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# Countertransference reactions to psychotherapy group work with HIV positive children

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**2008-03-28T11:09:27Z**
http://hdl.handle.net/10539/4717

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APPENDIX SEVEN

INTERVIEW LS I

Perhaps you could just start off by telling me about the work that you are doing with groups of HIV+ children and what your theoretical orientation is.

The work started in 2001 and the initial work that we did was running psychodynamic groups with children at Hospital. That was in the perinatal HIV research unit and there were three therapists involved. My group included a child who was hearing impaired because I had a history of being able to work with the hearing impaired. My group ran for the entire year and was very much an art psychotherapy group. That was the frame-work in which I was working. So it was non-directive as much as possible, it was around using the art materials, the children using the art materials in a way that they felt comfortable with. So it wasn't being based on the fact that I came in with a pre-conceived theme like an island, we're going to do an island, what would you put on the island, who would you take, what animals would live there, it was very much left to the first feeling of the group, the sort of feel of the children. We would sit in a group at the beginning and they would talk, telling me how they were, what was happening, and from there I would pick up the feeling of the group and then sort of suggest, not directively, but suggest that maybe they would like to work with one theme or another. And the children rarely did, they usually did their own thing which was wonderful, and while they do the art work it's purely observation. If a child was to approach me and ask me to help, I would. So most of the time they did their own thing and I was watching the group dynamics, watching what they made, how they made it, and then we would come back into a group at the end and do reflection. And they were little, they were not very old, they were about six, seven, eight. So reflection was really like how they felt, in one or two words. They couldn't really name the feelings in any comprehensive way. But that was enough to hold the group at the end and then they went home.

So you didn't really offer interpretations about their work?

Yes I did. While they were making it and also at the end. The framework for art psychotherapy is that you do it at the end. You do the interpretation and reflection at the end. And that was too difficult for these children. They needed interpretation as they go. So there was a shift in the work as I went along. So there would be interpretations during the making, while I was observing.

What made it difficult to offer interpretations at the end?

Their concentration by the end was very short, and also I found what they were working with in the moment couldn't be reflected back, they couldn't hold that thought and link it back to what they were doing, so it was much better to do it in the moment they were present and they were able to cope with it then. They were also children who were not used to the process. They hadn't been in any kind of a group before, so it was a very new thing to sit in a circle, it was a very new thing to talk about feelings. It was a completely unknown process for them. So it was trial and error as I went along. Out of the three therapists, I had the longest group. We

tried to see what would work the best. My group ran for 12 months. The others ran for 6 months then changed. We looked at what was better for them.

What did you find was better?

It was much better in a psychodynamic way to do the 12 months than the 3 months. But with regard to the infrastructure it didn't work to do the 12 months. There are too many children to deal with, so the luxury of six children for 12 months is just not on. Justifying that to funders is extremely hard. The outcomes of any psychodynamic group are not fixed things, they're not measured, so funders find that quite difficult. Um, ja, it was a lovely process and the children developed in it, but practically you can't do that. And subsequently the group work changed. We then developed a program that would look at short-term therapy for children so that more numbers could get through the system, and that becomes far more directive obviously, because you've got six, eight, ten weeks, we started off with ten weeks, it got shorter and shorter as we went along.

Even individual play therapies?

All the work with children is group work, there is no individual therapy. And again because of the resources not being there, you can't justify one child when so many need therapy.

What criteria did you use to accept a child into the group?

When we started at (the hospital) it was purely from the doctors referrals. They would refer the children and then we interviewed the child and the mother or the carer. And we tried to put them into groups that we felt were suitable, you know that would work as a group dynamic. That's what we did in the beginning – there was quite a long process before, then the interviewing process and then at the end we did a closing process. We did that and then we used that data for the funders, as much as we possibly could.

Were the themes that you drew out at the beginning of the group issues focussed around HIV/AIDS or were they much more general themes that any child that age would be dealing with?

They were much more general themes. Specially in those first groups. What we're doing now is very different, its very focussed around compliance to medication, around sickness, so the directive process of the groups now is very focussed on being sick, going to the clinic, that's how focussed it is.

But right at the beginning, we didn't do that at all, and my group, their themes were about nurturance, it was about belonging, it was about having a home. There were issues around death, but it wasn't linked directly to the illness. It was about loss, about losing people close to them, losing parents, loved ones, and not understanding. I think there was always an underlying feeling around their own vulnerability, but it couldn't be addressed

It was too much?

It was too much. And also it felt like they would contaminate the space if they brought it in. Because the space became a very treasured space every week. They would come, and if the carer couldn't get them there or if they were sick, they would get very upset. So it was a very special space that was all for them and I think they didn't want to contaminate it with their own sickness.

What they did do, when I think of it now, they would always check to see if I was well. We had a doctors set in the room and every week one of the children would put it on somewhere in the process and they would check my heart and my ears and my throat to see if I was OK. And a lot around the supervision that we did with that was our own need and their need of us, to be well. So we almost had to hold the well person and then they would feel alright, that we were not going to die, or that I was not going to die…..

I think also there was a lot around sibling rivalry. Which was around who could sit closest, who could get the most attention, that sort of thing.

Did you understand that it terms of their deprivation?

Absolutely.

What attracted you to do this kind of work?

That's a very difficult question to answer……..Very difficult to answer. I think originally, I had gone over to London to do my training as an art psychotherapist and I had been funded to go over. So when I finished the training, there was a great need for me to come back, because none of those funders required me to return to South Africa. But I had a very great need to come back and to put that money back in a way that I could, doing hands-on work. So I think that was an underlying need of mine, that I had been given money by the country and it needed to go back in some kind of aid, I suppose. So that was where it started.

Our options,… I don't think we specifically looked at children. We looked at where the money came from and then what it was for. I had been a teacher before, for about 7 years, so I had worked with children and it seemed to be a natural thing that happened. And a lot of our work that came in, in the beginning was around teacher's support and then obviously around children in school. So I think that was where the need to work with children came from. And then the funding came in to do those groups at the hospital. So the funding was specific because the funding came from (an HIV funder that funds psychosocial support for children). So the funding dictated where to go and that was how we started. So that's how it started, but my needs probably changed during the first two years.

I found an enormous need in myself to try to make some difference within this huge hole. When you get into it, it seemed bottomless, it just seemed so dark and it felt like perhaps there was something I could do to help make it less dark. And that need grew, it became bigger and bigger, until I began to feel very, almost responsible for making a difference.

And then of course what happened, was that, because it was so big, and there was so much to do, and I think its probably about burnout and how much of this work you can actually do, is that I began to feel that I wasn't making a difference.

That set in as a great sadness and almost a grief that there was very little we could do. And no matter how much you put in, how much you gave up, what was the difference. A lot around working with children is that you put them back into the same situation. And I've always queried work with children when you're working with this kind of level of any abuse, any deprivation, the difficult situation where these children come from, is it ok to give the children a space that's different and hopeful and then put them back into such a dire situation. I've never been able to answer that. It's not so cut and dried, its not black and white.

But that was where I actually got to, and I got very tired, just really very tired, and subsequently have stepped back from the work.

So are you doing the work less or have you withdrawn totally from the work?

I've done less, I would say in the last 6 months very little, but,…. have I done any in the last 6 months? No, more support around the carers working with the children. And what the funders want is capacity building, so we train carers to do part of our work. They can't be therapists but we can take out some of the creative activities and help them structure it in a group format. And so that's what's been done. But this last year has been very difficult personally for me. I've had enormous changes in my personal life, so there just hasn't been the time.

And the work that you have done, the capacity building, is it easier or do you struggle with the same kind of hopelessness and despair around it?
No, I don't find a despair. I find a frustration because its slow. It feels like teaching again, and I don't want to do it. So its funny how where it started, with such a pure idea about giving therapy and support and the emotions, and working with feelings and thoughts and linking that up to behaviour, just disappeared. It became like handing over. It was like skills training in the end. That's what it feels like now, and I don't want to do it anymore. I don't want to teach. I don't want to teach people skills.

So where that fits in around, I don't think its hopelessness and despair. That came with the children, and that came specifically because I knew I was putting them back into the same situation. I wasn't changing the situation.

Did you feel at times like you were almost like a perpetrator?

Yes. Maybe not a perpetrator, but somewhere dishonest. It was like giving something, and a hope, that couldn't be sustained.

And I became very angry towards the funders. Because it is **really** driven by the funders, it's not driven by anyone else. And their focus is to get as many children through the system as possible. Obviously one has to think about that, but it was very difficult. Whereas maybe you could make a difference in 6 children's lives, really make a difference. Was that not better

than trying to push a whole load of children through a program? I don't know the answers. I think there probably aren't any answers.

Do you wonder if it's better to take a small group of six children and work with them in a more intensive way over a long period of time than to do short-term directive therapy with bigger groups?

There's no question about it. And you would work with a small group of children over a long period of time, and you would work with the social workers, with the family, within a team, so that those children were supported in many ways, not only in the therapy.

So that, you know that's first world country stuff that just doesn't apply here. So maybe the frustration too, Julia, was that I was trained like that. I was trained to be that kind of therapist and that's what I wanted to do. All my internship was well within a team, a lot of structure, a lot of community support and funding, and people went through a system of a completely supportive nature. If you had any difficulties, you had access to different kinds of support – if you needed help at school, or at home, you had an infrastructure to support you.

And what happened here is, my feeling is that we worked like islands, personally, and then I did question whether we were doing any good.

When I look at what has happened in the progress of that, from then until now, is that perhaps more good is done in that you're skilling up people.

You can work with children in a short process and then they do gain some kind of support, but its not so deep that they begin to change. It deals more with how they're feeling about going to the clinic, about their sickness. That's how I feel about it.

I do think there is a lot of good, there's a huge amount of good in skilling people up to do the work and the children can go through an activity program. It does have some emotional support for them. But it's not where I want to be.

It seems like the work with the children is based around life skills and compliance to medication...

Compliance to medication, how they feel about themselves in their sickness, that they are not only the sickness, they're many other things – so you're a soccer player, or very good at school work or .., so its giving the child a sense that they're not only the sickness, that they have things that are not only about death and dying and loss. That's very valuable stuff. The program's a very lovely program, and very valuable.

I think I struggled with it, more so than the program being the problem. I think that I am the problem – I don't want to do it.

What aspects of this work did you find most challenging?

The difficult aspects were…….I think the huge desire to give these children stability, and in some way to protect them from the very adult circumstances they were facing.

The other was that I was well and that everyone else was sick. HIV is a very strange illness like that. I began to know that I was negative. You know, you don't think about it until you work in it and then it suddenly, you are different. And that I felt very strongly about.

An identification with the children? Did I ever think I should also be positive? I don't know. I don't know if that ever really happened.

But there was another questioning as to why they were positive. They were children that had been born with HIV, because I had the little ones, unlike the adolescents where the illness had been the result of rape. The children in my group were all born with HIV. That I found very difficult. So how do you make sense of that for the child – that this is what they're born with, they're born with a death certificate.

A lot around my own feelings of being white and privileged, a huge amount of that.

Um, and I had an interpreter with me, right through the process and she's HIV + and she was struggling. She was very sick during the year, very, very sick. Often she would fall asleep during the session. Or she would be late, or she wouldn't come, all very disruptive. And she was very ill. She was actually very ill during that whole year. And I struggled with that as well. It really did feel like being inside HIV, right in the middle of it.

And I struggled to make sense of it. It's an illness I don't understand.

But I suppose also my feeling within the group was that change had happened in the country, there was a promise for better things and there were people who had (material things), and those things (unclear) thought about (unclear) being with all this death and destruction. I struggle to find positive in all of this stuff…….

There is. Enormous resilience. I've learnt that over the years but in that group I didn't find it. I just, my heart broke.

I really, really became probably too identified with the children.

You talk about the struggle of being HIV negative

It felt like you were privileged to be negative. It did feel like it, so it was like yet again, another privilege that came with being white.

That somehow it was unfair to be negative?

Yes, which doesn't make sense if you look at it rationally.

Were you able to talk with the translator about what was happening for her in the sessions?

Yes, we did. In the transference I was a mother figure to her.

And we did talk about this falling asleep and not coming. And she did try. I found her very difficult to manage because she wasn't present, it was like having another child. And she wasn't a facilitator at all. And it was trying to guide her through that and give her skills – this is what happens, this is how it's done. It got better towards the end of the year but it was a difficult one, a very difficult one.

So you were on your own, holding her, as well as trying to hold the group.

Ja, and also holding her illness, because she was very sick. She was very, very sick. All the children and she were on the trial, on the ARV trial, and the medication made her very sick.

It's funny, if I think of it now, I never thought of it then, is that I saw the children sick and then I saw her as an adult with it. What was the meaning of that? It must have had some kind of effect.

And what sense did you make of it?

Somehow with her, I felt she could get support around it. There were lots of people around her, there were, at the clinic they were very active with support, counselling, all of that. So I never had the same feelings towards her as I did towards the children.

I thought the children didn't get it. The children didn't get the counselling, the children were the ones that were born with it, the children were the ones that didn't understand it, they didn't understand why they were sick…….Ja, it was a very difficult feeling. I didn't have the same identification with her sickness as I did with the children.

I felt hugely responsible for the children.

Perhaps the group was not a great thing, in any therapy identification brings you, pulls you into a space that is not objective, its very subjective. Perhaps as a therapist I wasn't doing a very good job…….

Can you talk a little about your countertransference if we think of it not just as an activation of your unconscious conflicts but also as an unconscious communication from the children?

It's a very powerful tool to use. I was a newly trained therapist and I was finding my feet as a therapist. So the countertransference was huge and now I need to feel what the children were feeling. And because they couldn't verbalise a lot of what they were feeling it was a very good tool with which to assess where they were and what was happening. I'll give you an example. The one day in the group, only two children arrived, and there was absolute delight that they had managed to kill off the other children. And that was my countertransference around feeling their absolute delight that the other children hadn't come. They didn't verbalise it, but I could feel it in myself, their behaviour, it was like, 'my goodness, we've gotten rid of all the

others" and now they could have all of me. What they did is that they made…..the two of them went off and they did their own art-making and they got bits of like an egg box and a bowl of some kind and they mixed up clay, and they mixed up other mushy things and they put it inside. They then took a tin and turned it upside down as a stove, they put the bowl on top and they sat back in their chairs with their arms and their feet up and then every now and again they would get up and maybe put glitter in, that's the spices, and then stir it and sit back and wait for it to cook. They did this whole process and when they were finished, they had cooked this whole meal, and I asked them what it was – it was chicken and potatoes, with carrots and other vegetables. They had cooked this entire meal. Then what they did, they took these bowls and they wrapped them up in bits and scraps of material that I had, scraps and bits of material, and taped them up and then - it was towards the end of the session – and came, literally, with these bowls of food and gave them to me.

And then the countertransference was around being able to let them give and understanding the importance of that. So it was an appreciation of having me all to themselves. So I could understand that in a psychotherapeutic way, or an analytic way – they were able to take in and they were able to give and that was very positive. In all their deprivation and all the death that's around them, they still had that capacity to nurture, to create themselves and then to share that. And that was very important.

So I think in that countertransference you couldn't explain or talk about it with them. They were too little. But my feeling and my understanding of their art-making, and my feelings around it, because my feelings were overwhelming. When they handed me the bowls of mush, all wrapped up, I wanted to cry. I felt that strongly about it, it was such an immense feeling.

It was also perhaps in me an understanding that what is reliance on self. That there is such resilience in the most darkest, awful places. There is always something you can find that is good. So I think the countertransference played both ways.

When you wanted to cry, was it gratitude, or was it because of a sort of pathos?

Yes, it was pathos, very much so. Where did they find in themselves such enormous giving when they had so little.

I wonder if you struggled with feeling that you were never giving enough to them.

Always. I was trained in short-term work. And a lot of that was understanding that what you do is good enough. Boy did I struggle with that concept. I always found that there could be more that I could give, and more and more. And I think that's what brought the burnout toward the end. Always wanting to give more. Always wanting to give more time, more effort. There wasn't funding, could we cut the funding and get paid less and they get longer, all of that was there. So it was almost a depriving of myself in order to give to them.

Did you understand that in terms of your own history, or do you think that its very situation-specific, that this would come up for anyone working with these kinds of children?

Sjoe, is it white guilt? Probably. It probably is. And I am not South African by birth. I come from (elsewhere in Africa) and grew up in a colony. So that was (unclear)….around colonisation, around huge blame

So somewhere trying to make up for the actions of your ancestors?

> And I came from quite a racist family, so there was a lot to make up for them, and to understand why they were like that.

So (unclear) and also my sense of belonging, because I don't feel I belong to South Africa, and I don't feel I belong to (the African country of her birth) so I'm kind of one of those who gets lost in between cultures. So perhaps my own feeling of not attaching to anything made my awareness of these children's attachments being precarious, because they were forever being broken. I had a kind of sympathy.

You had experienced some of what they were going through.

Yes, definitely,my identification from the beginning affected the process very much.

I became the mother in the transference, and without it being a transference mother that the children could then take back as their own. So I wasn't a holding, thinking mother, I was just an emotional mother. So if you think of Bion's theory, there is the thinking, holding mother and then the child begins to think for himself, I don't think I even got near that.

Do you think there were ways you actually behaved in the group as the emotional mother?

Oh yes, yes. They're very physical and they want to touch. And they want to sit on top of you, or next to you, or 6 on top of you, you know. I never, I never kind of addressed that, in any constructive way. When there was a need to be held and loved in the group, that's what I did.

It must have been very hard to resist that, when I child is asking to be held and you must offer an interpretation.

Yes, but what's so ironical is that in the training in London, we were not allowed to touch a child, at all. So if the child wants to be hugged or not, you are not allowed to touch him, by law. That's how I was trained. There were times when you had a child and it was a child you could just see needed some kind of contact, physical contact, and you had to work your way around it, without giving it. That was the idea, but when I got to that point, where that went, I have no idea.

Maybe it was just such a relief that there wasn't a law in this country that prevented me from giving that physical contact…….

I think its very difficult to be in that situation.

Absolutely. How do you take a child off your lap and tell him to sit on a cushion.

You've spoken about your emotional reactions and how you feel they impacted on the work. Is there anything else that comes to mind?

I think the experience made me grow up very fast as a therapist. It felt like you were thrown in the deep end and you just had to swim. And you would make mistakes and you find a way to somehow work it all out and see how to do it. So I think there was value in the experience, and perhaps one doesn't get that sort of chance anywhere else in the world.

But on the other hand I also felt very alone. We were a team and it was very important, it was very valued, it really was, and we had supervision. But I felt very alone as an art therapist – we are very few, so there's nobody else to say, "well how would you do the art in this situation?". Because x being a drama therapist, who else in my discipline was there to talk to, and what were their experiences, were they having the same feelings as I was, was the work being done in the same way. So I felt very alone, andI felt very alone that there wasn't the infrastructure to hold the work. And I still feel alone, even out of the hospital I still feel alone. I still crave that feeling of having a whole team that you're working together, there are people to talk to, there are other ideas and thoughts, what's happening to them. It wasn't like that.

Were you able to get supervision?

Yes, we did. Very good supervision, very holding supervision. Um……ja. We did it with the three of us and we were struggling with one of the members within the team, it was a lot about that as well…….there was something else I was thinking of.

Oh! There was enormous stress around the funding as well. So you didn't just be a therapist and go to the hospital. We were running an NGO, we were setting it up, we were looking for funding, we were doing the admin work, we were making sure reports were in, we were looking, phoning funders. It was like we were wearing six different hats. And that was very exhausting too.

The luxury of being just a therapist wasn't there.

And then also the failure, when we didn't get funding. The enormous feeling of failure because then the work wouldn't go on. So we felt responsible for keeping the groups going.

You talk about the "luxury" of being just a therapist....

When I trained, that is what I was. I would go into a department, I was very lucky to be working in a very good department, um…that was my job, I was a therapist. I didn't have to look for funding, I didn't have to run an office, I didn't have to chase all over the country because…– you know, we had to look for funding, it came from there so we had to work far away, whatever. And I didn't have to face my own fears every month that perhaps I wasn't going to earn enough money to pay my own bills and be able to look after myself. So there was a very stark difference from the way I had trained and the way I found myself practicing. And it felt very luxurious to work the way I did when I was training.

I'm wondering about whether during your training you also had the space to think, and also to think about how to take care of yourself.

Absolutely. It just didn't exist when I was working.

(Unclear, but something like "And not having the luxury of just being a therapist, do you think it impacted on the way you worked?")

Yes, I think it is around that thinking space. You know you'd leave the group and you'd be straight into looking, phoning funders, writing reports, doing something else. There was never a space to do that thinking. I don't know how you resolve that. I know, one of the girls I trained with was (tape change)….the work we were doing then, we were travelling to the hospital, running a group, I think we were running two groups, then you came back, then you were trying to do whatever it was you had to do around funding, and you were trying to see some private clients, because that also helped to pay the bills at the end of the month and then you'd get to bed about 12, 1o'clock in the morning and then the next day would just start with that same kind of driveness. And where do you think about the work you are doing?

You just survive – its survival! A reflection of the survival of the children. That's how they lived – you survive. Lots of taxis to catch, you don't have enough money at the end of the month, you live in a tin shack with a whole lot of other people, when mum dies or dad does, or both of them die, where do you go? You're shunted from gogo, to auntie, to another auntie, or…It was a reflection of what we were doing.

And maybe there was a feeling that if you didn't drive yourself so much, that you weren't worthy enough. That if your clients had lives like this, you needed to match that with the amount of work that you put in.

Did it feel like you would be being "white and privileged" if you had the space to think and to take care of yourself?

I think community work in South Africa is quite, there's a lot to talk about. It's like there's this question, "do you have a private practice or do you do work in the community?". Quite a lot of talk around that. If you run a private practice, that is a luxury. And that is what I do here. I run a private practice.

And how do you feel about that?

I don't know, really. I feel its easier on me. But perhaps, so that I don't run into what would be going out, maybe it's a way of keeping myself sane. It doesn't mean I work less hours, but it certainly is easier work, I sit in my therapy room and people come and so at the end of the month there's a better chance of meeting all the bills and having a bit over……..

I've read somewhere in the literature that the countertransference when working with children can be so much more powerful because you're working with a lot more of the primitive, unprocessed material. Did you find that in your work?

I'm going to have to think about that and let you know……..What comes to mind is the real primitive feelings about survival that come up, so you really begin to understand what survival is. It's not about any of the luxuries in life. It's about being able to feed yourself, having a home, its about having someone to cling to if you're a child, someone who is going to be there. Surviving and staying safe from abuse – that's the surviving.

In the beginning group we actually fed the children. There was a lot of debate around that – was it a good thing, or a bad thing – it became a huge focus because the children would have a sandwich and cooldrink beforehand because otherwise they were too hungry. So how do you do this work if they're too hungry? So now what we've done is that the program that we run now, the children are fed by the NGO that we work with. So it feeds them, and it's separate, we don't do it. But in the beginning, we were not only the therapist, the mother in the transference, but we were also feeding – amazing!

Do you think that it impacted on the therapy, or do you think the physical need of the children was too great to ignore ?

I think it impacted on the therapy in that a psychological feeding – that full breast – it would never ever get there because you were actually feeding them, so I think you weren't left with a space of what is nurturing internally. It always got contaminated by feeding externally. If I had to do it over, I wouldn't do that again.

I'm wondering whether as the therapist, because the deprivation in the children was so huge, somewhere there was relief in being able to feed the children externally.

Oh yes.

It must have been such difficult work to do.

(Laughs), yes, but very rewarding. Because I grew inside myself, I grew as a person. Where its left me, I'm going to have to think about. Julia, our time is up.

INTERVIEW LS II

I think the last session was very, it was like a celebration. The feelings were quite cut off at that stage. I think it was the lead up to that final session that became a lot more loaded, and also in terms of my own feelings.

A lot around it was about loss which was a projection of their own sense of loss of their parents, siblings and loved ones. That was a consistent theme right through.

When I looked up the notes after I saw you last, it seemed to be a consistent theme in my countertransference notes, that I felt that there was a loss, I felt I wasn't, I was either too good

a mother or not a good enough mother. And too good a mother was I was feeding them, I was giving them a safe space, I was interacting with them, bonding with them, allowing for some kind of family structure within the group. That was the too good a mother because, as I told you last time, it set up a dynamic that I felt was unreal.

When I thought about it after I spoke to you, I thought what was the role of the translator? Because I mentioned to you that I found it quite hard to have her in the group, I often felt very irritable, she would sleep through sessions, she wouldn't come, she'd come late, she'd use her cell phone, um, there was a lot of irritation around her, almost to the point I didn't want her in the group anymore. I thought about it and I was thinking, did she represent that broken family. And if I could exclude her by my irritation, my sense of "she's not doing the work", I could then have the perfect family of children.

I think it had a lot to do about that and my own feelings that was she the ill partner, was she the absent father, was she the sleeping mother? All of these aspects of the children's experience around the parent seem to be, I think, must have been in some way projected into her, and she obviously took up that role, in addition to the fact that she was also very ill. So she did have the actual illness yet all those emotional acting outs that parents in the real situation must have been doing anyway. And that she brought it into the room.

And my sense, when I think about it now, was I wanted a perfect safe, space for those children. That was my need. My need was to make it as good an experience as I possibly could. And when I didn't get that, my sense was that (unclear) and it made me doubt. And when I wonder why, what was it, was it other needs of mine, like, am I a saviour by nature, or something like that, I don't think so.

I think it was the illness and I think it was the way it was set up by the translator. Because in the other two groups, the translators for the other two therapists, they didn't have the same problem. And I got the most ill translator, she was very sick, and with the most lack of insight. She was very difficult to work with and really now, to own it, its terrible, but I really didn't want her in the group after a while. But maybe she did embody all the illnesses (unclear)….. with the children, because she was very ill.

Last time you spoke about how the children didn't speak so much about the illness and about dying, as if they didn't want the space to be "contaminated". But it sounds like the space *was* being "contaminated", by the "contamination" of her illness.

Absolutely. Maybe I perceived myself to be the strong enough, well enough parent. And therefore to push the illness completely out of the group process.

It was around, the process was around the children, the needs of children - attachment, loss and normal things, feelings that children would go through. Those were the feelings, um……I think obviously loss was linked to their experiences outside and what was happening in the therapy (unclear). I think it was also about loss of a crayon, or loss of a piece of paper or somebody broke an art-work or something they had made. So it was very much at the level of the children's feelings.

If I linked it to what was happening outside the room it got lost, so I very much kept it in the process, in the here and now. Communications or interpretations would be made, sometimes they would be picked up, often they weren't. The children obviously heard them.

And also when they got to the end, we had what we called a "treat box" – the children created a box and then there was a treat every week for every child. There was a whole closing ritual around that, we'd pass the box around and having a treat. I bought the treat with money from my own pocket, so not only did I feed them, but I gave them a treat every week. At a level was that because I felt the therapy wasn't enough to feed them? I'm not sure if the treat box fed into that dynamic. But I think feeding them sandwiches and juice in the beginning was really not very helpful. Once you start doing that you bring in another dynamic of is the space good enough without the actual food.

I suppose there are those two realities – the social reality that the children are hungry and the psychic reality too.

What was interesting for me after talking to you last time was how little the translator had come up but how big a part she was of the process, and of my process - we're looking at the countertransference. Well my countertransference with her was huge. I really battled with her. She made a very strong bond with me but on a personal level she didn't seem very professional (?) at all. She made a bond personally.

Last time you spoke about how it was almost like she was another child in the group and she made quite a strong mother transference to you.

Yes, so those were the sort of things……

Something that also came up last time when you spoke about the translator was that she was an adult with the sickness, but the children had got the sickness when it was transmitted through birth, and you sort of struggled with, you wondered about that.

(Pause). That was more on the level of ability to cope, rather than in any way a judgement.

That as an adult, you have resources that you can call on. It's a dreadful disease and its devastating to anyone's life, but as an adult you have different resources and you have more resources. What I felt around the children was that they didn't have those resources. They were very much at the mercy of the fall-out from such an illness, but they didn't have any weapons, or any skills to deal with it. So they would be tossed around as things happened in the families. If there was an unavailable mother, they didn't have the skills to deal with that. Whereas if you had an unavailable partner, there were other things you could do as an adult to manage that situation. That was a very big issue for me with the children.

I felt they were at a huge disadvantage, but subsequently have learnt that children are so resilient. That's been a very interesting learning curve for me over the years, that children are resilient, have enormous resources if they are allowed to use them. That became a lot more the focus of the work later on, than it was in those first groups.

When you talk about how the other therapists had translators who were much more able to participate in the group, and how the illness of your translator set up a dynamic in the group around…….could you talk a bit more about that?

Pause…….It was a strange set up, the dynamic between the three therapists, the fact that we had different translators, is that where you want me to go, or the dynamic in the room with the translator?

I meant the dynamic in the room, but talk about whatever you think is pertinent.

I think perhaps both, the dynamic around the three groups, the three different translators. I think there was a feeling in me that I got the most difficult of the three. I also had very difficult children in my group in that I had a hearing impaired child, so trying to involve that in the process was also quite hard. I also had a mentally challenged child so I had two disabilities within my group, whereas I felt the other therapists had a more homogenous group, it definitely felt like that to me. Whether it was true or not, I don't know. But that's what it felt like to me. Then I had a handicapped translator too, so I kind of ended up being a member of a really handicapped group. At that point in my practice I would have embraced that and gone into it, without too much trouble, but I certainly would reconsider now. To make a definite decision as to whether I wanted to do that or not. I think at that time I just would have just done it and I did. So perhaps there was a bit of envy around that – is that they had "weller" groups – interesting way to look at it – with "weller" or "well" translators.

But then there was a side, when the decision was made that my group would run for twelve months and their groups would run for six months and then they would have to pick up another group. It was almost the feeling that that cancelled out the difference. There must have been something around the three of us as a team when looking at,… about the wellness and who got it and who didn't and how did it balance out. There definitely was a dynamic around that.

The dynamic in the group…….well I've explained how she was in the group and how that impacted on the children. And then she was the absent mother, she was the falling asleep mother, she was the distant mother, she was the ill mother. Whereas with me, they knew that I wasn't and somehow they knew, and they needed to keep me from the illness. So I think they were quite happy when she fell asleep and didn't participate. They certainly didn't try to wake her or it didn't seem to upset them. It was more very much well we're a group, we'll stay as a group, which meant that she was on the periphery – she came in when she could and she when she couldn't manage to stay awake. So the dynamic for the children was that they had one parent, which was a reality in their lives and the bonus this time was that this parent they knew was not ill. So the chances of me dying, metaphorically, were very slim. And perhaps they were afraid of her illness, because it represented death and things that they were managing outside.

It sounds like a very difficult situation to manage because it sounds like there was no way to address it, because you weren't just addressing it symbolically, because it was real as well, in the person of the translator in the room.

Maybe that was it. And a lot around the early work, that I remember now, was around having a stereo, or having a TV, having mlungu stuff, the white stuff. So the fantasy was I came with a big house and a fancy car, a beautiful, nice home. Their play in the beginning, their artwork in the beginning, was very much around creating these perfect environments, these perfect homes. And the dynamic of the translator was that she would contaminate that, she would make the reality…….more, for them more of an awareness than it was. So they could stay in the fantasy, they could have this fantasy that I came from this other world with all these things. And in a way I set that up, didn't I, because I brought the food with me, and I brought the sweeties with me and I kind of brought the wellness with me.

Do you think a way to understand what was going on is that it might have been a manic defence against the losses around the illness.

I think there was a lot of mania around that. And that manic defence was to keep the illness out. It really was a denial of it – it doesn't have to come into this space, this space is about nice things, this is a space around things being consistent and stable, every week having me there. No matter how disruptive their lives were, I was consistent in their lives. So it brought in another experience for them which they weren't experiencing outside, very often. And it set up a denial…….it did! I was setting it up.

Do you think it contributed to your burnout, that at some level you knew that you couldn't sustain having to play a role in the fantasy?

Mmm, I do think so. And I do think a great need to make a difference. Just on a, not even on a social level, just on a humanity, on the level of being human. It was hugely draining though.

What I feel now is that it is better to skill people from the community, people who are in the culture, who understand better. It doesn't set up such a split, it doesn't set up all those dynamics. And my work is to be continued in a different way, not to be discontinued. So our role is more around supervision, because the carers themselves, the counsellors themselves who live the things in that culture, that world, don't split with the children because it is familiar. They don't bring in fantasy of this other magical world. I think its hard to come to terms as a therapist with this difference – what is the role, what is our role as the white therapist? Or is that making it too much a distinction between different colours, I don't know.

A lot of the reading I've done around intercultural therapy in the UK – the reading I've done was all in the UK, it's a very different situation to here. A lot of their arguments, well, do they fit? Ja, so intercultural therapy is that no matter who you are, its about the relationship you create…….(we are both laughing as she says) but it never worked like that in my group, so ja. So those were the things I remembered.

And the other thing I did remember about countertransference when I looked in my notes, that we discussed in supervision but we never came to any understanding, is that I would have to go home after the group was over and I would need to have a bath, not a shower, but I needed a bath.

Was that because you felt contaminated?

Could be……

Perhaps by cleaning off the contamination you could stay in role, in the fantasy, so you could face it again next time?

Its part of that. Also trying to make some kind of adjustment to another world when you came back. So maybe the boundary, we did think about it in supervision, maybe the boundary was taking a bath, was my way of making a transition from one world into the other. I've always used a soaking bath when in emotional distress, so maybe that was my way of emotionally destressing. And if I couldn't do that I was miserable, miserable as anything. I needed to go home, and I set it up so that after every hospital group I could go straight home. I would not plan anything, I wouldn't set any other engagements, or any other responsibilities, I needed to go home. I remember that, it was a big part of the countertransference.

What it also really says to me is how burdened you felt by this difficult work. I see our time is up. Thank you so much.

INTERVIEW: K

Perhaps we can start with you telling me a bit about the work you do with HIV+ children and your theoretical orientation

OK. I'm a drama therapist, ok……and……..ja, which I guess is a form of psychotherapy, just using drama as a way of working, so instead of there being a dyad, there's a triad, so that you're working through the third element, whether its drama, image, roles, story. I suppose the basic premises are, they draw their working methods from lots of different sources, but its essentially its a, I wouldn't say its a purely non-verbal form of therapy, I certainly like to work with a verbal input, that's the clients I've chosen, I think meaning has to be made, but it mixes both. I mean its an expressive form. I think the power of it is that it gives the client a bit of distance to work with whatever's going on internally. So its not as confrontational, there's a bit of distance, and when the client is ready, to make those kinds of connections, the connections are made. And I suppose it's also premised on the belief that when you're in touch with the creative part of yourself, that's a healthy part of yourself, so all of those kinds of ideas.

So in terms of the group work you've been doing, have you been working with teenagers?

I've been working with children and teenagers.

Ok, will you tell me a bit about them and how long you've been doing it for?

Ok, at the moment, I'm not at the moment, well I've just closed a group with some children. So now we're busy looking at the next stage of the project and if it carries forward or not. Um, I've been working with children and adolescents, all with HIV, since about 2003, where we got funding to run these groups. In 2003 we ran full year groups – well I ran a six month group with children and six months with adolescents. And then over the last couple of years, we've been running mainly with children who are HIV+.

Also for six months?

No, last year we ran a 20 session group with some facilitators. The adolescents I ran for six months and this group that we've just run now, we only ran for eight sessions – it was very brief, short-term.

And is that one session a week?

Yes.

And how big is the group?

The group that we've been running at the moment, the maximum was ten, but my adolescent group was five and when I ran more kind of intimate, probably about five, five or six children, I don't like to work with more than that, but we've had quite a few facilitators with this last one,

so the group was ten, it was quite a large group. Last year's group was about eight children for the 20 sessions.

And are you working with a co-facilitator in that group?

Ja

And is she a translator or is she also a therapist?

X therapist and I worked together last year, and we worked as co-therapists. But we had facilitators with us, helping us as translators, and co-facilitating. Where we're taking the project now is we're working more in a directive creative arts approach, so its quite a tight number of sessions and we're seeing how the facilitators manage - I've been an observer in the group, and the next phase will be supervising a very tight structure. And they're counsellors, so its not pure psychotherapy. That's where the project's gone to, but still working with HIV positive children.

And in terms of being directive – can you talk a bit about the difference between these groups and the less directive groups.

Well the less directive groups were far more um,……..I suppose they were a lot more dynamic, because I could work with whatever came up, but also I didn't have all these other things to consider – working with other facilitators who aren't trained in the same way. They don't have the skills, they don't have the confidence and they don't have the training. So that wouldn't be ok. But the directive group that we've just run, which has just closed, was run in conjunction with the care-givers group. The care-givers had a support group – the aunts and the mothers and the grannies - helping them talk about HIV, whether they've disclosed or not, their difficulties around it, talk around their feelings about their children, discipline, all of those kinds of things. We were running the children's group really to look towards disclosure for the parents, that maybe they could disclose in a helpful way, and that we, for the children, were helping give them support around their feelings about coming to the clinic. Some of them hadn't been disclosed

So some of the children don't know their status.

Mmm, that's what its like. I mean last year we ran a group of children who had been disclosed to and a group of children that hadn't been disclosed to, and we wanted to see the differences. It was quite an interesting group, and that was run quite non-directively, that was x therapist and I running a group for 20 sessions, just to get a feel, and from that we've chosen some sessions and some structures and some techniques that we're now using with the facilitators.

So just to go back to your other question about directive, I suppose we work with a theme each week – we've got eight weeks and we start with who I am, where I come from, my illness, who supports me and anyway, obviously feelings come up that you can't direct. The more non-directive would be going in, you'd have an opening ritual, a closing ritual and we'd see what comes up. And we'd work using an art form, if that felt appropriate, so a lot more about here and now.

So in terms of drama therapy - I don't know a lot about it – but if you were to work non-directively in a session, after the opening ritual, would you step in to provide input to scaffold the work or would you sit back and just wait to see what emerged like a psychoanalytic group therapist might?

I think both and I think it depends on the group, and I think it depends on the stage of the group as well. If it's a group and we're just starting out, they don't feel – it depends how long you've been working together. The work I've done in prisons is very non-directive and I would do exactly that. We would have our opening ritual but then I would wait. And then there would be – you know this is where the choice comes – what would be the moment when you go in and work with stuff – someone gives you something and so much stuff comes up, just in that opening ritual. So often they would come with something, but it just depends on what stage of the process we're in.

Certainly with children, I certainly do have an idea, but even if you do have an idea, that's the thing about drama therapy, it doesn't direct someone's process that comes up, it gives them almost like a container – what's there will emerge anyway in the here and now. So I suppose it was a bit more like that with the children. With adults you can be a lot more, I suppose analytical, and sit back and wait. But with the adults I had worked with them for like five years, so they'd grown in their confidence and moved on in that way.

What attracted you to do the group work with HIV+ children, or was it because of a set of circumstances?

You know, I think it was probably a mix of both. I had to train overseas, because you can't train here yet to do drama therapy. So I trained overseas and I came back to the country in 1999. I started really working and practicing in 2000. The first thing we did, x and I, was we had to write our board exam to register. So as part of that we got to know each other. So we decided we needed to formalise something and we set up an NGO and it was through that we tried to make contacts. So it was circumstantial, because at the time, someone had said to us, 'there's kind of interesting work going on at x hospital and maybe you want to hook up, maybe we can put together a proposal', which we did, and our biggest funder who was interested in us was y, who wanted to fund HIV projects. So we sent them off a proposal so that's what happened.

But I think the other side is I've come back to South Africa quite passionate about working with HIV, in the field, to give some kind of input.

And when you reflect specifically on your choice to work with HIV, what comes up for you?

You know its kind of ……..its hard work. But I just don't know how you can not work, I suppose what I think is that we're all affected by it, even more so, I mean we hear it all the time, so much so that we think, I don't want to hear about HIV again. I think having gone and worked in it in the way I've worked in it, I've got a completely different understanding of I suppose what it means to have HIV, what it means in our country.

So I think its been a very rich experience in many respects. I think I've, you know its not just something that's there and we all know about HIV, its something I'm genuinely concerned about, and I think that's what's happened for me in working with it.

And at the same time, its also become something I'm not afraid of, its become something that I think its possible to live with it and have a good life. So I've almost become quite positive about it and not (she makes a sound expressing terror). And I'm quite keen to carry on, this project that we've got going, I really want to see it growing, because I think it has just had such a positive effect on the children's lives and it would be nice to see that those kinds of groups can sustain, but that's always the problem - how to get funding to sustain.

I wonder if you could tell me a bit about– it might be more helpful to think of a specific group you ran, or it may be more helpful to draw from all of the groups and your experiences with the groups you had – but maybe you can just give me an idea of those kinds of children that were in the group, the kinds of attachments, the kinds of relationships you formed with those children – just so I can contextualise it.

Ok, all of them have been, I think that, as you're talking I have a vision of the different groups in my head, of the circle, of the little faces, ja, of the relationships. The first group that I ran was the hardest, that was the hardest. First of all I ran that group on my own, with a translator who was also HIV + and who was also a counsellor. So there was a lot of stuff going on. He and I had a very close relationship, which was quite nice for the group because there was a male-female, mom-dad kind of figure in a mixed gender group. But during the group, and I'll talk about him, the translator because he comes to mind particularly and he was part of the group, his child died at one and a half, of HIV during the process of that group. So that was a very, very, very hard group in terms of the emotional stuff.
I still remember each of those children very, very clearly. You know you don't only form relationships with the children, but also with their care givers. The care givers used to bring the children there and it was a difficult thing to manage.
Plus we'd be providing food, that's something we'd never do in our frame of training, but in this kind of context, children come to the group, many of them are hungry, we have to give them a sandwich. We built that in and made that part of our ritual, part of the group process.
So there were also these other sort of difficult things. You can't just run the group and get on, So I was kind of, I suppose, that group was my hardest experience, I was very tired, I often felt I didn't know what on earth I was doing, but we were also very unsupported by the clinic and I think that that makes such a difference.
The adolescent group was different for me because I had more of my own internal resources, and these last groups have been such a different working experience because of the support. There's been a psychologist at the hospital who has co-ordinated the project, we've had weekly team meetings with the care givers group as well as with our group. Its just been such a difference. It means it really can be rooted.
The adolescent group that I bonded with, I formed quite strong attachments to them, and there were only five of them so I suppose they all knew their status. The children don't know their status. They all come to the clinic, and they're all on clinical trials, on the anti-retrovirals, but they don't know that they're HIV. I think they do know, but they're not being disclosed to, and that's why we, this last group was to try to facilitate that so they could be disclosed to in a

helpful way, because there's so much fear about disclosure. And lots of children are disclosed to either directly or indirectly in ways that are sometimes not nice. And other times I think many of them know, they know, they're not stupid, they know exactly what its about, but there's no space to talk about it.
But the adolescents I grew very close to, especially one adolescent, I was very concerned about her, and she came back last year to the disclosed group, but she's not in a good way. She pulled out of the group and the last I heard of her she had just fallen pregnant. I just found out because many of them still come to the clinic, because they're still on the trials. These children started when they were babies, they were mother to child transmissions, so their moms were on treatment and they've carried on. So clinics have been part of their lives, for many of them. So many of them come back, come to the clinic every month. So I often ask after them and how they're doing.
And not this group, but the previous group, there was one little boy in particular who I could have adopted (laughs). Oh, there was something, and also he formed a strong attachment to me and the group. And he doesn't have a mother, he doesn't have a regular caregiver. Ja, all this stuff…..

I'd be interested to hear about that

He……..he loved, the group became a very important part of his life and he was always the first person to arrive. He'd get himself there – he was only eight years old. And just a lot of little things that happened I suppose at times in the group and after the group, that were very significant in some ways. He particularly attached himself to me, so there was definitely something there. He was the one child in the whole group who was the first child to cry in the group, he wasn't afraid to cry in the group. And the other children were at first quite afraid of his tears in the group, and he was quite, I mean we also referred him on for individual therapy, because I mean there was so much deprivation at so many levels, and I think there was developmental stuff that needed to be worked on.
But more than anything, I found myself connecting to him on an emotional level, I felt very much to be a mom-figure to him. And the one group, he came in and his hair was shaved off, he'd had his hair cut, and he'd developed a rash, which a lot of the children do, as a side-effect of the medication and also the HIV, and he was very sore. And he could speak English, but he'd rather make sounds and get very frustrated. And he was very, very sore and at one point he started to cry. So I went over and sat with him with the translator and said, "what's this about?, What's hurting you?" And he said they had put vinegar on his head to stop the rash but it was really stinging him. So I said, when you go out of here, I'll go with you to your mommy just to… and he just looked at me and said, "I don't have a mommy". And of course most of those children don't. And I kind of just assumed the mom's there, or someone to look after him. And then I realised, you know what, this child actually doesn't. This child's brought by his cousin, and then his aunt will bring him, and he doesn't have a consistent care-giver.
And he grew in the group. He grew beautifully in the group. He loved the group, and he was very, very intense in all the creative processes, you know. But then he would also sit out at times. Ja, he was also acting out quite a lot. But luckily we could hold that because we could understand.
But he still comes to my mind, and I remember the one time I came home and I said to (her husband), I want to adopt a child. (laughs). He said, 'well, ok, but wouldn't it be better if we

start when the child is young, not at eight?". And I said. "no, no, you don't understand, this child!" Ja.

So the feeling of wanting to adopt him, was that about the fact that he didn't have a mother and was so deprived, or was it also about something in him that was resonating in you?

Something in him that was resonating in me. His struggle with um,… just his struggle with being, just learning how to be. And I think in a way that did resonate with me.

It sounds like in some ways he just laid it all out.

He was very open, and I suppose he cried, he just allowed himself to cry. Mmm. Something very beautiful about this little boy. An emotional beauty. But yes, somewhere I think there was something that resonated with me.
I think the fact that he was also…….ja, I don't actually……..he just loved the arts as well, and I think that's also something.
He just loved the opportunity to do what he was doing, and this was a safe space, and he could just be, to feel those feelings, and I think that also resonated with me…….

Do you think that had an impact on the way you worked in the group?

Mmm. He would always pass me the ball. One of our opening rituals was to take a big ball and pass it, as a way to say hello. And he would always pass me the ball, and struggle to remember and say my name. I think I did look after him a lot – I would often stand quite close to him and he'd stand right next to me. Certainly I was aware of it, I would have to watch, and try to be quite protective over him.
It was a very male-dominated group, lots of boys, not many girls, quite bullyish. That's the other thing, as I'm talking about it, the other thing that connected me to him, he often got bullied, I mean its that kind of thing – he was a very vulnerable little boy. And probably I responded to his vulnerability, that was probably what I felt the most.

What comes to mind as you speak, when you talk about protecting him, I was wondering in the beginning when you talked about some of the carers choosing not to disclose to the child, but how the child at some level knows anyway and then perhaps protects the caregiver from that information.

I think its about they protect their friends, they protect their schools, they protect their mother, they protect their sibling, and I think its..I was thinking of one instance in that same group. One of the little boys, he was in shock and I think he knew his status, he knew he had HIV. At one stage he said very strongly, because we were telling stories and HIV came up - we were talking about being sick and who do we tell when we're sick, and all of those kinds of things. He said, 'we do not tell anybody. We don't tell our friends because then the school may think we have HIV and we don't". Those were his words. In this recent group, the caregiver gives her child her medicine in the cupboard because she doesn't want anyone to see, and its always quick, and "don't tell anybody and leave the medicine here". If anyone comes to visit, the little girl now hides all the medicine so no-one sees it. And she doesn't know what it is but

she knows its bad to be sick, I shouldn't be sick and that kind of stuff. So I think they do protect them.

What is the child told about why they come to the clinic?

Some mothers tell the child they're just sick, like high blood pressure, which is quite a common thing amongst black people to talk about blood pressure, often you hear that being spoken about. But many of the children, they don't feel sick but they've got to take this medicine. There's a whole thing about adherence, taking the medicine which is often difficult as well because they're horrible, they're bitter, and we do a lot of drama around that and they can play out their feelings about taking the medicine and act out the doctor - they make up a clinic story.

And what are the children told about why they're coming to the group?

What happens is the doctors who see them and do their check-ups. They see the children regularly so they pick up when the child is struggling with stuff, not coping at school, and then the child gets referred to different places. I think you can't run trials like they're running without providing some sort of psychosocial support for these children. So they get told they're going to a drama group and we interview the parents and get consent for their child to join the group. Everything gets done in the open and we even tell the parents this is a group about being ill and having HIV, and then sometimes they start to cry because they can't themselves, and they get very worried that you would tell the child their status. They want to make absolutely sure that we're not going to do that, and we tell them, we're not. We'll talk about what comes up but we're not there to tell them, that's your job. And the children think they're just coming to an afternoon drama group.

But the difference! One little boy in the last group, he was HIV+, they all knew their status in that group. He was in a children's home. His mother had recently died and he hadn't been told. He was about 14. He came to the group and he was angry. He just started to cry in the first session. The other children were thinking what was wrong with him. No, he was really really really angry because he was told that this was a soccer team and this would be about soccer, and why was he here on his own, why aren't his friends here, why is he the only one who has come. He wants to play soccer, he's not coming back to this. And our feelings were quite – he would not be consoled, he was not interested. After an hour he wouldn't even come near, usually they get interested in their box of all art materials, he was not interested. It was that feeling, why me, why am I here on my own, what's wrong with me? He could have that understanding. Whereas the other children, the smaller ones, I mean we learned, that was a bad group, it was a terrible group make-up and set-up because of we were told you have to have so many people. But we had 14 year olds and 8 year olds. But we set it up because all these children had been disclosed to and needed support.

But we stopped the group after ten sessions, normally it runs for 20. So we had a non-disclosed group that ran for 20 sessions and the disclosed group that closed after 10. It just did not work.

So it was sad for some of those children. He was part of that group and he came with "there's something wrong with me". So for this year we decided we're not splitting. We're having all together, disclosed and non-disclosed, so they can talk with each other if it comes up. It's making it normal, I suppose.

But that little boy worried me actually. There was a lot of stuff going on for him. He knew he was HIV, he was coming to the group for HIV, but he didn't even what to be there. It made him feel even worse – what is wrong with me?
Whereas the adolescent group that I ran just before then, they had all been disclosed to. I interviewed them with their carers there, they had all elected to be in the group, the doctor had told them about it, and they all knew their status. They all came voluntarily, wanting to do it, and yet it was even difficult for them to say, they could not say until it was about, it was only a 12 week group, and only in session 4 or 5 could they even say the words HIV. It was hard, and they all knew it, but it was still a secret. And I think of the other groups, we were working, that first group, what made it so hard, is that you're working while keeping a secret, and how much of it am I part of colluding, part of this whole, of keeping the group sick in that way. You know, why not just say it? And I'd get very afraid of it myself, in that first group, very frightened of it. And it was interesting because the facilitators, the young facilitators that I was working with, are so afraid of it coming up. Its amazing, you know.

So in the first group, was the issue of illness, general illness ever talked about?

Always talked about. I had this doctor's kit with a stethoscope, and props and costumes and sorts of things. And often, we always talk about illness. And they know they're ill, in a sense. They know they come to a clinic. They don't like injections – you know we get them to talk about all those sorts of things. We talk about how they handle their medicines, but just never why they're here.

What other sorts of things have you found challenging about the groups?

Well you know, I think so often one has these difficulties just living in our country, you know. Here I am, a white therapist who doesn't have HIV. And I think it just feeds into lots of feelings about being white in South Africa, for me. That's a lot of stuff I had to think about and work with, and still struggle with. I go in, and I leave, in my car, to the hospital, everyone else gets R3 for transport or has to walk. And it's just the differences you have to face, even when it comes to HIV, I'm not saying that white people don't get HIV, they do, but in this kind of context, its black children, and lots of deprivation
and I suppose the other difficulty for me, is something I thought about a lot. What must it be like to be born with HIV? And to get that from your mother. And I think, in terms of Melanie Klein's kind of stuff, the good object, and breast feeding, and to have milk that is bad – its good food but it's bad for me, and now I'm taking medicine, it's horrible, but it's good for me. I often think about those kinds of things. These are little 8 year olds. And when I think of that 16 year old who has just fallen pregnant, she's had a terrible life, there was sexual abuse and a whole lot of stuff. How does she make sense of that – that you are born with, you are given this thing?
Ja, if you're not taking drugs and the child has it, you don't have a good chance of living a good future. We hope they will, things are changing medically, but to have to make sense of it. So often I struggled with that, and you can't talk, you know children aren't engaged in that kind of way. So you're kind of holding that and wondering.
And then, at the same time, just children's enormous resilience and love of life and they get a cold and they get flu, but they still so want to play and be there. So its not all, as I think I said at the beginning, its not all just, oh god, this is terrible. Its also an amazing sense of life.

When I think of that little boy who I so wanted to bring home and adopt, ja, he could also just run around and play with a ball, he just wanted to be an ordinary little kid.

When you talk about struggling to make sense of the child whose born with HIV, instead of someone who's contracted it , whether it be through their own sexual behaviour and through rape for example, what sense do you make of it?

I think about it a lot. No, who knows. I think, what I think of is that we're all vulnerable, we're all at risk, including me, at this stage of my life, I suppose the thought of negotiating sex with or without a condom. You know, all of those kinds of things. And how hard it is to do that. So I suppose I don't think it's a punishment – you've behaved badly and this is what you get. No, I just think its here and we've got to deal with it.
So I suppose I can't make sense of it. It feels cruel for a child to have to deal with it, and everything else, and not have a mother, you know, because your mother's gone. And you don't have that support.

Working in the groups with those children who sometimes didn't have mothers, or a good object. Did that ever set up a conversation in you about trying to be the good mother for them?

Possibly, We worked in supervision with this as well. And you know, the need to give food and to provide and give nourishment. Ja, so I think so, definitely there was a conversation going on inside around my own internal stuff around it – I'm always ready to deprive myself of a lot internally, so I think there was a lot around that. I do connect with that – you know my decision to work in the prisons – I do, a strong part of my own process which I think I acknowledge and talk about.
But I think there was certainly something about me needing to be good enough as a mother, and needing to make the food nice and sweet as well, it wasn't just sandwiches. I wanted to give them chocolate breast milk. Enjoying giving that milk, because they loved milk – that first group. These last groups we haven't done that this time. Food is being provided but another HIV organisation is doing that. So the kids first go off and they have a juice and a pie and then they come to the group. So its been a lot more manageable, because we're not doing every aspect and I think its been healthier for the children as well.

So in the first group you were being the carer as well as the therapist?

Doing everything – buying the food, arranging all the food, setting the group up, giving the food, cleaning up afterwards. I can't tell you how tiring – just arriving and leaving, locking the door, cleaning up and not only the children but the mothers as well. Often they would hang around in the corridors afterwards – have I got any clothes, can I help them. Dealing with all this – it was just so tiring.

When you talk about how you're quick to deprive yourself of your own needs. Is that what you're talking about?

Yes.

What other aspects are difficult?

I suppose when you think about the disclosure and you think about how to talk about it, that's very challenging. How to approach it, especially with children. What's appropriate, what's not appropriate. How much do we say, how much don't we say. And its not about educating, its not an educational group you know, but, I never answer questions, I interpret, but you kind of wonder what happens. I'll tell you what happened in the disclosed group last year which is why it was probably such a disaster. The children all knew their status, they knew they had HIV. In about session three, I said, I think we need to look at our fear of saying HIV in the group. And I think we've got to say it. Because if we don't say it, its not going to get said. So I brought it up, but I think it was premature. So I said, we are here because of HIV, everyone here has got HIV, and even saying that, there's always the feeling everyone's got HIV except me.

And its such a - I suppose its that feeling of setting up that kind of patronising white person coming to help Africa, you know, and I hate that and I so don't want that to happen, and I hate the fact that I can't speak the language, you know.

But to go back to the HIV thing. I brought it up and the group went into this space where they just fell into the abyss. And the co-therapist and I looked at each other and realised we had gone into a major therapeutic space.. And that was OK for us to handle, but for the facilitators to handle – they then witnessed a very dynamic process. There were only 4 children in the group, each child was asked to draw their illness. It was amazing, the 16 year old who's pregnant, she was getting counselling and counselling other people and engaging in the process. She drew these black dots and wrote, "AIDS will kill you". One little boy, he couldn't cope with it. He tore his piece off the wall and tore it up and then regressed. He got under a cushion and just lay there. Another child, younger, the same age, but younger developmentally and emotionally, he just went down as well with him. He couldn't understand. He could draw the AIDS ribbon, but he was in complete denial. So they just went dead quiet. And after that, no-one came to the next session.

And I think it was too soon, and I asked my supervisor and said, do you go in and say this is what it is, and we spoke about it and said no, and I thought afterwards, how can you provide a space where it can be talked about in a more gentle way. And I don't know, I still don't know really. It felt it was too soon then, for them, but it could have had something to do with the differences in the groups, their maturity levels – but this group just couldn't cope with that. They just went, they freaked out more.

That's the other thing – working with a translator and a facilitator, because their stuff comes up and many of them are HIV positive as well. And they're watching these children and you're also holding that and its hard.

A splitting happens between the white therapists and the facilitators? An idealisation of the therapist?

Yes, absolutely, and I think in all of the groups that's one of the hardest things to manage. Because I so don't want it to happen, but it happens everytime. There's still this internalised, that's this whole white-black thing. All of these children are in school in Soweto. They don't see white teachers and you have black teachers as the norm. They don't really see whites at all. So I become a whole white, magical thing.

And in the last group, I was the observer, to observe the facilitators, but I was part of the group, so part of the opening ritual, I would put my chair in the corner, we'd do the opening ritual together, but I wasn't facilitating. At the end, we did a closing activity and I had made cards with each child's name on it and each child signs each others' cards and they all go away with something to remind them of the group. I hadn't made a card for myself. And they wouldn't carry on unless there was a card for me. So we put a card down for me and then it was like a fight – literally like puppies grabbing at I suppose the good breast – who could get the teat first and write in that card. And not just write, but like draw and write. And I do find that quite hard.

And also what happens in terms of the split between facilitators . We've never spoken about this – it would be interesting to know what their internal processes are around this – you know, you come in doing this and that and we're just here doing the translation, and you get all the – I mean its not really true, because its not how we do things.

Because I know, I know that for many of the mothers, part of the problem is they say that their children are too naughty, because they're kind of saying no to their mothers. Which I think is quite positive. Initially the facilitators would get very strict with them – it felt like they were in school. I managed to work with the facilitators and they went on child ECD courses, we've done full day workshops with them and they've had a lot of input. They're in a very different place now, where they also say, ja, we could have had some of this when we were children. This space to be. Its not like school – all very strict. I think it would be interesting to hear what the facilitators think, you know, about us, about me.

…quality, yet you're saying that's not the way that you work.

No, no, it gets set up in some kind of way. Because I suppose we were going to run the groups, to help them get set up. So I suppose we come with the expertise. And I did sometimes wonder – are we the experts? Should we be talking more – I don't know, its part of the difficulty with working in South Africa. You have to be careful. And still, in the end, there's a sense of, "We're not sure we can do this on our own. We want K there, we're going to have to imagine her sitting there in the chair.

What comes up for you when they say that?

Part of me wonders, are you just saying that. Particularly this one facilitator. She's always praising me and I kind of wonder what that's about.
But we've worked so hard to get to this point, they must run it now. And they can – I've watched them and they can do it. Together then formed a beautiful facilitation couple. So part of me feels very frustrated and that they need to get going on the project.
But on the other hand, I see how long this process takes. Its about an internalised,….. its an internalisation that hasn't taken place yet. So I suppose I realised that they havn't got the confidence yet. I want to see it growing because its beneficial to the children. But what I realise is that in all of this work its really slow. You really want good solid work that's making a difference.
The other side is that we're desperate for interventions that are working and are seeing large numbers of people. But then they just touch the surface.

And certainly this kind of process has definitely touched those children. Something has changed. And we see it in the post-interviews. Differences in relationships with siblings – parents report, their relationships with the child, stuff happens at school that's different. Ja, its not major and huge, but there are changes.
So when she says that kind of thing I don't like it. I hoped I could just be the quiet observer in the background. But I realise its been a dependent relationship. Even though we've been working at changing that, hard at it, but it also takes time.

Can you give specific instances where your own emotional responses have impacted on the work?

(Long pause). So many things. Do you want to know – when it happens on the children's behalf or on my behalf? There are lots, but maybe I need to just think specifically. Well, there's sometimes, I'm thinking of one, I suppose I'm quite engaged with working with the children. My response at one point, one little girl who had a severe learning disability, and she was quite small and the rest of the group was these bullyish boys. One of the boys was playing being a doctor and came over to give her an injection. And she got a fright and didn't know what to do. So I jumped into role as her mother, and I became her mother and I said, "have you pricked my daughter". And he just turned to me and said something like, "yes, well, Mrs orange shirt", or something. But there was a moment. Jumping in in that kind of way.
Also with the little boy, being more involved with him and forgetting other children's names.

What do you think that was about?

I think at one point being totally focussed on him and somehow the rest of the groups fell away. And thinking, what's going on, as the therapist, thinking where's the group, how have I only focussed on him. And so a very strong, I think more than I've even actually acknowledged, a strong connection with this little boy.

Was it somewhere about his need to have you all to himself and the other children just being somehow killed off?

I think so, I think so. He was also trying anything to get my attention as well. He was playing that out, And um, lots of that kind of. Or fighting, fighting over things in the group, if I offer something. Fighting over who would get that – almost to the extent that they'd hurt each other, get into a physical fight. A lot of aggression – that's a lot of the stuff that gets acted out around us. As facilitators. A desperate hunger. If you offer something, they all want everything and they want it all. And its like a pack.. they're like little puppies, they all get in and they want everything, you know.

And how did you deal with that situation, children fighting over things.

We don't allow fighting in the group, its part of the contract we draw up in the group. So if its over one particular object, I take it away and say we're going to just keep later, we're not going to use it now, we're going to put it somewhere else. Then I come down to their level and tell them to take a deep breath in and lets calm down. But there was one instance with two little

boys, it'll carry on to the next week even, because they hadn't dealt with it. One child broke something of the other child's.

Also, with needing to please us all, wanting approval, but we don't do that in drama and art therapy, oh that's good, and I suppose quite frustrating for them at one level, not getting," oh that's a nice picture".

One little girl also took an absolute liking to me and would come into the group, and she knew – we said no eating – she would took out her chappie and then would watch me and write me little notes and at the end of the group leave me little notes, how much she loves me. You know, in the group, instead of doing something, she would make sure she drew me in the picture. And it's a hard – Ja….

How would that (unclear)

Mine? S even said afterwards, oh, you are the good object. You're going to have to watch yourself. I try to be very neutral, I'm very aware of when that kind of thing is going on. And it's a hard thing because you know that she absolutely only wants to engage with me and she wants to kill off everybody else. She only wants you and I to have a relationship. So you smile and acknowledge but I don't want to go further than that. And through the letter, I would accept it, you know, thank you and then I would escort her out or try and distract her quite quickly. There was a lot of that with that one little girl.

I wanted to ask you about something you said earlier – your struggle with leaving the hospital and coming back here. Like a split between the worlds. And I was wondering what it must be like to be in the group where in a lot of ways you are the idealised object, and how that relates to the discomfort of having to negotiate the two worlds.

You know I get very tired. It makes me very tired. Even as you say that. My nitial thought is tired, tired of being that

The idealised object?

I don't want to be that. That's why its so nice to work with the facilitators because there's a sense of a team, a sense of an us. But I suppose that's me wishing for that. I so like the work and I so like being involved there. I hate the, I just get tired, tired of what that means….

That sense of an us - that mitigates the difficulties around being the idealised object (unclear)

I guess what I think is its not only me doing the work, we're trying to extend the work, so its not only staying with me. And there's a team of people and we can kind of share the experiences with and share the feelings.

So the group participants can begin to see more than just one person as the good object

…….Ja. It's interesting because there was a male facilitator- female facilitator and me, so two females, one male. He was cool, they liked him and they liked me. She was the one who took on the bad, the bad stuff. So its an interesting thing in terms of, I suppose, certainly white still has this thing that's kind of idealised, and something about men as well that's interesting. Something I suppose about the black woman who has the harder role. She had the tougher role. They would often not say her name, forget her in the circle, never forget me and never forget the male facilitator. And I think it was hard for her – she struggled with, she didn't know

what to do with that. Her kind of way was, oh no, its sad that the groups ending and there was a whole lot of stuff going on there that she never processed.
But I do get tired of it. When I come back from the groups I am tired. So I quite like the little journey back. I suppose sometimes I just can't think about it – I don't think.
You also mentioned the feeling that being HIV-negative is another sort of level of privilege. What is difficult?
It's put me in touch with kind of…….what that means, you know……. And it does make me feel more privileged. It adds to my whole package – I'm white, I live in the suburbs, I have a car, and I'm HIV negative, and I'm educated, you know. And I've got this training that no-one else has got, that I'm trying to get going. And I hold a group that's about loving the child, not disciplining the child. So I don't know. I think that kind of stuff comes in, and that makes it hard to work, to give skills. I don't think that that's happened with the children.
Well its interesting, because often the facilitators ask, what do we say if the child asks us if we're HIV positive. So I ask, well what would you say? And they say, 'oh, no, I'm not telling them. It would freak me out, I would want to run away from this group'.
What are your feelings about that?
Well I would want to be honest. The faciitators say no, no! But we can't be honest. I don't know what I would say! Sometimes I wish I was positive because then I could sit in the group and talk about "us", say "us", because it makes me think well maybe us is – that's why we thought of the group as being disclosed and non-disclosed – there's some positive, negative, its about being people. So I suppose I am leaning towards working like that. But I don't know what I would say, if the child asked me, if we were talking in that kind of way. I suppose I would want to say I'm positive to give them hope or something (laughing). It's an interesting question, an interesting thought.
(Unclear) negative, to say you were positive, what would that mean?
I'm not, so it would mean then, I don't know, I suppose it would be lying. But also, I wouldn't answer, I wouldn't disclose that kind of information. That's how I get out of the question here as well (laughing). I'd put it back. I wouldn't answer that kind of question as a therapist. I would explore with them, 'well, maybe you think…' That's the thing – they all thought I wasn't, of course because they'd make me into being something that wasn't, even if I was, because I was this idealised object that was not…….. real, or something.
It sounds like what you might be talking about is the tension between on the one hand the desire for the group to be the same, for people to be the same so you can relate, or the common humanity of the group can be affirmed.
Yes! And at the same time acknowledging that this exists in our society. Some of us are positive and some of us are negative. And what does that mean? Does it mean you can't have people who are friends on either side, does it mean you all have to be the same? No it doesn't. So in a way, as I'm thinking about your question, if I was part of a group I would be honest about that. But I am still, everyone uses the word a lot, I am affected, we are affected by it. But I don't have it but it's going to impact on my life and it does impact on my life.
I suppose another reality is the stigma around it – to say in a group, "I'm negative" is not as simple as just saying I'm different.
Exactly. It means I'm not positive which would mean I've been badder than bad.
Unclear
(Sigh) I suppose my hope is just that a space would be made to just talk about it. And I realise how hard it is, and how hard it is for me.
Can you say how its hard for you?

I suppose there's guilt, guilt about a lot of stuff – there's guilt about I'm *not* HIV. I suppose it's the same thing as when you work with very ill people. Do you feel, what should I say, what shouldn't I say.
So I suppose its this mix of feelings – I want people to talk about it and its certainly positive with the caregivers, but that's when you're working with adults, not when you're engage with children, in a way that you can help them – because they have a hard time at school – they're specialed out – and I guess just feeling that I don't want it to be like that. Feeling will we get to a point where it's, I don't know, because if you do disclose publicly –and one little girl did – she told everyone in assembly – because the teacher asked, is anyone here HIV positive? She's the one little girl who had this transference to me – she put up her hand and said, yes, I am. It was her way of trying to be accepted – because she was such an outcast, she could never have friends. That became so important and the group was so important to her because there she could have friends. And what happened is that the children who used to bully her and take her sandwiches from her stopped doing this because they were afraid of getting sick, but she understood this to be about her being more accepted
It's so complex, what goes on at school and what goes on in families – hiding the medication so no-one will know, and what does that child feel like? You know that not everyone's the same, you're not going to be equal, but you start to feel after a while that you are like this bad thing.

Even when people are being counselled and they know their status and they're counsellors, even for them its difficult. The facilitators find it very hard to talk about and interestingly enough I find it very difficult to talk to them about their status. I suppose that's what I'm saying. I realise how hard it is actually. I think its something else – ja, you do this and this is what we should be doing, but actually its quite a thing to negotiate.
What makes it diffcult to talk about?
I know how afraid they are, to say it, but I kind of feel like asking how you're feeling, what's your CD4 count like, what's going on. But no-one ever talks like that so I feel like I collude in a way, I suppose. It's a weird thing – you know it , and you're sitting in an HIV organisation, but you don't feel you can say, how you're doing with your status, what's your CD4 count like". Until somebody offers something and then I talk, but I also kind of…..it's a weird, weird thing.
Is it the stigma thing?
Somehow its always easier to get other people to talk about their stuff, but for themselves, to talk about their own stuff is very, very difficult. And what it means when you sit in a group with a caregivers-facilitators and she's so thin, because she's quite ill and the moment, and there she is sitting next to you, facilitating and she's got no weight on her at all, and you know that she's suffering and stuff's going on, and she's at the point of AIDS. And its so weird, it really is.
It's a whole mechanism to protect - because it's an illness I suppose.
Mmm! But I don't know why – it's an illness, but so is cancer. I don't know what it is around – because it's a sexually transmitted disease? I don't know, people act as though its leprosy
maybe fear of contamination
I think contamination's a big thing. I didn't have that – at first I would wash my hands a lot, but that was it. But lately I've been feeling more energised by the work, maybe because there's more support, or it feels like the work's doing more and its not just me having to take all the responsibility and the emotional responsibility, being able to separate myself and look after myself more and better after four years. I'm less fragile than when I first started.

Reflects how hard it is to talk about, and that she's somewhat disengaged, as a protection.

INTERVIEW: L

Just tell me a little about the work you are doing with children with HIV/AIDS, including your theoretical orientation.

Sure, yes, I'll start at the beginning. I'm a Drama and Play Therapist. I did my training in England in 1998/99. The model that I'm working with is as a Creative Arts Therapist using drama, play and also bits of art with adults and children. My work with children who are living with HIV, starting in 2002 and I completed that phase of work in the last year 2005. So I worked for 4 years based at (an Aids Care Centre) which is a children's home for children with HIV that have been orphaned or abandoned … and primarily in the first couple of years my work was with group work, small groups, I usually had 5 in a group.

And as time went on I realised that I'd be doing the children and myself a favour if those groups actually got smaller, so I started working with groups of 3, even with pairs and then ultimately last year I was actually working primarily, individually, because I found that the most effective therapeutic intervention, so I'll be talking more about the challenges of group work.

Yes, initially the groups of 5 would be with children of similar ages and circumstances, so I started with a group who were all about to start school in grade I - they were all of the ages of 6, 7 and 8 and I worked with 5 boys and I then had another group of another 5 boys who were slightly younger, they were kind of 5 or 6 years of age and I had a group of 3 girls, actually the only 3 girls in the age bracket, they were between 5 and 7. So small groups.

So all these children were HIV-positive? And they knew their status?

Ja, that was part of the idea of the school's group was to be part of the disclosure to them and we kind of felt that was important once they started going to school that they be aware of their status and have as much information as they could about what that meant, because they were a lot of reports through other organisations that I had also worked with where children that started going to school, particularly coming from organisations of kind of known communities dealing with HIV-positive children, there was a lot of stigmatisation and bullying and things happening, that I think kind of led the process of raising how important it would be to know … (inaudible) empowered and they knew what HIV was and be better equipped to manage it.

Why were you attracted to this work?

My training was in London and I'd worked for a few years in HS, in a kind of variety of fields, like play therapy training … a couple of years later I started working with a childhood bereavement service and I was getting fantastic experiences, I was really enjoying the work I was doing but I think in England a lot in the media around HIV and particularly children and it was just like … my awareness grew of what was happening here, particularly with children that had been abandoned here… and the separations and losses that were happening. I just found it was strange that I was working in England and there was obviously a lot to be done back home. So that I came back quite purposefully to working within the HIV/Aids and children who

were affected. And I ended up working exclusively working with children living with HIV at (the AIDS care centres) a little bit as well.

What are the challenges of this work?

Many challenges. I have to say I'm probably still unravelling what the challenges are all about and what they are related to. I feel that the overriding theme through many of the sessions is the complete lack of containment, you know, all the children exhibit extreme challenging behaviour. I guess it's all relative, but real, very difficult group dynamics. I think a major challenge was trying to operate as a therapist, when I was almost becoming a policeman most of the time … a lot of acting out.

Children needing to have their space and claim their space and have my attention and although the children weren't related to each other, there was a lot of kind of sibling's dynamics, they were all living together. In the early days there were 20 living per house and my sense was that the children didn't have a space that was theirs. And there was a constant fight to have their own space, to be seen and to be heard and to have attention and the extraordinary thing about the organisation really was that there were people coming in and out of those children's lives like a train station.

There were international volunteers coming six months to a year and leaving - this kind of serial abandonment, you know when they had already lost their mothers or primary caregivers and often arriving at (the care centre) at the children's home would be the third or fourth placement they'd had since losing their parent. So I felt like it was a lot about needing to find a space that was theirs and not having that reflected on where they were living. I was giving some thoughts as to what was it really about, mostly I had these feelings of needing to contain and hold and it was very challenging.

And feeling very frustrated at times and ja, overwhelmed as well at times and not necessarily only about needing to contain children that were climbing the walls, but just the, ja, sort of needing to … I guess what would happen is that every group would start with children all over the place and just to try and start in a circle and just trying to form that circle would be one of the biggest challenges. And then once, because the drama and play therapy is very active, we'd work within the story and play and once we could get to that stage where all children were involved in one kind of play, things would feel kind of more contained, we'd be in the same place, but often the kind of material that would come out of the play would be quite overwhelming, there would be quite sort of intense themes and structures.

Maybe to give some examples that I was thinking through … there's one session that probably sticks in my mind the strongest out of all … I'd been working with the three girls, I'd worked with two of them individually over some time and then ultimately they were working in a group of three and most of their play was around 'sick'.

They'd sort of come to sessions and say they wanted to play about 'sick' and they would play various combinations of one or two or three of them being sick and needing to go to hospital and being looked after by one of the nuns and they would kind of cast themselves and me, sometimes they would cast themselves, sometimes they would cast me, initially it would

become more sort of as them playing they were sick and I would need to be the mother and I would need to take them to hospital and look after them and they'd be throwing up and having fever and bad tummies.

It was only reflected at that time it was very early days of anti-retrovirals - a couple of them were on trials but they weren't - I mean they were sick children - that was their life - in and out of hospital. Children were being sick a lot of the time and then they started casting me sometimes as being sick as well and they would be looking after me as well, which was quite interesting.

Them being the doctors and injecting me and playing quite positively at times, them being nurturing, taking the nurturing role and being self-nurturing - they were also doing that, but also working with the dolls. They would sometimes use the dolls to be the babies and there were all kinds of combinations but it was always a play about 'sick'. I remember one particular session, I was cast as the sick child, and it was quite repetitive, I was cast as the sick child and the three of them were nuns and doctors and what have you and I became ill and was taken to hospital.

They stretched me out and started to inject me and give me medicine, listened to my cough and did all that, and I was lying there and then they crucified me which was quite a profound experience. To put it into context, it's a Christian-mission run children's home, so a lot of the stories that were told by the volunteers was around Christ, hence the story of my crucifixion … sort of magical thinking I guess … equated the experience of dying was to be crucified by the doctors and then had to die and then went to Heaven … and interesting because the model of drama and play therapy that I work with … one does enter into the play which I think makes the transference and counter-transference quite profoundly, I don't know, embodied - you are literally in the role and the child is leading the play. So I went to Heaven and I met Jesus there and I did all kinds of things in Heaven and then was brought back to life as well … so resurrected in a way …I think that session sort of stood out because it was … I mean the whole idea of crucifixion.

What was it like for you and the children to have you crucified? And go to Heaven?

Ja, I suppose there were different things going on in …(inaudible) being in that role … it felt overwhelming. It was sort of …I wasn't in control, that I was in over my head and where is this going to, are we actually going down this route? I think you hold that in your mind, particularly when I was working with a sick HIV child that death and dying is part of the work and we are meant to go there in one or another way during therapy but it felt like well I'm being killed … you know the therapist being killed and what is its meaning.

What it felt like was the children needed to go there and I was happy to … I wouldn't just be this person that would go wherever the children wanted to, there would be times when I would intervene in the play and it was quite important to go because the children needed to cross over to the other side. One of them became Jesus. The roles that they were taking were quite interesting.

Was there cruelty to you?

Not cruelty. It felt serious, now we must crucify and it was a serious thing, it wasn't joking, but it wasn't, it wasn't, it was neither light nor kind of very heavy. It was kind of like other-worldly, like … like passing into another world. It did have those kind of feelings which I guess left me on the edge there in terms of life and death, those sorts of major archetypal kind of questions and my feeling the first children often, even though they wouldn't necessarily know cognitively or understand what it meant to be HIV-positive, they had a sort of innate sense of dying, death and sickness and what that meant.

Most of them would have experienced their own mothers or fathers or both dying and then within the children's home, two of these three children experienced one of their room-mates dying - a little girl died, in fact, you know, probably within the year before this kind of session happened, and so it's so much about the experience in the body and their feeling . I think I would have experienced some anxiety in those moments, thinking whoo, and feeling how does one deal with this now we're in Heaven and being crucified and you know, so that kind of wondering where's the line going to come and where's the ending for this story which was the big question, how will this end … but at the same time being able to reflect as we were going through the play how valuable it might be for them to actually walk this path, you know, and not having them be the one whose sick and dying. I was left having to contain that experience for them and they were very watchful actually to see how I was managing it.

That was also quite interesting. The choices of how to play that and then they were quite directive in terms of how I was to play … they were quite used to at that stage knowing that I would just play freely, they wouldn't need to tell me how to play so they would just be telling me vomit now, or you must do this or that, this is going to prick you, it's going to be sore. I'm sore! And then the dying … they were hammering in my hand and that had to be sore. And then they said, now you must die, just die … and then they quite quickly moved into Heaven and Heaven was quite a playful space because there was Jesus and things kind of lightened up a lot.

So it was magical?

Yeah, so Jesus was playing and reading them stories, playing with them, and it was you know a much lighter space and the resurrection… I mean they didn't talk about the resurrection, they said now you can go back. It was kind of like a quick kind of thing and then the play was over and it was like having … (inaudible) and they became the nuns and I was well again.

So there was quite a lot of … at other times when they were playing being sick children, they would sometimes say: "Now die".
They ask questions in the play like: "What's going to happen now?" and sometimes their choice would be: "We get better" and sometimes: "Now we die", but that was the only time we literally crossed over to Heaven … so they would die but they wouldn't kind of necessarily play, you know it wouldn't last for a long time, they would just die. Okay, now we're dead and the game would be over. Ja, that would be one experience. I can't remember such a profound experience.

What sort of impact did the work have on you?

I think it was quite a … I was going to say 'reality check' which I'm not sure is the right way of putting it, but I mean if it weren't for the fact that this is really what's underlying a lot of their experience and I'm not so sure it would still necessarily be still now, all those children are on anti-retrovirals … (inaudible, over speaking).

Were there no anti-retrovirals at that time?

No, or the trials might have just started, anyway they were still sick children at that time and now their experience is quite different. They're like healthy children and they're all attending school. One of those girls has actually been reunited with her mother. She was the only one who still had a mother. Ja, to your question of how it impacted … I think it brought me closer to what at the time was maybe the core of it.

It wasn't just about … there were so many things, it wasn't just about having lost a parent, dealing with a sick relation, or loss issues. It was about death and dying. It was kind of what that would mean for each child and how they would be handling that and I think actually having gone there, maybe there's a kind of a relief, like how much further would it go. I suppose that when you work that way with the child's play and you're part of it, you might often have the question where … wonder where this will go and how will you manage to contain those things. So I suppose as a therapist, just having gone there, I would feel more able to contain those things. I would imagine - but it hasn't been all as challenging as that.

(a sense of the unspoken being spoken, in a very sort of natural way and that sense that they weren't allowed to grieve ..Interviewer inaudible, very faint, not able to hear her question.

Ja, and as you say that I'm thinking of how much, how many taboos there actually were, working with them, and one of them was the idea of death and you think you might die … I mean there was a lot of…. when it came to disclosure and actually disclosing HIV status that was again another big, you know, not kind of wanting to say those words and not wanting to arrive at that place, where we would actually just say: "So you have HIV in your blood" so there was … and then again sometimes the children came to (the care centre) even when their mothers were still living but very sick, there often would be a parent dying while they were living at (the care centre).

So there was a lot of not talking about a parent dying, you know, the organisation getting away with not giving the child too much information about that, not assisting them through the process, so things like attending the funeral …(inaudible) … looking through some things in sessions… I wrote to the organisation, trying to get one of the children to attend her mother's funeral, which just seems so obvious, but anyway, it was not obvious to everybody. I mean there were a lot of things that weren't spoken about … even just getting the children to go to school …(inaudible), but I think a lot of it came out from the therapy.

But I think another major feeling I would have would be that these children didn't have a voice and I think that would arise out of therapy, I felt like in that space they were able to kind of share a lot of their experiences and feelings in a very intimate way where there wasn't the space for that in the size of groups of children that would be assigned to one mom, and I would try to make this space, where they could really express things that would not necessarily be heard elsewhere. Often in sessions I would feel like I needed to be their voice, there needed to be something beyond the sessions, just expressing and containing … (inaudible) I became quite active in the organisation just to try and lobby for their rights and I think that arose also out of the therapy.

(very faint). …extending the children's voice?

Ja, absolutely. I would be translating for them as well. You know, they obviously acted out a lot but it was behavioural, it was how they were, what they were trying to say, they would get so frustrated, they started breaking windows, they threw stones at white people. I think I can get very angry on their behalf, there were things that were being seriously overlooked and …

What sense did you make of their acting out?

Well, it was firstly and primarily that they needed to have families … the children's home as a model was just not working at all and they needed to look at a foster care model, where children would move into foster care or be reunited with family members who would be able to take them. I think primarily it was that - a lot of the sessions were about playing moms and a lot of the children having strong fantasies about who their moms were and where their moms were … this kind of desperate and basic need just to have a primary caregiver I think, it was a major things for these children were being held in this children's home.

I didn't feel it was right…(inaudible) and I think that was a good basis of a lot of their challenges to other things. And then, secondary to that would be the amount of people coming in and out of their lives … a kind of lack of understanding about attachment and how crucial that was …and so I felt very supportive of children breaking windows and I was thinking: "Go for it, smash all the windows down!" You know, these children need to be heard. Ja and that feeling of not being able to do enough was a very constant feeling. Not being able to do enough for these children.

There were many things that children should have more of, more of a kind of say in how things should run in their lives and maybe they actually were not consulted at all. Decisions were made for them. I tried as much as I could in the therapy to give them a kind of choice and autonomy. Mostly they would self-refer to therapy as well, I wouldn't tell them they needed therapy, they would go themselves and decide if they wanted individual or group therapy, you know sort of ways like that which would give them a feeling like they could have their space and we would build memory boxes for them so they would have a physical space of their own.

You've talked about your sense of how the children were let down in the care systems, and the serial abandonment. Do you think that impacted on the way you chose to work with them in the groups?

Ja, I think certainly those kind of feelings would enter into it a lot, also making sure they would have a level of autonomy and they would have their own space and that this space was really theirs and I think that I really moved away from where I think I started initially working with themes, games and activities … and more and more kind of gave it over to them to kind of lead sessions, you know, have a lot of choice.

Certainly there are different ways of working with drama, and one would be to have a kind of open session where the child would lead and I guess in terms of how I'd work with them … there was a time where I would do far too much as well, that was probably from the feeling of not being able to do enough, and there was never enough and there wasn't enough nurturing. I was to take on that role of basically … generally the sessions would take the path that they did when the child led, and at the end there was always a strong focus on kind of containing.

I remember in one session there was a … the three girls again … actually the one became what she called 'the ugly mama' and she was basically abusing her baby doll and she was abusing her and hitting her and sitting on her and not caring for her and throwing her across the room and there was another mama who was 'the nice mama', I think she called herself. My point was that they could carry out the kind of … in the session there would be a lot of space in allowing that child to kind of abuse this baby doll but it was very importantly at the end, would be like okay we need to contain that whole experience and they would try and find ways of nurturing that baby.

So I suppose towards the end of the sessions the feeling was needing to look after her, contain her, and hold all the experiences that had been expressed, that would become quite important, maybe mostly important because I wasn't sure, didn't feel like they were being nurtured enough in the right ways.

How would you contain children in a session?

It would be through the play … that doll that was quite smashed up, I would ask them if there were ways in which we could look after her. It would still be in the play, so they would be getting plasters for the cuts … bandage her, wrapping up and singing songs. We'd get in a circle and sing her a song, put her to bed and to rest until the next session and then we'd always just have a closure out of the play, where we'd sing some songs or …(inaudible).

There was often … one of those girls in the group came from the DRC and had been through a lot of trauma amongst everything else and she would have huge kind of trauma response to little things that might go wrong and she would just start screaming and crying and crying … in a way containing her, because she would not allow you near her to comfort her. You would just make her worse … would be to collect her doll to start kind of soothing that doll, singing and holding and containing, and that would work to get her to stop, she would start noticing the baby, she would start looking and slowly the tears would abate a bit as she would start getting more interested in looking around. I would give the baby to her and she would take it and start looking after the baby and through nurturing the doll she would find her own self-nurturing. So in a way we would try to use the play in the way that I found most effective.

Interviewer indistinct. ... I wonder how you coped with this?

Ja, there were moments that were very very painful and very sad and very desperate, you know feeling really desperate that these children need a mom, you know there were all kinds of feelings that arose like fantasies of adopting. I think that supervision helped a lot, they would be able to talk very freely about all of these … ja what came up in sessions and how it felt for me and how my fantasies about adoption and those kinds of things, but I think a big way I did deal with it was to become kind of an activist in the organisation.

I would become quite angry. So I wasn't always heard, there were little changes, there were some changes, which were quite big steps like the children initially were just, it was too insular, kept in this little place - a strange world which was like another planet and they weren't going to go to school and I just found this the most bizarre thing, I really lobbied for them.

They weren't going to go to school because of their status?

Ja, because people were afraid of what would happen, how they would manage their … a lot of them were developmentally delayed and sick and all that. I really kind of lobbied and pushed for that, it was crucially important that they go and I just have another experience outside of that, how can I say, a fundamentalist Christian kind of environment which was all too insular and bizarre.

The children stopped speaking Xhosa because the main language was all in English which was I guess also a part of a strange irony in this country. I guess I was trying to speak Xhosa in sessions and …(inaudible) … they did have Xhosa mamas but the international volunteers who would be 18, 19 they were 20 years of age … they would kind of take over the show as English was the major language. That's also shifted, now the children go to Xhosa schools and are having to learn Xhosa again and we encourage the mamas to really speak in Xhosa. Ja, so getting them to go to school … the whole disclosure issue, people are very afraid to disclose.

Will you talk a bit about disclosure, how it worked and what were your responses.

Ja, I worked … it felt very important to the disclosure would happen around the age of 7 when children started going to school … that it would be, as it needs to be with children a process rather than an event, I didn't want it to be something that was just spoken about in therapy.

It would be discussed in therapy so we could contain it, deal with the feelings, would be very important … but also by the mamas in the cottages, they would also be talking to them and there were also nurses who were working there, when they were being given vitamins and anti-retrovirals that they would be able to talk about why it was happening, and why they were getting medicines.

So we came up with a kind of process that it also felt important that we would all use the same kind of language in framing what HIV was.

I drew up a kind of sheet that explained how we would speak about it, basically to describe that HIV is a sickness that sits in the blood and the blood must try very hard to fight it and sometimes the sickness is getting bigger and sometimes it's more like things that can help to keep you healthy, taking medicine, sleeping well, eating well. We needed to speak about stigma, to say that there are some people in the world who are really silly and they don't understand that HIV is just a sickness like other sicknesses and so they might be scared of HIV, but there's really nothing to be scared of but it might … you would want to make a choice as to whether you would tell everybody that you have got HIV.

Maybe it's something that you would want to wait until you were older to discuss but you could always talk to anyone at the care centre, to the mamas or to me. We talked about stigma and then also the safety things like not to touch each other's blood and if you get a cut go straight to the teacher or … that biting's not such a great thing to do. So that kind of talk would encourage everyone to stick to the same kind of language around it and then, in therapy, I chose to work with puppets in the current disclosure sessions and that was quite interesting because the sessions had been so free and out coming.

Every now then actually I would try out a particular theme. These would be more directive sessions on child abuse, inappropriate touching, that kind of thing. I preferred to work with puppets where I would have a puppet and the child would have a puppet and the puppet would enter into a conversation which would pave the way with the child around HIV: "Have you heard about HIV" and checking out how much the child would know, it would happen over sessions, it wouldn't be sort of on one day.

Then the puppet would explain what HIV was and then there would be a puppet that would come from the care centre that the child would introduce .. There was one puppet who was the 'all-knower' who stayed through the sessions as the one who had most of the answers … and there would be a child with a care centre puppet.

This puppet would talk about how the children who are living at the care centre have got HIV and basically it comes into the puppet that she has HIV and how does that feel. So it's kind of checking out the useful things about working … and you could check out emotional responses that were still quite distanced from the child as well. When I felt that the child was ready and had a fair basic understanding about HIV and wasn't freaked out … I'd be able to have more discussion and talk to the child directly about it. Living with AIDS, that there was a childhood HIV, you know, getting to those words, that there was HIV in the blood, that was quite difficult to … difficult to just say it. …(inaudible sentence, very softly spoken).

Difficult because it's the reality for the child?

Ja. It's not wanting the children to have HIV. It's like feeling that they just shouldn't. They just shouldn't Why should a child have HIV, why should anyone have this HIV, but why should a child? They were all born with HIV. It just felt like they shouldn't. I didn't want them to have HIV actually. And I suppose just to say, ok, you do, and to acknowledge it and to them to have to deal with whatever reactions there would be, but the reactions were always, you know, contained. It wasn't .. I don't know if it was because of the kind of process we went through, the a long process or…….obviously they had quite a limited understanding of what it meant.

But also what I was saying earlier is that they have an innate knowledge anyway that something is not right.

Just going back to when you talk about disclosing, saying those words to the child that you had a feeling that the child shouldn't have HIV, you do you sort of come to terms with that for yourself... that these children have been born with HIV?

I think I have found a lot of anger about it, at who or what, or why, I don't really know, maybe God … . I mean it's not only working with children, but also working with adults living with HIV … it just still seems that has been my whole kind of working world anyway. I've been working with it for 5 years now.

I think it is a difficult thing to accept which is crazy, because I work so much with it but it doesn't make any sense why there should be this thing called HIV. On any level, you know, why women should contract it from their husbands, why … you know the whole act of love and why that should happen, that kind of shadow side, why a child should be born with it.

I suppose it's easier to accept if someone was sleeping around, knowing about HIV and not protecting themselves, you know, you kind of... it's easier to see there's an action and a consequence in the world that we live in where we're so educated about it, and making that choice. But a whole bunch of people aren't making any choice at all. And I think that was a profound part of working with a lot of women whose husbands wouldn't be kind of faithful … and of course children would be born exposed to the illness.

And also angry at the Government in those earlier days, where they knew there were ways of preventing it and they were taking so long to wake up to that. It was infuriating. I just want to take Thabo Mbeki to a place for one day for him to see how all these children were born with HIV and they didn't need to be. A lot of anger … how does one really deal with it? Well, it's just the reality, I can't say I fully accept it as it is, and that's alright. I don't think that it's alright, it feels like a fight, it feels like apartheid, like equating the struggle against apartheid, the struggle with HIV, it does feel a bit like that. It does feel like a struggle, it feels like something we should be able to contain.

I'm very pleased to not be working on the prevention side of things because I wouldn't know where to start. In terms of having to change behaviour or … ja, it never felt right that I mean, in the same way that a child or anyone who gets cancer or something like that would also elicit feelings and questions like why. Maybe working in an environment where there is such a collection of so many of them, 42 children, all living with HIV, so you just become … it was very overwhelming, the awareness, the feelings….. it was difficult to make sense of it.

But obviously working as a therapist, one is constantly processing all of those feelings and I mean I feel okay. …(Inaudible) … there are a lot of other people who haven't had the kind of training I've had, working with children as young volunteers, they would be so overwhelmed and not be able to cope, to understand it all. I guess I found a place of being, of acceptance that it's not something that does sit comfortably, nor I think will ever sit comfortably, it doesn't feel right, I think that is part of the impetus in the work, to kind of continue on.

I guess I do feel that I'm part of some, a minute part, but a part nonetheless, of some kind of struggle against it, of trying to contain, trying to kind of manage it, trying to be part of a response to this thing of HIV and how it's affecting us in South Africa.

Thinking of your contribution, do you think, in terms of an outcome, that there is a particular outcome to your work, that you can say to yourself that you made a contribution ...

No, it's interesting, but I think it's a struggle sometimes when you're working. A huge frustration that I had at the care centre particularly, was feeling there was such a limit to what I could actually achieve, because the environment of 42 to 1 was always contributing to kind of ongoing issues like they were not having space, what they needed just in terms of having their own space ...

So in terms of the outcome, I felt like there was a real limit to what I would be able to achieve and did achieve. I think the space was very valuable for the children that I worked with. I do feel that and I think that just giving the children a space that was their's. I worked with the children in 8 week blocks, but I accept there were so many children I wanted to work with ... there was never a feeling like one had achieved enough. A lot of it was kind of on-going and although I saw them for 4 years and could still be seeing them in terms of what I would say was their need, because they need that space. What were clear outcomes of the work? In that particular environment I think that would be ...

Did you define the outcome? When you talk about the feeling of having to tolerate the uncomfortable feelings around just working with it ... the impetus of you trying to make a difference ... what would you define as the difference.

Okay, I don't know if I'll be answering your question but my move and the focusing more on training, I had a very low level of training, working with careworkers for example, all the mamas and the community workers at (the care centre), I worked with foster parents and different organisations, various counsellors, social workers, working with people, adults who are in some kind of care giving capacity with children affected by HIV giving them some very basic skills in using the creative arts to enable them to listen to and respond to children in their care. I mean these basic level skills are given in a kind of 3-day workshop. It's amazing to see these caregivers making a kind of paradigm shifts in terms of how they view children .. huge amount of ... engaging with them through their play and in the kind of creative things that they do.

And so my shift has moved away from kind of working directly with the children, but now kind of capacitating organisations and care workers with the kind of skills to where I felt where it would never be enough and not only for those children, but when one looks at the amount of children living with HIV ... it's just a drop in the ocean.

It will never be enough. It does ...(inaudible) in a different way I guess. The children are receiving therapy from the care workers ... (inaudible) receiving that kind of attention ... hold

some of the experiences in the process. So I don't know if that kind of answers your question. That I needed to move on. I miss working with the children, very much.

What about it do you miss?

I miss them. I wasn't aware of it as I was working, but the whole kind of boundary issue of keeping them safe. That is incredibly challenging. And all kinds of fantasies of adopting. I mean particularly because of that environment where the child just has the basic need to have a mother and they would express that so clearly ... And I was never able to do whatever I could do, I'd do cartwheels and all kinds of things. I couldn't be what they basically needed. Some more that others .. they really jumped into my heart in a big way.

Ja, I just felt that if I could be their actual mother ... and it also seemed so possible ... I would fantasise that I'm a young woman, I'm not a mother. I knew and I still know that I could, although it would be a cross-cultural situation, there's still no doubt that I could give them a whole lot better environment and nurturing, what they needed. If they were my child I could give them much more than they're getting in a children's home. I mean the honest truth is I still have adoption fantasies but I always knew I would not have been able to have adopted any of those particular children I worked with because it's the message it would send to the other children would be wrong. I would have ended up adopting all 25 I worked with.

The message ... that you sent to the other children?

Why was she picked and not us. Because that would be every session anyway. They would all be at this pre-school on site and I would go in to say, to call different ones for different sessions and they would all be: "take me, take me, take me" you know just for a session, that would set up a whole lot of dynamics. A lot of it was just trying to keep the limitations, reminding children, you know, your session is tomorrow, remember on Tuesday at 2 o'clock ... Today's Monday ... It was just amazing, every day it would be: "take me, why are you taking her?" So much of this needing thing, needing to be seen and taken.

What are some of the other feelings that came up in your work that you struggled with?

Ja, I guess there would be times in sessions that I would feel either profoundly sad, which is not a bad thing to feel, you know in terms of the experience of the countertransference, for us to understand better what's happening for a child and you know, to work within those feelings. Ja, I suppose a lot of it is about unravelling what's yours and what's theirs. One looks from the outside on the whole situation, I mean it's desperate, it's a worst case scenario of .... When I was in England and about to move over to South Africa my supervisor and I were processing my desire to come out and work with children with HIV. She was saying it is almost like the worst case scenario.

I suppose I held a lot of that, I think my feeling response to those children, before even working with them, is that it was profoundly sad, you know.

Where their lives had ended up and yet so needing to hold that, that I came with that and I guess a part of that was to try and save children from that place, and kind of having to work with that and not to be the saviour obviously, and not to imagine that these children were sad all of the time, because of course they weren't. I think there would be times when they would express that or not be able to express that.

So a child kind of draws a picture of their mother in the session and their mother had died, which is … I mean I would be almost consumed by sadness. The child would be drawing away and not necessarily expressing that and I would need to make a choice – how much was mine and how much was their's. What would I do with that. Would I give voice to my feelings or would I not, and those kinds of choices. I spent a lot of time wondering what do I give voice to … all those people who work in the field, one encounters a lot of ones own feelings ….

And often having to let go of a lot of ones own preconceived ideas of where the children would be at or what the plays would be about, so a play about sickness, there were a lot of plays about moms, but there were also plays about all kinds of other things – fighting, dynamics about sibling rivalry, so you'd just sort of go with what was there.

what you talked about ... the feeling that you wanted to save the children and then found yourself in a session having to ...?

Ja, I think basically what I was meaning was using my therapeutic powers in not colluding, not colluding, just to keep some kind of space, that I was there as a kind of individual, not to be emotional, because I can be very emotional, not all consumed … (inaudible) but to remain as the someone who would be the container as well. That was important for them to have.

And I think the need to be a kind of saviour was in part and I was kind of conscious of that … (inaudible) what one would like to steer away from really. I wouldn't be there to kind of save anyone from anything, I'd really be someone to be with them, to kind of walk down the road with them and support them and give them kind of their own journey, understanding their HIV, their loss of a parent. Imagine if I was too consumed and their own feelings were ignored that wouldn't really be achievable, so in that way to maintain feeling contained myself. It wasn't so easy in so many ways because sometimes there would be children flying around the room, you know, trying to kill each other, breaking windows, you know in that way or being crucified … they were quite intense moments, there was so much going on.

So you know you just kind of keep oneself together and be kind of emotionally contained and just present, allowing what was going on … just maintaining oneself. At some times the children would physically try and climb all over you and hurt you and it was quite … in a physical way one would have to try and put up some boundaries in the space and say: "We're not going to able to have a session if you climb all over me"… They would hurt each other and equally try and just rein that in. I would have to stay calm and collected.

How do you think working with a group is different, in terms of your emotional responses, to working individually with HIV-positive children?

…(Inaudible) … sometimes it wouldn't feel so safe …(inaudible, speaking very softly) … about boundary setting, very difficult in terms of if the child does bite or …and how do you manage that, the consequences of that? It was very difficult because there was no … it didn't feel like there was any support, you had to try and deal with it yourself in the session … there wasn't much support from outside. There wasn't a particular system. We tried hard to begin a particular system, but with the children you might have a time-out call or something and they would go and reflect why they had become disruptive or you'd ask them to go and spend a little time in their room and you'd just come back to shredded things, so very angry, a lot of aggression. In terms of how to keep this a safe space and not a free for all, ja feeling that things were not quite contained and you're feeling very stretched.

One would be doing one thing and another would be attacking another one and everyone would be sort of "whoo whoo whoo", especially in the early days when I was just getting to know them and it was really part of the choice to work with smaller groups and ultimately only individually. Because it was quite unmanageable a lot of the time.

You wouldn't get around often to … the first years were the most difficult with that kind of thing. Individual sessions were running concurrently and the children were really able to use the time to kind of weigh up the values. I worked a lot with pairs actually, it can't really be considered a group, but it was quite an interesting dynamic where you'd still have another person and you'd still be able to work on some of the relationship issues which the children really needed to work on. It was more manageable.

Interviewer's question inaudible.

Mmm, there were many sessions where it was just about trying to get everyone to focus on one thing and so stopping one child from attacking another child … sort of just trying to get some kind of order, law and order in the room, you know, I kept reminding the children of the contract we'd made and … what would happen if someone overstepped the line and I think what happened in the group work was I became … I had very strong boundaries and I stuck to them very clearly and I didn't always feel nice, you know.

I always thought therapist would be very gentle and forgiving but we were getting nowhere fast so I needed to establish exactly what would happen and before things could get out of control one would have to move into the consequences of whether the child would have to go straight back to school. I'd call one of the mamas and I think the mamas had different ways of managing the children although I'd never really gotten to the bottom of it, but they certainly had some fear. Because they had no fear when it came to me. I think the mothers had in the past been certainly hitting them and we'd hopefully worked on not doing that so it would sometimes be enough to say maybe we should call one of the mamas to talk with us about it and then the three of us would sit and talk about what was going on, and the child would certainly settle down.

I mean that was quite a constant thing which might have also been because I was white and most of the volunteers that came were also white and they would let the children get away with absolute murder so they were like jungle gyms, the child would climb all over them. When I

started speaking Xhosa with the children that would also shift the dynamics a little bit. And then I started positively affirming them the minute I would see them, I would be like : "Wow, it looks like you're in a great mood today" and "We had a lovely session today". I was sure there was not going to be any hurt in giving them positive affirmations right from the beginning and continuously through all the sessions and the children wanting to meet that expectation rather than the expectation that we're not going to be able to have the session.

Interviewer's question inaudible. Disputed because ...your experiences and ... and some of them being forced to ... into that position ...or on the other hand indulge them, which is another kind of collusion ... that kind of familiarity.

Ja, I mean it was a good decision to move into smaller groups. … (Inaudible, cell phone signal) … one as opposed to five very kind of, personalities that needed to be heard and seen. Ja, it was an absolute headache. It was kind of the early days when we … (inaudible).frustrating …I had worked with challenging behaviour in England …(inaudible) .. and in fact my last year working when I knew I was going to be leaving, the kind of workshops with caregivers … links between the care centre and other organisations in order for them to be able to refer children.

The one was the behaviour unit, the behaviour clinic at a hospital … and a lot of their work has been understanding how HIV itself is affecting children or children's behaviour. So whereas I'd seen it very much about the environment and living in that kind of context, there were other contributing factors where HIV is actually affecting the brain as well, which is quite interesting … (inaudible).

And then again even more so, anti-retrovirals and now at the care centre we see this as the major problem and the children are all getting older, everyone's becoming a little more serious. When a child is biting someone, it's a hard blood-bite and the caregivers have to go on to anti-retrovirals. It's getting quite extreme.

Isn't that unusual?

No, not unusual. Certainly, when I was there, I saw children biting each other and it was happening quite a bit. Along with it was the broken windows, all the time. What could you do? And hitting each other, children hitting each other and I think that would become more problematic as they go to school. If a child bites another child at school and draws blood, there are all kinds of consequences, I think it's a major challenge.

INTERVIEW: C

Just tell me a little about the work you are doing just about the groups with children with HIV/AIDS, including your theoretical orientation

Um, right … well I have had a bunch of different experience. It started, my interest in HIV … support groups started in my community service here. So that was when I was in (a clinic on the East Rand) and it was … ja… a very interesting set up. There were two rural clinics that we were working in and this tiny little hospital and it had never had psychological services before. It's all very new and exciting and then we have got groups there that I got running in that year. So that is where the interest started and then there was a period there where I wasn't doing anything. I was working at (a psychiatric hospital) with the adolescent in-patient ward. And then I got the job here and basically we've started them up. The HIV groups for the care givers have been running a bit longer and then the adolescent groups have … I am just trying to think, have been running for about three months now. So they are still quite new.

And what sort of ages are those adolescents?

Um … Well what they are terming as adolescents are not really adolescents. Some of them are as young as ten. And then they go up to fourteen

And how big are the groups?

Six

Six in a group?

Yes

How often do you run the groups?

Once a month but there are different groups that run every week, ja … so each little group is supposed to meet once a month

What are the different groups that you run?

At the moment there are two separate adolescent ones but they are going to be picking up as we go along. So as more parents disclose, because the aim of the groups for the care givers is actually to push disclosure. There is a lot of politics going on between Hospital A and Hospital B in terms of the medication. So they want the children from 14 to go and get the medication at the adult clinic from the Hospital A. Its not great because some of them haven't even been disclosed to, by that point … and its chaotic that side. Here it is very friendly, there is Sister A, the same doctor. It's a lot more protected and so what they are trying to do is encourage parents to disclose. That is the aim of us starting all these groups. So there is somewhere that the children can be contained once they know. And then the care giver groups, it's about … just dispelling the myths and I think that parents are very afraid of telling

… telling their children their status. There is a lot of kind of fantasy that they hold in their heads. The child is going to get sick and die or the child is going to hate them, you know, and not forgive them. And all that sort of thing that happens and so they have been quite successful.

Sorry can I just ask you, do you run the care giver groups parallel to the children's groups? Is the idea that they feed into each other?, so you are encouraging the care givers to disclose and then once that process is happening then you contain the children?

Yes and then we also offer individual sessions when they are ready to disclose. They can make an appointment either with me or (the other psychologist at the hospital) if they would like a psychologist present when they do it.

Okay, great. So are you co-facilitating those groups with the children, you and (the other psychologist) are working together?

Yes

Okay if you think a little bit, what emotional responses of yours would you regard as central responses to your work with these groups of children?

Um … its quite a sort of complex response …I think …I have thought about it a lot, why I like these groups so much, why I like working with terminal patients, you know. I mean what is it about that? Because these are my favourite patients I would say out of all the things that we see here. And I think there is an intensity to the groups that is, that you don't get anywhere else. There's … I mean specifically working with children, there's something that is … ja … completely humbling I find, for me. Just with these little children who are so immensely strong that is what it …it provokes something in me in a very kind of mothering - nurturing. There is something more special about these little patients.

More special because they are HIV positive?

Yes, yes so ja … I think that with a lot of the patients … I think a lot of your own mothering instinct emerges and especially when you are working with children predominantly. But with these patients it is almost something more special. There is something that pulls more with them. And so ja … I mean often or I would say most sessions I feel like crying, sometime in the group session there will be a time where something is so incredibly heavy or sad, but also hopeful. There is something incredibly hopeful about it as well so it's a bit of the both and. But I think overall it's the intensity – I think and ja … in me I think that that is what it inspires. There is a huge sadness that I think it links onto but also hope, so it's that both things that they carry. It's the most …

Can you talk a bit more about the intensity – is it the emotional pitch of the session of the group or is it your own sort of response, the intensity of your response …

I think a bit of both really. Working with children especially – you know the children's groups. I mean the adult groups are also very intense but not as quickly as the child groups. Children are incredibly honest and frank about their experiences. And their defences are a lot more transparent. You can see straight through them and it's … the stuff – it feels like the emotion is a lot more out there. And they are a lot more honest so for example:- in a first session with a group of adolescents they will discuss having lost a parent straight away. They will ja … talk about how lonely they feel at school. So the accessibility to the emotion I think is … is very apparent. I mean you do get children that are struggling, very anxious, very tearful, can't go there, you know, that haven't quite processed it. But the children who have processed it are a lot more emotionally aware. I think the emotion comes out a lot quicker. But in terms of my response to them and I think there is … you know a lot of your own stuff if you can call it that that comes out because of the intensity of the group. So ja … I think it is a bit of both and.

What is the theoretical orientation of the groups?

Well I mean again it gets a bit complicated because (the other psychologist) is predominantly systemic and I am predominantly psychodynamic, so it's interesting to discuss sessions afterwards. But we were both trained at the same place. The entire department is split down the middle, it's like dynamic and systemic so she just preferred the systemic way of thinking and she runs the family therapy clinic as well, whereas I tend to do more individual work so it's more psychodynamic. So it's a bit of a mix that is … ja … I think we look at both and but it think … ja … for myself I have always looked at is as they mirror each other. Systems and psychodynamic, you are either working with the internal or the external system and they tend to reflect each other. So you can work in either or both but the groups are … in terms of … we don't … there is some structure to them, I mean we institute some structure in the beginning. So it's not completely unstructured but at the same time it's very much … they bring what they would like to bring. A lot of choice is offered, a lot of you know … right this is your group what do you think is important, you know, that happens here in this place. So they bring their own stuff, so it's a bit of a mish mash. And it seems to work alright.

You have talked about what you find appealing about the work. What has attracted you besides that to work with children?

Accidentally … it happened, ja … I never thought that I would work with children and I was very intimidated to work with them I remember in my "M1" year. I just thought, Oh Heaven they are like little aliens. They are completely different to adults and the more work I actually did, I did six months in my internship with children and you kind of get used to it. And then later on experienced working … children and psychotic people … they are a lot more honest and it … *(Laughter)* ... it feels that way, but those are my favourite types of patients. And so it happened completely by accident. And the first job that I got was at the adolescent unit at (a psychiatric hospital) and then I was offered the job here as Head of the Department. And the child stuff was ohh, a bit intimidating. But it was fine and I love it … ja … And I think it does force you to explore a lot of your own child issues. And in a sense … I have been in long term therapy the entire way through … the process and if I had to track the process a lot more of my … ja I would even say my memories … you recover memories a lot more when you are working predominantly with children. Your own experience where little bits of you are hooked by certain patients and when you think about it, why, why is that certain patient is hooking this

in me and exploring it. Ja … it just brings it all out and in therapy I think I have just been lucky to have that space the whole time, you know in which it can be contained and thought about and … explored. And I think that's what's been incredibly beneficial in that sense. So actually … ja, the child stuff is good, to work with them.

I know that it is quite difficult to talk about but is there anything that comes to mind that you can talk about when you say that when you work with children, some of it hooks your own stuff, is there anything specific that you can think of that you would like to talk about.

No, well I mean obviously when I heard you were coming I started thinking about all of this, ja and thinking about what it is specifically with the HIV positive children, you know, why them specifically and what it is I love about working with them and I think it … when I started exploring it, it was something about … these children have something I don't have, it's that feeling, that they are so... that makes me feel so humble.

You know the rest of the work you can start to feel that you have a grip on it, you know, there's an idea where basically you've seen this much anxiety, this much depression, and I think you can't look at patients, you know, as labels, everybody's an individual, but then I think what is it specifically about the ones who are sick or are dying or there's something there, and for me when I just sort of linked it back to my own stuff, death is always, has always been an issue and I think that was why I specifically went into psychology.

There were losses, I mean for me there was a friend in matric who killed himself, then an ex-boyfriend who killed himself - those sort of things that happened that pushed me into psychology itself, but then to think even further back, what is it about children and death and I think, ja, like most psychologists I had a depressed mom. She was ja… kind of very anxious, very neurotic. She was very badly depressed after my sister was born. I had a younger sister who was four years younger so from about the age of four and a half/five I became mom when my own mother was kind of very sick and tired all the time and I think it's been difficult to go right back to think what it was about the very early years and I think that's where my own therapy has helped so much…

Because it was only later on when I had conscious awareness of what my mom was like and the worries and things… because there were attempted suicides, my mom had tried to kill herself and things where I had to be the mom for my own mother as well that were, ja, extremely anxiety-provoking … and thinking where I was an intensely anxious child.

Then sort of exploring that in therapy and thinking where did all this come from? And I think even younger, very young. I had an awareness that my mother was not okay. She was depressed, there was the sense of the possibility of losing her, there was that the whole time. So I think that's what links very strongly with these HIV-positive children who can talk about both their parents and how they feel about it, and for them having confronted these things which I think were my worst fears. I do very much believe in that "wounded-healer" concept where we go into careers to try and heal ourselves and these children, they hook onto something in me that I think is very intense, very primitive and very pre-verbal. So that's what I

think brings the intensity. As well as them. So I would say it's that sort of stuff where I think my own fears, the anxiety that was around, very primitive stuff like mom not being available, mom not being there or being around, and you know the way they, these children, a lot of them are forced to become very precocious and independent, and I think I was like that. So there's something that reminds me of myself … in a way it's the 'me' I'm trying to mother, to nurture, the own internal child in these little children.

In these little children and at the same time you see how they survive it, their resilience.

Completely, and I think the humbling part is, you know, they've seen their parents die, they know they have the same illness. They're dealing with their own mortality at the same time. So it's like they're these little old people in these little children's bodies. That is the part, I think, that hooks so strongly for me. So, in a nutshell, that's probably where the attraction comes from, what makes it so challenging, so much of your own stuff that you need to deal with, work through, as well as their stuff.

Have you had an experience, I know it's just been three months, but I was wondering if you had had an experience where you've been able to see how something is happening which is hooking your stuff and you've been able to use your experience or your feelings in a way which has been helpful in the group?

I think … working with them, there's a sense that I have to be more vigilant for my stuff, because I know that there's such a lot of it and there's so much that hooks … and it's very much a case of with these children .. the feeling in the room can get very heavy. And then for me there's a pull, and this is where I know my own stuff, is to move away.

I want to teach them to intellectualise, you know, cope like I coped and my own experience in therapy has been very much about learning to sit with these terribly painful feelings and not move to change them because for me my experience has been that I think I became a very over-achieving child, to cope with the feelings, they had to be … it was a way of almost, perfectionism as a means to bind my own anxieties and so very much I think there is a pull for me to do that in the group, sometimes is to move away from these feelings. In those case where I have to be extremely aware and one little incident that happened, I'm trying to think whether it was last week or the week before, (the other psychologist) will probably talk about it as well because for both of us afterwards it was kind of "sjoe" what a moment.

And there was one little boy who is trying very hard to be the little macho man, very strong and he doesn't want to... like he's very quiet. He's not giving a lot of input where the rest are kind of being just children. Adding their little bit of sixpence in. And the one child who is … he's kind of the little leader of the group who will bring his stuff quite easily and you could see he was hinting at bringing up the fact that both his parents have died, but he wasn't quite getting there.

So there were little hints and things he would talk about and then eventually I asked him straight out: "So where are your mom and dad?" "No, they both died". Okay. And then it was amazing what the group did with that because I think we are still in the initial stages of the group so it's very much an acceptance, also where they are, developmentally speaking, these

children are very much about acceptance and bonding, peers, and because of the HIV, the huge stigma which they feel, so lonely at school.

This group offers something more, like there's more of an acceptance in this little space, so straight away they all start to speak 'tchi, tchi, tchi' about who's lost who and how and everything and then the one little boy eventually said oh, no, his daddy died when he was three months old, this was the little strong one. Now it's almost as if he feels he has to be part, but there was something so intensely sad in this kind of macho, strong boy admitting, giving a little piece of vulnerability there to the group, to fit in.

It was as if everything suddenly went very quiet and very heavy in the group... and I think the hook for me there is, you know, oh there's this boy who's trying so very hard to be so strong and there's the vulnerability that is so very painful for him, and he kind of puts it out there in the group. And so there's this moment of silence and in that I can feel this, you know, this urge to end it because it's ahh, what if it's too much for them. And just to leave it. And eventually it was (the other psychologist) who asked this other little boy in the group who had been very quiet: "How are you feeling now", and he was, like, "Sad", and that was it, that was his answer. And I mean "boof" there goes another notch, and in the sadness you literally, as well as figuratively in your head, sit with it. That's what it's about, and then we talk about it, how sadness feels, and I think that's what's so incredible about these little children… that 'out of the mouths of babes' - there it is for everyone to see, let's be honest about how we feel.

He is very real, this little boy. At the end of the session you say: "How are you doing?" "Tired" (laughter). Yes, we're all there with you. Ja, so it's that absolute honesty and the strength that comes with their vulnerability. Ja, so it's those sort of things, those moments where I do have to catch myself. They can hold it, and I think it's also very much about myself - I can hold. We can sit with this. It was a poignant moment.

What other aspects of this work are the most challenging for you?

Ja, I would say suicidality in these children, to talk about that is very hard, that I think is a button for me as well, it's my button … in terms of people dying and my related sort of responsibility includes everyone, you know the responsibility, my omnipotence. It's a difficult button. Sometimes with these kids you do have a feeling where you would be better off dead.

You know, sometimes there is that feeling with these children where they are so abused, so neglected, just so completely left that you just think whew …

Does that bring up other feelings for you?

Ja, I think … rage is something you feel, but I think it's a lot more with adults, funny enough, you know, the HIV-positive adults, that comes in. Ja, now and then, with children, there are times… There's one patient that I worked with, I remember sjoe … she was a tough one, and she basically was 16 years old, pregnant, HIV-positive with the most awful venereal warts ever.

Basically once you become pregnant, these warts just grow and grow and grow and there's no treatment you can give her because she's pregnant and she's immune-suppressed, so I mean they just go mad. So for this girl who's 16, both her parents have died .. and … the boyfriend, he's about 30, married to someone else and not really supportive of her. Very strange relationship with her mom's sister, her aunt kind of and she was suicidal at times. It was so physical, as well as mental, spiritual, everything, this girl … there was a horrible smell around her because of these warts, she couldn't walk properly, there were all these things, and you just think: My God if I was you, I would have killed myself a long time ago.

How she was actually coping with such sort of assaults to every aspect of her being as a child and needing protection, you know, everything was giving out … her body, her family, any source of intimate supportive relationship, everything. And now her own trying to consider being a mother and worrying about her baby and whether the baby's going to be HIV-positive. Ja, so those sort of things, the rage, you hold a lot of their helpless rage, you know, at the world. How is this allowed to happen to people?

Do you feel a helpless rage about the children that some of them may be considered victims or don't you really think so?

I think you do at times. I've got one patient that died where I did feel a lot of rage about that, but it was rage against the medical system, it was, how could they … she was just treated so badly at the end, I wanted to just let her die, stop trying to feed her with a tube down her throat, she doesn't want it, and she's throwing up and she's not going to survive, so let her eat sweets and drink Coke, as much as she wants.

Is she one of the children in your groups?

No, she was a child … I think I saw the mother first and then she ended up being admitted in the ward and so I saw her three, four times a week ongoing for months. At times she was … watching her sort of struggle to accept what was happening ja, how she couched her anxiety in the beginning because no-one had told her: "You actually have a terminal illness". She was so scared she's not going to be able to go back to school, had a huge issue around that, and it's … she had some knowledge already … that she is going to die. Ja, and just her fear at the end, she had lost so much weight that … they do look like little animals … their teeth get all rotten, and they've got these little stubs.

And the expressions on the face, ja there's something completely primitive, primal about the emotions. I think of those times, and how she withdrew in the end, she just got under the blankets and didn't want anyone else, and how sort of deprived she was because her mom could only come and see her once a week. She was six, six years old.

She was Six?

> In the ward, and the whole time she wanted physical contact, that's all she wanted the whole time and .. difficult to manage, you know. In the ward setting, in your role as therapist.

What was it like for you?

Very painful, there was a lot of rage. I think there's a lot of her stuff you end up holding. I think her emotions and I think in those cases, that is your role. You're the therapist; you're there to take and contain all that uncontrollable, un-containable stuff. The word 'stuff' keeps coming out and I think there are no names for that kind of emotion right in the beginning you know, when these children are so young and dealing with something so huge like that. And so I think you hold a lot of it, it does bring up a lot of the unfairness of life.

It brings up a lot of despair. There are times when I think that spoils it completely and hope I never have children, it sounds terrible, and it has that sort of effect on you. I think it can sometimes make your own relationships meaningless, your own life seems meaningless, and that these kids make such meaning out of such trauma … and …

The child makes meaning while you struggle to?

Mmm, their acceptance, you know, eventually where it was a case of she knew, and it was never worded as such, but there was definitely an idea that she knew and an okayness with it, and whereas for me I was struggling to have an okayness with it.

My okayness only came a lot later and an ability to make sense rationally of a world where children die and how it was okay, you know. I held a lot of rage towards her mother you know, how can you only come once a week, you know, your job's not that important. But her job is important, she has other children she needs to look after and ja … very much (pauses) I think the question that you ask about the child's ability to make meaning.

There's some sort of … (pause) non-verbal meaning that gets conveyed and I think it is a bit of a co-creation where you're helping them to make meaning and they're helping you to make meaning, it's very much this idea of venturing into the unknown with this patient, there's that feeling about it and getting to a place where I can be comfortable with death.

I think that was the whole, how would you call it, in ways a little mission of mine. I don't think it will ever be completely achieved, but it's almost through these children, and these specific adults and their caregivers. It's partly my journey as well in this process. I would say they help to make my world more meaningful in that sense. I think that in the beginning it was completely draining to work with these types of patients, very…

Like you get home and just want to sleep, like two hours you're out and then you wake up, then you can carry on with your life and your day. There's something that you get from these people, these patients, like a hope in life, that there is so much strength in the human spirit, that people do accept these things and do come to a place where it's okay and they find so much meaning in it later on. Where they can say: "My relationships are more important to me now because of the HIV or the grass and sky looks more beautiful than it ever did before.

They can find those little things where the illness and the suffering has some kind of meaning. And I think that is the reason I stayed there and have not burnt out completely. I'm not despairing altogether, but it's holding the both. I think there is something about the beauty and

the both, suffering and strength, you know, the vulnerability and the strength, the humanity that you see in these specific people.

Are you talking much in the group with the children about the fact that they do have a terminal illness and they will die? Or has that not really come up?

I think the thing (the other psychologist) and I decided right in the beginning that we were going to do is speak the word "HIV" right from the beginning, so that's non-optional, but we are not going to bring anything else.

So all of the children ...(inaudible) and right from the word go you talked about how everyone's got HIV?

Right in the beginning it was very much ... because they were all spoken to initially on their own either by Sister A or Dr K. They knew what they were coming into, they did have an option, they were asked: "Would you like to be in a group like this?" and they got permission from the parents, from the granny, whatever. And then the children come into the group. Some of them protest ... you walk into ... but I think HIV lends another - a whole other layer to them because of so much skinner because when you walk in through that door you know that all these people now know that you have HIV.

Its been ... It's sort of an odd quirky thing that happens, I'm assuming in most hospitals, but here all these caregivers and children, some of the children know why they're at this clinic, all the caregivers know why they're at this clinic. They sit on these little benches waiting to see the doctor normally, and it's kind of like this parallel suffering idea where they all sit there but nobody speaks. They all know but nobody says anything and I think that is the aim of the groups, is to kind of just rub that off and that's why we said we were going to speak it right from the beginning. It creates a sense of relief among a lot of the people I've spoken about. With the children how they will talk about it ... it's nice to be around children who are the same as me... that sort of feeling ... and that there is some hesitance and some reluctance to talk about it.

Some of the kids will never even mention the word. (pause) Ja, I'm trying to think in these groups we haven't gotten anywhere near kind of them dying. We kind of talk about other people dying - that's been an issue, how horrible it is to take the medication, how some of them will not take medication, that they feel angry that they have to have this illness.

Which I think is something so important, an important function that the group holds, in terms of encouraging compliance because you don't want these children to default, to go onto another regime.

Yes it is, it's unfair and you feel really angry and you explore other ways of feeling angry rather than punishing the self. It's the, like, internal, sick, vulnerable child they're trying to kill off, you know. In a sense it's like a denial can emerge and it's very interesting in all HIV patients, whether they are young or old or whoever they are. That denial kind of emerges and then it decreases and then it will be back again. It's I think such a coping mechanism, you know, for a moment to pretend I'm not HIV-positive and not have to face this every day.

But then, the harsh reality of that is if you don't take your medication it does cause a lot of really big problems. Ja, and you know, a lot of these kids look different as well. They're either smaller or there's some kind of … some look just like normal kids but others deal with physical disabilities that have come from the illness as well. I think that creates another whole difficulty in mainstream schools, normal schools and now in this group that's accepted, that's okay, but we don't really ...(pause) we haven't sort of really explored around that yet but those are issues that I've had in individual therapy before.

Can I ask you, in terms of the stigma are there ways that's is played out in a group, you know I'm wondering whether sometimes the group sets itself up to be ..... I'm just wondering if they're so used to being stigmatised, I wonder if that is somehow played out in the group or whether it doesn't really come up?

The only time I've seen that come up so far sort of in these groups is in the beginning with one group, it was five boys altogether and two looked horribly anxious in the first session. This is completely overwhelming and scary and the other three were thinking this is just the best thing since sliced bread. This is great, and as they sort of relaxed and talked together, in the end they were saying: "Can we all get T-shirts, like matching T-shirts, to say we're in the group?" and then "Can we go to other schools and put on plays on the stage" you know. And you can see that the two who were a bit anxious in the beginning had eyes the size of saucers thinking "Now who am I going to have to disclose to and what am I going to have to do?" and then to contain that in terms of what the reality is.

Sometimes not okay for people to know because people are not all nice. So there's very much a reality checking that also has to happen. You know, there's can be this sort of euphoria that I'm okay, I'm so accepted in the group, everything's alright and I can go forth and spread the news and everyone will accept it and it doesn't happen. So a lot of the time there is some curbing. Who is it okay to tell, when do you know that someone is okay to tell, and trust … trusting people.

I mean that's something that comes up obviously in the first session and it's repeated, it's constantly repeated through sessions where it's ja: "I told this person, he's my friend, and he also stays in a foster home. He's not HIV-positive but he knows".

There seems to be a lot of stigma around also not living with your parents or a parent. If you live with grandparents or foster parents, that is you don't want people to know about as well. So it's a whole, sort of, other element. So these little things do get played out. I think it's because they're all linked in such a complex way.

I think the stigma comes from shame and secrecy and, ja, trust … those all link up with it and so you end up exploring those a lot of the time in terms of … because of the stigma, you know, who can I tell, who can I trust. I have to hide stuff about myself all the time. And I think that links in with adolescent issues a lot of the time in terms of; Am I okay? Am I not okay?, ja…

In terms of boy/girl relationships the interest is starting to peak and I think that causes a lot of angst in terms of: "Am I going to be able to have a girlfriend?" coupled with at the same time

you know: "Girls are gross". And if the boys are a little bit younger they don't want girls in the group. Ja, a lot of those sort of issues ... ja and feeling ashamed of what you are and what your parents were because it's stuff that does come up in groups - a lot of very heavy things.

Does anything else stand out? What sense do you make of your emotional responses to this work and how have you been able to use these responses within the group?

(Pauses) There are just so many ... It's kind of like ... ja, I'm trying to think ... one day we had this group that basically a lot of the people for the first session didn't arrive and there were two boys and the one child is very high-functioning, he's older, his mom's very together about the whole thing. He's very depressed though and I think because he has a greater awareness of the impact on his life.

And the other little boy is quite badly cognitively impaired but he's delayed, so whereas he's 10, he's probably functioning at about sort of 6 or 7, very bad speech, not that much awareness of the impact on his life. So that was the most awkward group to kind of deal with because there's this older boy who has this huge need for support and it was actually incredible to see how he kind of just adapted to the other child and became quite protective of the other little boy ... ja and then those moments where you just feel torn (laughs softly).

There's such huge need for this one child and to rather just let the group go and talk about how disappointing it is that other people haven't arrived and to try and make it bearable because it felt like such a huge disappointment and this little kid has no idea that this is disappointment. It's fabulous, and the older child is so disappointed. I think it mirrors what happens in their lives a lot where the real issues are overlooked a lot of the time because people don't want to talk about it. I mean even if mother who is very together, she's very much an HIV-activist type at the moment, is not willing to sit with the really painful bits of it. She wants to be strong and cope for her children, she doesn't want to go there, to that stuff and her child so desperately needs people to go there and here is this little boy ... *(End of Side A)*

*(Beginning Side B)*

What comes to mind when you say that ... remember when we talked earlier in the interview about feeling strong and coping can be a defence mechanism ... as a way to avoid the anxiety of having to just sit... and it must be quite difficult, there must be quite a pull in the group, you talked about that, to do as a way to pull away as opposed to just sitting with it and to deal with it, to tolerate it ... (inaudible, muffled).

There is ... I think what is useful, what makes group structure so much better is that there is always someone else who is in a different place, who will pull that stuff out of the other people. Ja, that is what I think is the most useful thing about groups is they feed off each other, it's not so much work for the therapist in that sense, although I find groups quite taxing, ... for everyone, so there's that feeling, you know, the bigger ... you've got to pay more attention. But at the same time it works for me learning to trust that these children can sit with this, tolerate it, and catch each other's stuff. They do.

These little kids … and I think that's very much my own stuff, the pull to, ja, in a sense not trust their vulnerability, to feel the need to make it better, and for me it's been a complete education, I mean a psychological education for myself in terms of sitting with the pain, and sitting with the stuff that's ugly and not nice and there is no way you can make it better. That's just how it is. I think it can get very complex in terms of your own stuff, because I think for me there's a very strong split in me which took years in therapy to try to integrate and you're always trying to crack through that. In terms of my own vulnerability, my own strength, you know, what is real and what is not.

I think that is a very difficult thing to kind of hold in your head where sometimes strength is a defence and sometimes it's okay to be strong and not face those scary, horrible feelings, and sometimes it's important to be there and be vulnerable and not cope and it's that constant balance and the movement … I think that's what makes the group so dynamic, each of the individual children so dynamic and they each choose their own little unique way of being in the world that has their own little defences and their own little everything, and to find each of their balance, to find their specific, unique balance and I think the group does, it can bring out, it can highlight very quickly which children are not coping in terms of a child who suddenly will not say anything or finds it excessively difficult to be in the group… where you can comment on that.

Eventually it does bring what is so painful for them. It's hard to talk in a group about stuff because my family doesn't talk about it, my mommy doesn't want me to say anything to anybody else. The little girl in the group I'm thinking about, she uses like her pretty cuteness, that's her little defence, so she smiles nicely and looks pretty and doesn't want to say anything, but ja, for her to find a voice in the group is so important and I think that, when you link it back to her family and what's happening there, I don't think she has much of a voice there.

So it's about each of them and their own little needs and I think different needs get attended to at different times in the groups, so I think it's a constant, ongoing process inside the therapist, inside me or inside (the other psychologist).

I mean that process as well between two therapists, you know, where you look at the other one and think: "She's about to cry, too, whose going to hold the ship together here". It all falls to pieces. Ja, to see that kind of vulnerable strength in another therapist for example, and to trust that. That is so important to trust the therapist that you work with. I think in that sense (the other psychologist) has a sensitivity that I don't have.

She, I think, can sometimes find the words for the wordless in terms of that whereas I think I sometimes am better at the bigger tracking, processes that are happening in the whole group she can hone in … so it's a kind of whole dynamic thing, the whole time that happens that I think is incredible. And learning to just be and for me that would be my job as a therapist, and to use my own personal therapy, just learning to let myself be … to let these children just be and blossom, but at the same time we acknowledge vulnerability, the needs and strengths and all this sort of thing.

I want to ask you, in terms of the limit-setting in the group, how is that?

Well, I mean, straight off, it's just in my experience I've learnt with HIV-positive groups is that is done, the trust/confidentiality, that is the first limit that is set down straight away and normally it's done at the end of the first session, but it can happen whenever. Someone can bring something that is appropriate. With kids, we see if they would like to see them choose the rules in the beginning and you write them down so this is this group's set of rules, you know, we don't talk to other people outside about what we talk about in the group down to you handle complete details like okay, how do you handle an event …

Say you're with a bunch of friends from school who don't know you're HIV-positive and you see someone from the group, do you go and say hello to each other in public. Is that something that would be okay for them. Ja, sort of all little odd things like that … because I do think they get caught up initially in the beginning … oh this is all kind of new and exciting. There can be little blips and mistakes that pop out.

In terms of the group (inaudible) other groups that you've handled, you've often talked about how especially children from very deprived communities are extremely attention demanding and this can lead to the group being quite unmanageable. You don't experience this?

Uhm-uhm. I think the groups have to stay small, stay the same kids. You know, the bigger the group gets, yes … completely uncontrollable. Some of them do have quite severe attention problems, you know, but it's not too bad, you can bring them back, but what other experiences … they tend to run here from the clinic, jumping and smacking all the ceilings on the way here and then they run away. That's how they go back as well, but when they're here, they're quiet. Ja, respectful, something quite respectful about each other and I think having to cope with what they have coped with, they are more emotionally sensitive to each other.

And are most of these children in … you talk about most of their parents have died … are they staying with family or are they in care centres?

Some are with foster parents, some care settings and some are with granny. Some of them are also with one parent.

And they're all from … (inaudible)?

So, it's predominantly coloured and black with the odd white child, so it's an interesting mix. The language can also sometimes get very interesting. There will be a kid who only speaks Afrikaans and another child who only speaks English and then another child who speaks Zulu and struggling along with the English, but it's kind of like making a plan and translating for each other sometimes and things like that.

They're quite eager to involve each other in the group which is quite sweet. Some are very attention seeking in terms of they will dominate the conversation and you have to move away and ask has anybody else had an experience like so-and-so's experience and this child will try and jump in again. You know, but I think that's any group, splitting it up. And then you'll find

there will be someone else who will interrupt when you're talking, all the time, doing the therapist's job.

Good, is there anything else that you'd like to add?

No, I'd say that's pretty much it in a nutshell, I think. There's a lot of themes that come up in me. I just find from my own research as well that where similar themes the whole time and just linking it with my own stuff, the reason I work with these kids is that I have the opportunity for my own stuff transfer to come out, I think.

That's what makes it so much more intense and rewarding. That's why you do it a lot of the time. It makes me think a lot harder about myself and what I'm doing in the session, that sort of thing, where sometimes I think you do get a bit lax, the workload overwhelms. These kids bring you back to home, down to earth with a good thump. It's good.

Thanks.

No problem.

INTERVIEW: J

Would you just start off by telling me what kind of work you are doing and how long you've been doing it for.

I've been working at (the hospital) specifically for almost a year now and before that I didn't really have much …

Just the groups with the children.

We've been running the groups since the beginning of June, specific groups. I've been seeing HIV-positive patients for the duration of my time here.

Individual?

Individual ja, that were kind of identified by the doctors as needing some support, one that was kind of disclosed to accidentally by a doctor in the waiting room who said: "Oh, this child can go first, she's got HIV." Too late. I've picked it up once or twice in the groups that we've run as well. I don't know how much you know about the groups as they work here.

Tell me?

We run support groups here, basically what happens is when the kids are 14 they need to know because they go to Hospital A and Hospital B, as it kind of runs at the moment. They join

the adult clinic there, so the support groups that we've been running since June - it's a very new project, to kind of contain the transition and to make sure that as many kids are disclosed to as possible, before then. So we run a support group for the moms first and then the group with the kids. Initially we wanted to be very boundaried, kind of we'd have 10 or 12 max people in each group, but it doesn't work like that, there are 200 patients, so we take whoever's there and kind of do our thing. So we run groups with all the moms and then the disclosed-to children, so not the kiddies who don't know. I haven't been involved a lot with the kids because there only groups starting to be disclosed to now, so that's picking up a bit now in the last few weeks, maybe three groups. I've much more experience with individual stuff. Pretty much it's very unstructured with the moms who have introduced the topic of disclosure, putting as little pressure on as possible. It's sort of stated that we can offer a service where we also put the mom and the kid if the mom wants the disclosure, in a group together but that hasn't happened yet. What has happened because the groups in theory run once-monthly with the same people but they keep getting bigger and bigger - last week we had something ridiculous like 16 people - and just feelings around HIV, feelings around disclosure, what you tell your child when you bring them to the clinic if they don't know, a lot of the moms say it's because you have asthma or you've got kidney problems because kids ask: "Why am I coming to hospital when I'm not sick?"

In terms of the groups you've been doing with the children, how've they been running?

Pretty much we just take the children that know and we haven't had any paternals as yet and the last three we had have been first time groups and those we want to keep much more structured than the mommy groups

Ok, so there are different children in each of the three groups?

Yes. And also very much open, very much kind of so far getting to know each other. What we think about HIV, kind of stuff. We kind of started off: "Oh you guys are different from the other groups, you know your status, how brave of you, responsible." A lot of them, 2 or 3 of them, come on the taxi by themselves - we're talking 10 year olds. They come on the taxi by themselves, they go to the doctor by themselves, they take medicine by themselves, they take full responsibility and that's the kind of ideal. I think what the doctors want as well is some kind of a mentoring process where kids who have known for longer are available to the younger kids to help them sort things out, to understand what's going on.

What are the ages?

We're talking about 8 to about 15.

Did you find yourself getting involved in this kind of work because there was such a need or have you had an interest in HIV-positive children?

I'm the dedicated HIV-psychologist here, so kids from the, they call it the ICT clinic here, they jump the waiting list, they come to me, so a lot of my patients are HIV-positive, moms, kids, these little families.

Did you choose this position, or did you find yourself in it?

Um, it's actually difficult to answer because I could have not been the HIV-psychologist if I'd wanted to, but I took it on. I never set out to be a child therapist, I was much more focused on the adults, it just kind of evolved that way in my life … I'm pleased that it has. I think that standard clinical training doesn't really equip you to deal with kids much, but a lot of it is by the seat of your pants and making stuff up and reading on your own and, because kids speak a totally different language. It's so much more symbolic. And so much more kind of easy, a lot of them. And HIV kinds I find a lot of them are so honest. Oh you got a little bit of a cold there. Are you scared when you're sick? Yes. What are you scared of? I'm scared I'll die like my mom did. There! They're so honest. It's just kind of right out there and you kind of manage your response which is: "Oh, my God, there's a little baby here and they gonna die and it's so unfair and it's horrible" and you have that *and* you can explore the kids feelings and their processes around it.

What aspects of this work are the most challenging? I know the groups are quite new.

I'm thinking in terms of the individuals as well. I struggle, um…….the patients I find the most emotionally difficult to manage are the ones whose parents have died as well.

And I kind of have this, sometimes it's horrible, feeling of adopting this child and taking him away from this horrible, awful socio-economic circumstance, you want to protect them and care for them. Because it's hard to explain why you love them for only one hour a week. When they're not understanding, they don't have a mom, they stay with gran. Gran is sick nine times out of ten and they ask you: "When gran dies, who am I going to live with?" "I don't know, let's ask gran," and we do.

So a lot of the therapy is about confronting stuff, but to manage my feelings of how unfair it is for a little kid to have to deal with all that kind of stuff I mean compared to our traditional white privileged background as well, there it's all kind of straightforward really.

And how do you manage, how do you make sense of it?

I don't know if I do (laughs).I talk about it a lot, I think about it, I write about it, I take it to supervision……Just the language of it makes a difference, just to language it, to express it, to think about it in a meaningful way, and sometimes I bring it back to the kids not to say: "Ah, I'm feeling terrible", but "It's quite hard to sit here and be scared of what the future holds". And that's also pretty much what I feel and what I'm picking up from the kid as well.

What other challenges?

Okay, on a very concrete level, kids often can't get to therapy, they're kind of stuck because it's too expensive, or because gran's in hospital or in one case particularly, gran's recently been diagnosed with lung cancer. Gran's a bit out of it and not managing so well, so I find it difficult with kids especially. With an adult who doesn't come for therapy, okay well the

responsibility is theirs, if they come or if they don't come it's up to them, whereas with a child somebody else has taken responsibility for that person and it's frustrating for me to be in the middle of a process and to have it kind of artificially truncated. When I'm seeing where the next step in my head might be going and they don't come back, there's only so much you can do. You have a heavy schedule and they don't come again, there's a waiting list as long as your arm, so you do the next one.

So do you experience some of the feelings of helplessness which the child might be experiencing ...?

Absolutely, helplessness and sadness and that kind of thing. That makes me very sad to see in the child. That's one of the most unfair things, the hardest things, is to see a child who's terminally ill and it comes out in the groups with the moms. I can give you one specific example where one of the moms in the group said: "I'm not like these people, I didn't give my child this". She's negative, but her child is positive. And the other moms say: "Well what does this mean about me?" and I think HIV is very special in that way, it's a moral disease. Society perceives it as something you bring upon yourself, or you're promiscuous and you behave in a particular manner and there you end up (giving it) to your child. I think a lot of the mommies carry that guilt. I think it's difficult for the kids to make sense of it. I never got to the point with a kid where we have discussed that, because they're normally little, kind of 8-ish.

Do you battle with sometimes feeling angry towards the mothers for infecting the children?

I feel angry with the mothers about not taking care of their kids I'm amoral … as a therapist. And it bothers me because it's quite immutable and I think sometimes I need to watch out for it because I get very judgmental, where I feel like the adult should take care of their children first. And if there is some kind of a choice between an 8 year old and an adult who's not managing the 8 year old, my first response is to kind of kick the adult's problem in first, that they kind of take responsibility for this little child. And that's not always productive. I need to watch that.

You've talked quite a lot about how this work brings up feelings of it being so unfair. I wonder what sort of other responses you have, what sort of emotional responses you have to this work?

It makes me very sad in a very helpless way. I feel I do damage control a lot of the time. I'm containing and catching stuff without necessarily being able to make a difference at the end of the day. A lot of the time because the kids don't come back and a lot of the time because the circumstances (are hard)… they are really poverty-stricken and a lot of horrible stuff going on …

really abusive dads, you know, this kind of stuff. In this particular community there's a lack of caring men. That comes through in just about any therapy context you see, if they are in family therapy. With most of the kids we work with, there's an abusive father.

It makes me sad for them. I feel sorry for the moms, a lot.

It makes me angry, but in a global sense. I'm not angry with a particular woman who slept with a particular man and got HIV.

There's more of a feeling that the world is unfair and I don't like the way it is and there's nothing I can do about it.

I try in small ways to make it easier, to give words to unspoken stuff. I think that's mainly what I do with the kids. I give them a place where they can talk about how horrible it is to have HIV

because there is so much silence surrounding and so much of a theme of not knowing who to disclose to, moms who don't tell their kids because they're afraid of what the children's friends will say. I've seen it in therapy where I've got a particular little girl who told her friend who then told the rest of the school. Now nobody will play with her. It's a very, very real fear and that pushes my buttons in terms of I want people to be understanding. It feels like there's a lot of talking about HIV on one level - on another level, it's a dichotomy, on the one side we're very educated as a society, there's a lot about HIV on the TV and kids ask questions as well: "Gee mommy, why am I taking this particular drug as well as that person on the TV who's taking anti-retroviral". On the one hand very much openness, very much awareness and on the other hand, fear and ignorance in some ways, where the other kids will not play with that little girl and tease her because oh, you know, we might get HIV if we play with you.

That kind of stuff and that feels very, very unfair. It clashes with my kind of ideal, my idea of the world where: "So you've got HIV, so you've got diabetes, it's the same thing", but society sees it in such a different way.

So having to confront the disillusionment in terms of people's limitations?

Yes absolutely and working with very practical stuff. I remember my first HIV patient, I said: "Do you know what HIV is?" and she said: "No". Nobody's ever told her. They just said you've got this thing called HIV but she doesn't know how it works. In my spare time I told her how there's this thing in your blood and this is how it affects you and when you take your medication and this is what that does and very much psychoeducational. "Oh okay", and now that's manageable".

So that's a limitation of the hospital system?

Ja, I think our system is totally overloaded, really I do. Just in terms of having time as a doctor and having a kind of bedside manner, I think, you've got 200 patients with the same thing, you don't have time to sit and contain, do handholding, you know and once or twice there was accidental disclosure, I think I told you. There have been a couple of those. One little boy went to the hospital because his mom was so sick and the doctor said: "Do you know your status?" and he said: "No, what status?" and the doctor told him: "You've got HIV". I remember he cried for the whole day and I had to phone mom to come and fetch him. That little kid we saw in a group and he's so sad about it. And this is six months ago and he's still …

they talk so freely, that's what's so beautiful about them as well,

about wanting to hide in his room and not wanting to talk to his family about it. It's an underlying shame feeling as well. It's about non-disclosure, not talking to your friends because on the one hand it's a thing of protecting yourself, but I also think the fact of having a secret says that there is something undisclosable about you. There's something bad about you that you can't tell other people because they won't understand.

And that's unfair for them, it's hard for them and it frustrates me because I don't want the world to be like that. HIV is almost a global thing, I look at it as an existential thing, I think it should not be this way. You have all these little vulnerable kiddies and they have this terrible thing and then the world doesn't understand.

Yet you still manage to do the work and you still manage to sort of rage against that the world is unfair. What helps you to still manage?

I'm still not sure. Each case has its own little microcosm or something. Each case has its own person at the bottom of it. At the end of the day, it's not the disease you're treating, but the child. So each child will experience it differently and have a different kind of process about it and you interact with the kid where they are today. One little girl draws me her HIV monster which is this red ribbon with teeth! Like a big mouth! And I thought: "That's beautiful". And then we had a lot of conversations with the HIV monster. We asked it about things and we asked if maybe it could be a friend as opposed to this horrible raging enemy that was going to eat us, maybe. Could we live kind of comfortably with it.

It sounds like in your relationship with the child there are kind of creative solutions that come out of it that shifts the perspective?

I think kids are profoundly resilient as well. They really are. It's phenomenal what they can take on and manage. When you think about the groups, most of those kids have lost parents, they've all lost loved ones somewhere along the line, and the moms too, in our groups. They know about death, they know more about at their age about death than I do at 29. And more about accepting it, and more about living with things.

It's very humbling as well, especially the moms' groups. They kind of listen … a lot of the grans, they've kind of lost a daughter and are now taking care of this child, but they barely know what they've taken on, yet they're prepared to do it and they're here religiously to get the child his medication and there's so much love, so much strength underneath and that is beautiful.

What helps you to stop getting burned out?

Oh, I don't know, for a few weeks I was feeling pretty burned out. I took a holiday and pretended I wasn't a therapist for a bit (laughs). It can get quite overwhelming, but you've got to take care of yourself in terms of taking the time off when you need it, talking, debriefing, I talk a lot about my work. My husband's a psychologist so I'm lucky. When something really terrible happens then he sits and cares and contains and we do that for each other, I think that’s quite nice, it's very necessary as well.

You talked about challenges in your work. A similar related question is, what emotional responses would you say were central to your work with these groups of children?

Sadness, I'd say. A lot. For me, acknowledging that I'm doing therapy with a child when they die. And also for them the fact that they've lost someone, having lost parents, having lost the idea of yourself as healthy, having lost the behaviour you see in other children where they cut themselves and it's okay, you don't have to chase people away and say : "Don't touch my blood".

I think it's sometimes like a modern-day version of a leper, outcast and unclean. It's like a plague, it's like a horrible thing with a moral attachment to it, where people are too scared to come close to people with HIV and it's (too cute) because you so get used to that here. "Lets play with balloons. Should I blow it up or should you blow it up? No, I'll blow it up. (makes a blowing sound). You blow", "Hmm" and then you manage. It's been a learning experience for me too because when I started working with HIV, it was not something I had dealt with before. And so kind of a little bit of… fear… for myself, you know, you have sick children, what if I get sick. I didn't find it a particularly big thing but I think it was there. Especially in the balloon incident, right, wipe it off. We share bodily fluids, it's a thing (laughing), and then you manage, because if I was to have a fit about it and insist on washing the balloon, what am I telling the child?

How is it different now from how you used to feel about it?

I'm a lot more comfortable with it, and I think just exposure to it.

Just being around it, a tolerance almost?

Absolutely. I got experience, I got education, I've done a lot of reading around it. Kind of getting to know a bit more, but I think that's my standard process of managing an unmanageable thing, I want to find out more, I want the knowledge. And that helps me in terms of being able to translate it for them as well, because they find the medical context very overwhelming. The doctors say stuff to you and you don't understand and you don't ask because the doctor's a big, scary man and he's very busy, and now he must do the next patient, and who do you ask, and you don't want to ask mom, because mom will get upset, so you sit with the questions without answers. That's kind of the idea of the group work with the kids, as well, if they have any questions, we say to them: "Ask." And we'll find out if we don't know.

You talked about sadness as being a primary feeling. Do you want to say more about that?

A lot of the kids are sad. Because of stuff, because of loss, loss of parents, loss of health, loss of an idea of yourself as resilient, that happens all the time, take care of yourself, a lot of the time their sense of immortality that kids have and adolescent have, get challenged really very early.

And sad for me because this is not the way I think it should be. Sad for me that an 8 year old has to manage the death of her parent, plus her own imminent death, plus gran dying with lung cancer, I mean that as well. Gran stopped (…) and now she's lost (…)

I kind of hold that and I think I wonder what she thinks about that and I can't ask and it's kind of truncated for me so I'm probably sitting with a lot of what she's sitting with as well in terms of this is something unfinished. There's stuff in the air that I would have liked to have addressed with her but didn't get a chance to. And I think when there's any kind of terminal disease it's full of "but I would like to have had a chance to".

So much lost opportunity. And experiences.

Yes, and the thing I've struggled to hold which I know and which the people in the clinic wouldn't know is that there's five anti-retroviral protocols available in the country. You start off with a CD4 count below 300 before you go on and each one lasts about three years before you build up a resistance. So from the time when you're on anti-retrovirals the first time it, you've got fifteen years. That's not hell of a long. This I don't tell the kids.

Why not?

Because I want them to feel like they're not going to die in about five months' time, you know. And in fifteen years' time, things might be different. And one of the first HIV patients, I don't know if you know about him, he was diagnosed, they gave a lecture at varsity, he was diagnosed in the early 80's and he still hasn't been on anti-retrovirals ever.

He still hasn't been on?

No, his CD4 count is fine, his viral load is minimal and he's done stuff like NLP processes with himself, hypnotic stuff, and nutritional stuff, exercise stuff, just to keep himself healthy. And it is possible to be healthy with HIV. So it's a difficult thing with the kiddies being diagnosed - not downplay it to the point of non-existence, but also to not frighten. Like this is a bad thing, you don't need to be scared. If you take care of yourself, you'll be okay. But they don't always have the resources to take care of themselves. And I've heard that if you take enough garlic, as suggested by our Minister, it will counteract the anti-retrovirals. You're dealing with Zuma in the shower (laughs). Make sense of that! (laughs)

You talked about your own feelings of loss that this child may die?

I never actually had a child die of HIV and that . …(inaudible) and that's really bad. I tend to pick them up when they're relatively healthy and on anti-retrovirals. So it's more a kind of thing in my head rather than an actuality. I worry when they're sick, I worry when they don't come to sessions. I worry if I'm sick and I come to work.

That you might give it to them?

Ya, it's a little bit of flu for me and I'll get better but for them they might get pneumonia and end up in hospital. These kinds of implications bother me. That stuff I don't really talk about

with them about in therapy because its my shit and because I try to give them the message that I think about them and I care about them but I don't necessarily hit panic stations if they're unwell. I don't really but it's in my mind when they are sick, I mean how sick are they really? And I try to keep tabs on it like every four or five sessions I'll have a feedback session with mom and like where is the CD4 count, and that's for me, I think, more than for anyone else because I want to know if she's well, is she okay. Is she managing?

And if she's not well?

Then we talk about it. I've never had one that hasn't. My kids have been really healthy, but then when they're away, I do think about them.

You think about the child.

Because they're never told their CD4 counts … The disclosed to ones. The non-disclosed to ones might be better(inaudible, rapid speaking, soft)

When you think about the possibility of (…the CD4 count), how do you manage it?

I think very much about the kids' stuff in the therapy. I think after the therapy I probably spend some time crying and feeling sad.

I try and get my head around it, because as I keep saying it makes so little sense.

There's a dear little thing, she's 8, so her dad shagged around and gave the mom HIV, but she's bearing the brunt of that. There's that moral process going on as well.

Someone's to blame?

Yes, someone gave me this for a present. And a lot of the moms bring that up as well.

There's also a fear to disclose, it's like if they tell their kids, then the kids will get sick. If they say it, then it's real. I think therapy is all about saying it, because it's real anyway. But there's a feeling that you'll invoke this terrible thing if you do. A lot of the time moms don't disclose because they're not comfortable with their own status.

They're still managing all their stuff and for them it's totally overwhelming and they want to protect the kid from that overwhelmedness, which is why I don't talk about this 15-year thing, I want to protect the kids as well in the same way.

And its very different for that adult perp.

So do you think you sit with some or a lot of the things that the mothers sit with about their children's problem?

Often, I'd say so. Because I think …These therapies can be so intense, and you're so connected and I feel such kind of affection for these children and a desire to take care of them

and make it all better for them, which I very seldom feel in adult therapy. There's a lot more pressure to make it okay and I know I don't have the answers and I can't make it okay. It's horrible and sometimes it's fine and that's just the way that it is. And it's not up to me to wave the magic wand over it (laughs)…it doesn't really work that well.

Are you saying there's more pressure with the children?

I feel more responsibility, yes, whereas with adults, they're able to carry it for themselves. I don't think I need to claim responsibility for the kids because they can carry it for themselves too. But I wish, it's more of a wish, on my behalf that I could make them be okay……. I think working with these kids brings out your vulnerable child, in a big way. So that you can't avoid it. Especially the ones who've lost parents, who've lost so much stuff, and they're just this little vulnerable person in a horrible big, ugly world, and you're sometimes the only kind of anchor, consistent caretaker. And I think everybody knows what its like to feel vulnerable and scared. I've never felt it to the degree that these kids must feel it. For them sometimes it's so overwhelming. And watching family die, that little one, I keep coming back to it, with the gran with the lung cancer because she's such, just.. she's got a cousin in (names a hospice) – the hospice. He's two, this little cousin. So I said to her: "Ah, are you sad today?" She says, "yes". "Why?" "C's gone to (the hospice) today" . "How does that make you feel?" "Like I felt when my mommy died." You know, the average 8 year old doesn't draw these lines, and it's hard to contain. Well its not hard to contain, you do it. You think, how much loss can this little girl handle. And she does, she does, next thing she'll be laughing about whatever. They're so strong……. And so vulnerable.

As you speak, I wonder about…. You've been sitting with a child who is vulnerable, in real life the child *is* vulnerable and how that's resonating with your own vulnerable child part. But then you see that between sessions she survives and that somewhere is healing for your child part?

More than likely. Ja. I want to feel that it is possible to be vulnerable and okay …

So life can be a bitch, but ...

Absolutely, but you survive……. I wonder how much of my feeling that the kids are overwhelmed is my feeling of being overwhelmed and also sort of putting myself in their situation, which is not really feasible. I imagine, oh my God, if that were me, I'd be totally screwed …(laughter). But I'm not there and I don't know what it's like really, really, if you see what I'm saying. So it's my feeling overwhelmed by the process as well.

So when you see it that way, is that a relief or does that make it more complicated?

I don't know if its a relief. To kind of understand my being overwhelmed is me being separate from them. Which I think is what I'm talking about when I mesh the two together and it's like … I'm struggling to word what I'm thinking of. I think sometimes I don't have completely serrated-edged boundaries and it gets a bit enmeshed.

It's comforting to know that they are strong enough to manage but I also don't think that I'm that important, its like, … I……I for them are not going to make or break. I can't save them. I also, by the same token, can't damage them completely and break them into small pieces because I'm just the therapist, I'm the lady that they come to talk to once a week and we talk and they feel cared for and it's nice.

One or two of them, they push the boundaries, there's always: "Ah, can't I stay with you a bit longer?" and that plucks at my heartstrings, because shame these poor little things, how do you explain it to them. You do explain it and they go away and come back again and it's okay.

So it's around my omnipotent process, oh gosh, I need to save them and rescue them and make everything absolutely perfect and that is a wish, but gee, I can't. And the person with the strength, who needs the strength is them and not me, if that makes sense.

Somewhere between attaching yourself, and putting your need for the world to be a perfect place onto them.

Yes, yes, exactly like that. And they don't necessarily need that at all.

Are there any, I mean I know its very new, is there anything that comes to mind, specific example of how feelings elicited by the work are played out in the group ... good or detrimental?

I think they play out all the time. I think me wanting to connect is evident in the way I talk to them and engage them. I'm nice, I'm unfailingly nice in the group, so far……. I'm very gentle with them, but I feel kind of really respectful. That's part of the process, too, me being gentle with them probably reflects my idea of them being hurt or vulnerable in particular ways and I think that gentleness in a group in the beginning is very important. If you're too confrontational with these little guys, they'll run away. They don't talk about this stuff, you should see their faces when you bring it up, ooh big eyes, like omigosh, just like "we're here today because we all know, you guys all know your status and what do we think". Ahh! There's tension, quiet and you chat a little bit about it and you make it normal, then they start chatting and in the first group we ran, by the end of the group they all wanted T-shirts. Can we please bond? Let's be on a team. And they're so isolated, these little kiddies in their classes with nobody that they can talk to.

So I think the desire to kind of protect comes out, and a desire to comfort as well, to be present. I don't know, it's very new, that particular group. I'm thinking of instances with kids… ya, I've got one little girl … but she was molested as well, but the molestation never comes out. I ask her: "How do you feel about it, do you know what that man did." "Oh no", she says. She can't tell me, so we draw pictures - happy face, sad face, whatever, she feels angry, okay, we kind of work through it. And then she draws me pictures and asks me: "How do you feel". Oh, right, so I say: "I'm sad that that happened to you but I'm happy that you can talk about it now, I feel angry with that man, too", which is very much my response, because if I'm asked, I will be honest. Oh, okay, now we can carry on. But they're checking the earlier response. How do I think differently of it now that we've discussed this. Now that we've been able to put that into language.

You talked a few times about this little girl whose gran has got lung cancer. It seems to have had a special impact on you.

She was the first one I saw. I think that was it and she's definitely did and I felt very much kind of unsure of myself as a therapist and I'm saying ya I've seen kiddies whatever, but this is a big issue, HIV with a capital H ... how are we going to manage this. Is this child going to be broken, and the stigma -kind of what does a child with HIV look like and she's just been disclosed to by the doctor and how's she feeling? I felt a bit overwhelmed and when she came over, she looked just like any other kid except her profile had a different name.

In terms of the difference between working individually and working with a group ... (inaudible, muffled).

I think individually tends to be more intense for me. The kids in the group, they tend to kind of deal with each other. You ask a few questions and somebody will share something and you ask the rest of the group: "How do you feel?" I feel very sad about that for that kid and they really much go with the flow with themselves. You don't have to do much, you just have to nudge a little bit.

That's interesting.

It's interesting for me the way the children interact with other children because its different the way they interact with adults. I don't know.

It's hard for me to distinguish where I want the group to go from where they want the group to go. Whose expectations are we working with here.

Because I've got it in my head as a psychologist talking about stuff makes it better, because if it doesn't I'm out of a job. Right, so let's talk about it. (laughter). And I do kind of feel like that. You language it, you get something. You master it, in particular ways. But a lot of the time they don't. I've got one little girl who doesn't talk to me. We draw pictures - that's it. You remember the one with the pictures about the feeling. We don't talk, we draw funny pictures, and sometimes we draw scary pictures.

And sometimes I feel like we know what we're doing, and sometimes I really don't. We just kind of go with the flow and things are working for them.

That's why I say, I think kids just speak a different language entirely.

What is it like for you if a child is speaking a non-verbal language?

Initially, it was really difficult to kind of do that. I kept wanting to put the words into place, because of the way I'm trained and as a Clinical Psychologist working with adults is easier because they've got the language. And then you kind of push in the beginning and then the kid gives you nothing because they don't trust you and they don't know you from a bar of soap. And then you learn to back off and then you wait. And then they come to you. And so it's been

very much about initially my wanting to jump in there with both feet, it was more about my own experience and my desire to be a therapist than about what the kid actually needed. So if she wants to take six months drawing pictures, then we'll take six months drawing pictures, and then see where we'll go. I think its about the relationship more than anything else. With some of the HIV kids, which was a learning experience for me, in that I was somehow, I don't know where it came about, I was expecting something different because having worked with kids with grief issues or bed-wetting or school issues or whatever it was, HIV was such a scary thing, the HIV monster will get you. So you need to kind of talk about that. As I said just now, it's the same kid, or a kid with a problem, but the problem's got a different name. And that's a particular response in me but that doesn't make the kid unmanageable with this huge problem thing that is going to self-destruct at any moment.

In terms of the difference between HIV and other difficulties that other children might have, what stands out for me obviously is that this child is going to get ill and die.

Ya, and then we talk about that. "What does it feel like when you're sick? How did your mom die? What do you think about it? What happened when she died? When she died, did it make you sad?" Obviously, duuh.

You have to keep the balance. You don't want to deny it but you don't want it to be overwhelming.

You don't want it to be overwhelming. We talk about all kinds of things. For me it feels so much like you go with your gut, make stuff up on the spur of the moment kind of process. You know I don't walk into a therapy session thinking: "Today we're going to talk about death and dying". You see where a kid is and if she's happy we'll talk about her cousin, the cousin's got HIV and you talk about the HIV and kind of, it's a conversation and if they're comfortable, they'll talk about whatever's on their mind. Or show me, or whatever.

To what extent has doing this work brought up your own issues around your own mortality?

Mmm, I don't know. I've always been comfortable with the idea of myself dying if everyone else dying straightaway. But yes, in terms of that, in terms of loss, yes, and loss of loved ones yes.

And in terms of ya, just managing, being the vulnerable child, the world wanting to be taken care of that puts me in touch with things in my past where I was vulnerable and I wasn't taken care of and the desire now from my big, strong therapist point of view is to take care, is to be the one to take care where I think I was missing it, kind of when I was a small kid. Ya, these are the things I think about when I'm confronted with this.

We were talking a lot about, well a bit how about recognising that you want to take care, the desire to rescue, that somehow places a child in a victim role which is not conducive.

Ya, it's does, it's completely patronising as well. Its completely patronising. There's this human, but I know best. You know, my desire is more important. That they can't get okay by themselves, and a lot of them are … In as far as you can measure okayness by psychological standards, they manage, they deal with it. They're sad when they need to be sad, and then they're okay.

In the beginning you talked a little about why … (inaudible)?

It does for me more with the mommies than the kids. The kids are more accepting. And It's me, it's not them. I'm aware that it's my stuff that is, it's like sitting in a group with this old gran whose talking about her life story and I kind of look at her and think: "You're so strong" and I look at the deprivation, the loss and the sadness … (inaudible) pretend I know what I'm talking about at the ripe old age of 29! … (laugher) Here I am dispensing wisdom. It's important to keep a sense of humour around it, I think. And then the flip side of that is that its not me dispensing wisdom. First of all the support groups, they talk to each other as much as I do. It's more my job to teach skills than to dispense answers. Listening, or asking questions or not even teaching. I facilitate the process. It's got nothing to do really with my experience. I'm not saying: "Yes, I was there!" or I did XYZ and now everything's fine. It's not that at all….. I often want to cry in the groups with the moms, not so much with the kids. Just listening to the kind of sad stories that they bring. One mommy, her husband or her boyfriend left her, and she's pregnant. He's HIV-positive. He never told her he was HIV-positive, she found out just before she married him and managing as a single mom, who can you tell this to. The man has just abandoned you completely and how raw her feeling of abandonment is and I suppose it touches my experiences of abandonment too and it makes me really sad. There's this granny as well, she was far more … her daughter died and it's too funny … she's left with this little baby, and the baby's three and she says “oh touch him”. And one of the other grannies goes: "cute, don't you think cute". Then the baby had a fit and the doctor said: "He can die in hospital or you can take him home and he can die there." And she said: "I want to be the one to close his eyes." She took him home, this little three year old. He couldn't turn over. She turned him, she washed him, she kept him safe and did everything for him, then he got older, he was fine. We did crawling, we did potty-training, the kid's like 10, he's lost 3 years, so he’s seven, kind of developmentally. But on her own, with fuck-all resources, she managed, she did this. She's got her child now. And she was worried about disclosure. She actually disclosed, the second time she came back she actually told him … (inaudible, laughter. You see he's a little bit kind of delayed. And she had disclosed in the gap between the one group and the next one. She told him about it and you can join now… (inaudible, laughter). .. (inaudible, soft)

Its quite a variety of experiences

I've found evidence of strength and courage and the ability to kind of roll with the punches. When you've got this little thing and you're dealing with the group you have because your child's dying, now you've got this other thing that you must clean and take care of, it's back to special school when he's old enough. This gran could manage that and she's laughing her head off and telling funny stories in the group - ya managing. Managing better than your average neurotic housewife. Its humbling. And I'm kind of prejudiced about that as well, where I have two jobs, I work here and I work for a company called () … (inaudible, cell radio disturbance).

How unfair is that, it's horrible. It's so horribly dismissive. I don't know if it's really relevant to HIV stuff.

These people, the work here feels really important, they don't have other resources. If we're not here, there's nobody here, and nobody will take care of them, whereas other people have a medical aid or they can afford to go to a session or they can get their stuff looked after. It's one of my resentments as well, kind of, hello I'm saving people who are poor and cannot do it for themselves.

It's so bad, it's horrifying. I think about this, oh my god, but ya, there it is, and it does seem meaningful.

It's nice for me to be able to build a relationship with a kid, not to save, not to do anything, but to be there, but to talk what needs to be spoken. And I don't have any illusions that I've made the biggest difference in the whole world …You know, because J is here …Not like that at all.

And that doesn't make you despair?

No, not at all. Because that would be purely all about me. The way I see it is my role with the HIV kiddies is to help them make sense, that's all, to talk and to offer a relationship of difference and that's my own idea about therapy completely is that it's a relationship of difference. You offer something to somebody because they're not being given it anywhere else, in their lives wherever it is. I mean these kids have the chance to be contained, to meet that, because it's terrible if the mom is also sad. And to talk, about the stuff. Make sense of it, or drawing, whatever. Make sense of it in a different way that it doesn't feel like this unspoken huge presence.

…(inaudible) … confront this head on. That's the way that you work?

Ya. I think I'm totally addicted to intensity. I think psychologists often are, because it's not intense, I don't know, and I get it that therapy with HIV people is intense and we move really quickly in terms of other groups that I've kind of been involved with, like these mommies, they share, they just sit there and (…). I've talked to C about it before and she says she's run similar groups before and she says it's almost as if there's a time pressure. It's almost as if they're not going to have the time they have and they do have it. They're so open with each other and they cry in the first session and the other one (gives and hug) and (says) it's okay. They comfort each other and they're just so …Its beautiful.

…(Interviewer's question inaudible).

Sadness is always part of it.

It's very honest. Very real and very much. It's kind of me, I find I really struggle with small talk. I'm more comfortable engaging with emotion and for me they are … that's what they do.

The intimacy?

Yes, there's a profound intimacy. When I think of them sitting in the clinic, they kind of sit next to each other and avoid each other's eyes, you see, because everybody knows that nobody's going to say anything. If you can take that sort of insularness, if that's a kind of word, away from them where they can open up, they're all in the same place and they've all got the same issues, they have the same questions and they kind of relate to each other very freely based on that and it's exciting to be a part of that process because you feel that maybe there's someone who is very lonely and couldn't tell anybody else. She's now got five or six other women who feel the same and she knows she's not alone. They're building connections.

As you talk I'm thinking of the idea of humanity. The groups are really about people's sense of humanity.

Ya. It's amazing stuff. It's like therapy you do … simultaneously I cant … (respondent speaking very quickly) … and at the same time so many people, it sounds like you're the doctor who gave the pill that's fixed it. (…) it's all in the conversation. It evolves by itself and it's not about you the therapist or the question of the patient. Somewhere in the middle, it's between you in the way that you interact. Things change and they become meaningful and valuable - and they are anyway. I can't talk about it, I'm thinking about it very verbally today …

and I think it's a privilege to be a therapist and to be allowed that. Especially with kids, because it's so hard sometimes to get a kid to trust you especially when they've just been dropped. They're kind of overwhelmed, they kind of talk a little bit, and play a little bit and give a lot of time. .. it's all very much in the feeling between you. You can genuinely care about this little kid, they'll know and they'll respond.

Has it shifted your idea of how the world is good? In some of the other interviews they talk about struggling with the despair of how dark the world is for the child. That there's no good object for the child. But listening to you now, I think of in confronting the darkness and tolerating it, this is how the world is made good.

Ya, I think a lot about that, if you spend your life hiding in the shadows, the light becomes meaningless. Light and darkness define each other. I remember reading somewhere and thinking at the time that it was really trite. I think of the beauty in suffering. Pain is beautiful as one of the human experiences as well, it's offering the experience that is different. I think that's also pretty trite … (laughing). But it does make sense as well. It's hard to make sense of it for yourself when you are in the place of despair. I don't know, I've seen some horrible things, very sad, and completely wanting to cry and curl up and hide away and never want to be a therapist again. And I've also seen some incredible things that are so beautiful and so powerful and so human and so true, like that granny with that little baby, I mean the kind of love that you have, that on absolutely nothing you can take care of a child - amazing. Accept him, love him and take care of him - he's not going to understand (…). Do what needs to be done. Its precious … everything in the middle, it's a big spectrum and you've got the bright lights on the one side of the human strength and resilience and on the other side the darkness and the despair. It's everything, the whole experience.

Thank you.