of frustration also emerged in interviews with all the doctors in the project.[4] They were experiencing burnout and anger, a sense of frustration about how little they can do, and anger about the delays in the ARV rollout programme and their own hospital's response to it.[19]

The doctor continues. He makes clear what he wants to happen next:

> **166 D She – from my point of view a 12 year old needs to know what's wrong with them if they tended to – and they need to start to understand. Starting to take responsibility and I think it's their right to know what's the matter with them….. I really feel we need to for the sake of yourself and respect for- I need to actually bring her into the process and explain to her what's going on.**

The grandmother expresses great reservations about the timing of this:

> **179 G I'm going to die! She'll be scared you know. That is the time she's going to lose weight. She's going to be you know. I don't think it's necessary Let her play to be a child and then when she starts to get sick, then tell her.**

and later:

> **189 G Let her be a child and play.**

She is very concerned about disclosing to her granddaughter and to others. Her reasons clearly lie in breaking a promise, shortening Anna's childhood, jeopardizing their relationship and the social stigma of the disease:

> **191 G Whether they are playing with the others she'll say 'Oooh I've got this you know'**

and

> **330 G Sometimes at school they're laughing at her. What is this? (unintelligible) before this rash you know?**

The doctor persists however and it is clear that he has concerns. He explains that disclosure is a process, taking more than one session:

> **336 D I hope it will actually give you a better understanding of each other and be able to talk to each other. In the same way she doesn't have to tell anybody about the HIV if she doesn't want to, you know. It's up to her. It's up to her and to some extent to you but it's actually up to her. You know she has to choose people in her life who she can trust you know and you're the first person who she hopefully can trust.**

and

> **347 D Ja. Look I'm not saying she won't be upset. I'm sure she will:**

He also strengthens his arguments by citing other reasons why disclosure is important. These relate to her age, her sexual maturity, the 'unfortunate truth' that 12-year-olds in the township where the family lives are sexually active and the possibility of her infecting others.

> **370 G She mustn't start with that. Nothing nothing**

He refers to the possible availability of treatment (which was not available for her late daughter) and the importance of timely treatment.

> **294 D And in terms of waiting till she gets sick well I don't' agree with that. Because if she needs treatment I might be able to offer her treatment I'm not sure.**

There are other concerns he poses. One links to the fact that at that stage the ARV rollout process had not started at that clinic. The other reflects that it is unusual for a 12 year old who has contracted HIV perinatally, to have survived, and he alludes to the possibility of sexual abuse or rape as a cause for the disease. He also stresses how important it is for a child of this age to come to terms with the true circumstances of her mother's death. By mutual agreement, they seem to conclude she has contracted it from her mother at birth or through breast-feeding, clearly because the alternative is possibly too much to confront in this session.

> **265 D It's possible that she – that her body is such that she's been able to fight HIV for 12 years.**

However, later in the interview, the grandmother indirectly returns to the possibility:

> **343 G Her sister is gone She's scared with the uncle Because the uncle drinks he's on drugs.**

and afterwards the counsellor whom I interviewed is almost certain that Anna has not contracted HIV at birth.

The grandmother then raises concerns about how HIV is contracted, and there is some discussion as to how to protect everyone at home. We see in this interview that the grandmother has some information about the disease. She refers for instance to the importance of good nutrition and mentions the epidemiology of the disease.

> **317 G So am I going to feed her now with vitamins or whatever?**

and

> **262 I think she got it from her mother because they came from Zimbabwe**

Great fears are also expressed by the grandmother:

> **303 G I don't want to lose Anna. I don't want to lose her.**

The doctor replies with sensitivity:

> **304 D Are you frightened how she'll react? I am also frightened how she'll react but it's the right thing to do. It's the right thing to do. I don't believe in- I don't believe in being unclear. I can't be dishonest with her and say it's TB or something else it's not you know. It's time for somebody to start to come to terms….**
> **312 G: Hai It's difficult. It's a difficult one**
> **313 D Ja**
> **314 G It's a difficult one**
> **315 D I think we can't always take the easy route. The easy route is 'bye see you in 3 months come back and we'll check up'. Some people do that I don't really agree with that.**

Later again:

> **362 G Ai doctor it's difficult, it's difficult. Difficult**

In both the above examples, we see the use of repetition for emphasis – a device we see also in examples below (lines 356 and 374).

The grandmother expresses her fears and concerns about disclosure:

> **452 G Even when she's playing with other children she won't be the same, she won't be the same child.**

And in a later example:

> **510 D I can give a letter for school saying she must come to the clinic**
> **511 G Will you say what clinic it is for?**
> **512 D No you don't have to tell them, if they phone me I won't tell them.**

She suggests again:

> **354 G Don't you think just leave it?**

The doctor challenges again patiently:

> **355 D What's the benefit of leaving, of not telling her about it?**
> **356 G She won't be the same. She won't be the same.**
> **357 D What happens if she starts getting sick? What are you going to tell her then?**
> **358 G That's the time we tell her.**

It's clearly a distressing decision for the grandmother:

> **372 G What do you suggest doctor? Oh!**
> **373 D I told you what I suggest.**
> **374 G I'm getting sick. I'm getting sick now. It's not all right for me to tell her.**
> **379 D I think we should tell her. You know it's up to you if you want to be, if you want me to tell her with you or without you. I can speak to her that's fine I can speak to her alone or with another counsellor.**
> **383 G Counsellor.**
> **384 D Is that what you would like me to do?**
> **385 G Yes.**

So towards the end of the interview, the doctor calls on the counsellor (who is in a nearby room) and there is discussion as to whether disclosure to Anna about her HIV status should come from the doctor, the counsellor or her grandmother.

414 G It will be better if you people tell her.

The counsellor draws on her experience. Of note is the fact that even this part of the interview continues in English although the counsellor and grandmother are both Xhosa-speaking.

419 C: You know usually when like today it's new to you (unintelligible) But usually we used for you to go home and think about it and then we must tell Anna and then you'll have the strength to speak to Anna. Or else is that you can now you admit that we must help Anna in front of you. So it depends on you. But if at the same time you say we can tell Anna now. But only thing I'm worried about maybe Anna will cry and at the same time you're not very strong to comfort Anna. That's what I am sorry about.

The dilemma is identified, the responsibility placed in the hands of the grandmother, and the burden is clearly too much for her.

The doctor commences the final phase of the interview:

426 D Maybe it's too much for one day.

This is echoed by the counsellor and then the Grandmother:

427 C Too much for one day
428 G Too much for one day. That's what I said

The doctor explains again the reasons why she must be told on the next visit but says:

441 D I realize that today might not be the best time for you guys.
442 G Today's not the best time.

The doctor perseveres:

443 D Do you agree in principle that we should tell her about the HIV?

Grandmother consults the counsellor:

444 G What do you think? Must we tell her?
445 C When, today?
446 G Not today.
447 C Yes you must tell her, but not today.

The doctor confirms with the counsellor:

449 D But you agree that we should tell?

The counsellor says:

450 C It's wise she must know she is HIV positive.

This doctor in a prior interview with the researcher has expressed the fact that the counsellors in that context do not always function as a part of the team and the doctors feel that sometimes they do not know what is being said, nor how accurately there translation back and forward. It is of significance in this interview that he has used the counsellor in a highly specific way – to reinforce his plea but he is acknowledging the differences between him and the other two participants on this issue with his use of the distancing term 'you guys' (line 441).

The doctor makes a final and impassioned plea for disclosure, which forms the last phase of this interview in a turn which takes almost 90 lines of transcript.

461 D We have to contain the consequences of this thing OK? You understand what I am saying?

He repeats the reasons why disclosure is important and then shifts the genre into narrative:

469 D I just want to tell you a little story. There was a little girl that I- that was in the same position. Exactly the same position some months ago in this room. I think she was maybe 10 years old, 11 years old and her mother had died. And she was never told why her mother had died. She was never told she had HIV and she was here with her granny. I spoke to the granny in the same way we've spoken now and the granny agreed that I should tell her ok? We sat down together with somebody. We spoke and I explained to her. She was upset. She wasn't very upset. She cried but she wasn't very upset. Um and the granny was there and she was upset as well and you know the next week she came back for treatment and she was actually so relieved. The little girl came to me and she'd drawn me a picture of her house and she'd made some beads for me… She

had a big weight off her shoulders you know. All of a sudden she could come out and just say 'I was OK'.
....she can come to terms with what's going on instead of living in a sort for a mystery. Do you know what I am saying?

He then shifts subtly into the present:

492 And it might not be like that with her. She might be very upset...but I think we have to give her the option......It would be different if she was 6 or 7 years old ......
But we don't have to do it today.
(to counsellor) **We can make another appointment in a week or two. I don't' want to leave it long cause she's going to lose confidence.**

This narrative provides a window onto the doctor's experience, wisdom, hopes, fears and his professional calling. His use of narrative is powerful and heartfelt. He is conveying his message in a culturally relevant way, and through this, we gain insight into a significant prior moment for him as a healer against a backdrop of a daily struggle with futility and thwarted attempts in his role. He is disclosing his own persona to achieve his goal and to hopefully save this child.

The grandmother concedes:

500 G When am I coming again? Next month?

and the rest of the interview is spent organizing a date and a mechanism of getting the child off school without disclosing the purpose of her visit to the hospital.

At the end:

518 G Next week Friday. Oh where am I going to get the money from?

The transcript ended here, and at the time, I did not know of course whether the grandmother would return as promised or would seek help elsewhere and take 'the easy route' to which the doctor has referred (Line 315). I wondered whether the doctor felt this too.

There is a sense of hanging or suspension in this transcript – a personal and political engagement in which the participants strive for common ground and then withdraw to a no man's land of what has been described as subtext or 'white space that signifies thoughts, disagreements, distress and indecision'[20] [p188].

Discussion

This interview seems to capture the type of engagement that is going on everyday in the paediatric HIV/AIDS clinic – a merging of multiple views and value systems, cultures and perspectives, the pivot of which is, in this instance, the issue of disclosure and the struggle about whose responsibility it is, why it should be done and when it should be done. In the analysis of this text, different attitudes to disclosure emerge. One comes from medical experience and training and another other comes from life-experience in a context of poverty, family loss and uncertainty. The third is the voice of the counsellor serving as a broker between the two worlds. But they are not in conflict. In fact, this interview provides a subtle and shifting picture of the nuances and complexities that pervade clinical decision making in this context and the lack of resolution that originates from both intrinsic and extrinsic barriers which are acknowledged by the participants throughout. Interestingly, the voice we never hear in this interview is that of Anna herself, whose role and attitudes remain regrettably unexplored and will clearly be critical in future management issues.

While such issues play out daily in the paediatric clinics of sub-Saharan Africa[21] with different participants, this particular session seems to stand out. The medical practitioner seems attuned, sensitive, experienced and principled. In fact through aspects such as narrative genre, the transcript glows with his presence. The grandmother is a symbol of resilience, adaptation and coping in the context of great loss and the shadow of future loss. The counsellor is drawn in as a partner to the doctor and he displays an attitude to her that she is equal, valued and collaborative. This is perceived by the patient, and their partnership thus appears as trustworthy and non-judgmental. The final decision is mutually negotiated, and all participants agree that the decision should be deferred. Although the outcome of this session may be inconclusive in one sense, it is a mutually negotiated outcome and reflects integrity of process and mutual understanding and locus of responsibility.

The consultation is thus truly a participative and collaborative one and contrasts with many accounts of medical discourse in general where a range of gender, power and cultural differences lead to a situation where the patient role is generally passive and there are documented reductions in spontaneity, initiation and interaction.[22,23] One can only conjecture as to why it this consultation is so different, and there are several possibilities.

The first aspect is that the grandmother (as a former teacher) is well-educated and apparently well-informed about the disease and its course. She has a good command of English, initiates turns and is capable of speaking her mind. She asks questions, is forthright about the diagnosis of her daughter and is willing to engage in a lengthy and difficult debate around the main issue. Turn-taking is smooth and there are very few instances of conversational breakdown or misunderstanding. She understands what is being said, and she clearly has agency and is able to express herself fully to the doctor and to discuss hopes, fears and loss.

The second remarkable feature of this interview is the fact that the doctor is clearly experienced, sensitive and above all willing to disclose his own perspective. Disclosure as a phenomenon has been documented as being a characteristic of the 'good' and trustworthy doctor and interestingly emerges as a theme in the medical education textbooks.[24,25] This doctor during the interview takes the time to disclose his attitude about the disease, the social context of health care, government attitude and then in the latter part of the interview what is meaningful to him as a practitioner in day-to-day practice. Through this process, he appears to be gaining the trust of the patient. Another feature of note in this session is the fact that the time spent on this session is much longer than a usual doctor–patient consult in this setting. This session was an initial consultation, and the policy of this setting was to allocate a period of at least 30 min for such initial consultations. The themes that emerge and the resolution which happens in part must be attributable to this aspect. Time is perceived as one of the largest barriers to care by many patients and doctors although there is strong evidence emerging that time spent in the first consultation will save both time and referral and laboratory services later down the line in the medical interview.[26]

Importantly, the doctor's use of a third party is carefully and specifically attuned to the individual dynamics of the session. As evidenced in the transcript, there is no uncertainty on the counsellor's part as to her role in this process and there is no misunderstanding that emerges on the part of the grandmother as to the counsellor's role. The counsellor, when she is called in, is recognized not just as an interpreter but as someone whose opinion on this matter counts.

While such features make this interview potentially unique, there are also features that share a common thread with other commentaries on the disclosure process.

Socio-economic factors are woven as a thread throughout the interview. The doctor exhorts early treatment so the child can 'finish school, get a job'. At the commencement of the interview, we discover that the grandmother is unemployed and surviving on a foster grant that the child's father is not contributory and at the end of the interview the grandmother asks presumable rhetorically, 'where will I get the money from?', reflecting other research in this context on the costs of care.[27]

Stigma is another theme. Interestingly, the clinic that these patients come to is housed in a respiratory clinic. Patients who have a choice of going to community-based clinics would prefer to travel a long distance to the relative anonymity of an unmarked clinic in a general hospital. We see the grandmother's concerns throughout the transcript. This is obviously closely linked to the anxiety about disclosure woven through the transcript.

The topics covered in the consultation are broad and interestingly echoed a number of the issues emerging in the literature and in Watermeyer's study with health professionals which all emerge as potential barriers to disclosure including fear of stigma, cultural taboos.[1]

Conclusion

This paper has examined a discussion about the process of disclosure to an adolescent through the lens of a particular medical consultation. The analysis demonstrates that an understanding of the intricacies of language interaction can highlight significant factors and reflect much broader societal and cultural conceptualizations of the illness and of barriers to care.

In this interaction, we become aware of the many facets of disclosure including its consequences, process, timing, agents and management. What emerged here is a joint locus of authority for the decision.

Through the eyes of the doctor, the consequences of disclosure are critically important and are ultimately potentially positive to the individual and to society. Through the eyes of the grandmother, there are huge personal risks and penalties attached to disclosure at this time both for herself and her grandchild. The impact of disclosure is clear: '*She won't be the same child*'. Through the eyes of the counsellor, we see emerging what has been described as 'epistemic vigilance'[28] and the need to understand both worlds of the health practitioner and the patient. We are reminded of Goffman's assertion[29] that 'when a word is spoken, all those who happen to be in perceptual range of the event will have some sort of participation status relative to it'. There is a burden of responsibility and of decision making which comes with disclosure and which is felt by all – '*Too much for one day*'.

We see in this medical encounter the essence of the issue and its dialogue. It is not just about dialogue between the participants in the session but between the individual versus society, innocence and experience, loss and life, the anecdotal and professional; the illness and the disease, loyalty versus betrayal – it is a dialogue cast not in the standard 'black/white, male/female, doctor/patient, have/have not' dichotomies but in much more complex and dynamic mutuality. HIV/AIDS may be a common theme, but its personal meaning is diverse. Even with mediation, or perhaps because of mediation, we are left with an uncertain future in this case – an uncertainty and ambivalence which is the essence and the horror of this disease in its current socio-political clothing. We are reminded that 'even at its scientific best medicine is always a social act'.[30]

There is thankfully a postscript to this session. Recently, I sent a draft of this paper to the physician concerned, still working in this context and he replied:

> 'Thanks for forwarding this paper to me. I remember the patient and the consultation well. It stands out for me too. Reading through your detailed and learned analysis of it is quite a humbling and revealing experience for me. It makes me realize the value and importance of the work that I do and reveals to me why I am drawn to it. I think that I am motivated by a basic instinct to act meaningfully with the people who I meet as patients without knowing whether I bring a degree of experience and developed skill to this after having been a doctor for some years.
>
> I also understand the value of qualitative research along with the drier quantitative research that we are mostly involved in. I am pleased that you undertook this research in our clinic and have used it to present to others, to teach students and feed back to us.
>
> There is quite a physical and emotional cost to the work in personal terms as a result of pressure of work, number of patients, frustrations and the sheer weight of the problems we are faced with.
>
> By way of feedback and for your interest the patient was disclosed to and started ART. At last check she was doing well and the virus is below detectable levels in her blood. This is what keeps us going…'

These words not only validate the method of analysis but confirm the important contribution of communication factors in the clinic towards the success of the process. They further highlight the fact that both for the researcher and the doctor this case is memorable and, as an outlier, generates a particular curiosity and impact. It is reassuring that the adolescent is eventually given voice and agency and became part of the team decision.

Of significance is the fact that Watermeyer's data on disclosure in children and adolescents, which reflects current practice in a different but similarly well-established and resourced clinic in South Africa, echo the issues of this earlier case study. This implies that in spite of the plethora of tools which are now developed as well as the presence of many guidelines, health-care professionals still feel uncertain as to how to manage the process. Watermeyer's data reflect confusion and tension often between different levels of health-care professions and the hierarchical factors that contribute to the difficulty of the task. The topic clearly remains a major barrier to care and a priority for clinics.

This case study does indeed suggest that this task of disclosure is sometimes intricate and difficult and that team processes are critical, as are temporal factors and the need for a process approach. The analysis suggests that the process of disclosure cannot be a 'one size fits all' one, but is very much determined by the context and the individual participants. In this trialogue between patient, counsellor and doctor a way forward is found and we see how trust seems to emerge.[9] The analysis suggests the need for a fluidity of role amongst team members depending on topic, patient and stage of interaction. This flexibility or 'mundane creativity', which Celia Roberts[31] has described, seems to be an essential component of successful practice in the context of an HIV/AIDS clinic.

This study clearly has implications for team training in the paediatric clinic. Collaboration in the clinic typically is a culturally determined event, reflective of the broader societal context. The findings suggest the need for an institution as well as its employees to recognize the potential role of the counsellor in providing knowledge translation. It is likely that solutions to the challenges of disclosure may thus lie in methods which enable an understanding of daily routines in naturalistic context of the clinic and reinforce models of training which are team based, geared at improving patient agency and developing sustained collaborative partnerships through patterns of communication which promote flexibility and trust.

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Conflict of interest

None to declare.

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