

Practice: Paediatric Disclosure

Title: Disclosure in the Paediatric Clinic

Author: Tracie Rogers

Target Audience: Social Workers, Social Work Students

Key Transferable

- Lessons:**
- (1) The Caregiver is the first point contact in initiating the disclosure process and hence the social worker's job to help caregiver understand disclosure
 - (2) There are advantages and challenges in disclosure; these must be explained to the caregivers/ non-dependents
 - (3) There are common misconceptions/ myths surrounding disclosure
 - (4) Tasker's (1992) model is used demonstrated the caregivers preparation for disclosure

Rationale

Disclosure refers to the process through which a child/adolescent receives, and copes with information about his/her HIV status. The disclosure process is unique to the child/adolescent and support/care system. It is important that disclosure is seen as a process as opposed to a one-shot dose of information. An individual proceeds through the process of disclosure throughout his/her lifespan. The first stage of the disclosure process is receiving the initial information about one's status; from this point the child/adolescent learns about the illness and learns how the virus behaves in his/her body.

Completion of a needs assessment identified the following challenges:

- There was no shared/unified understanding of disclosure among the staff members at Sinikithemba
- Disclosure was performed somewhat haphazardly by the staff members
- Children and adolescents were learning about their statuses in unhealthy ways
- Older children and adolescents were placing themselves and others at risk for HIV infection and re-infection due to their ignorance of their status
- Caregivers held many misconceptions about disclosure and were in need of specialized support in this area

I found an overwhelming need for a systematic approach to disclosure with patients with the objective of educating and encouraging families to treat disclosure as a process which will continue beyond the first stage of receiving the information.

Helping a caregiver understand disclosure

The provision of support for caregivers necessitates that the social worker possess the ability to discuss the advantages and challenges of disclosure in an informed and sensitive manner. Through informal conversations, I learned that many of the staff members had clear understandings of the elements of disclosure, and that it would prove beneficial to staff and patients if their knowledge could be pooled to inform a formal policy. I embarked on interviews with members of the multidisciplinary team, supplemented the information gathered with research on current approaches to disclosure of illness to children and adolescents with chronic diagnosis as well as HIV/AIDS and

my experience of disclosure with my current case load. The results were three working documents, a policy, protocol and guidelines which were subsequently approved and adopted by the Clinic. The following are some of the material these documents covered. (See the Disclosure Protocol and Policy in the Appendices)

Advantages of Disclosure

With an understanding of his/her HIV status a child/adolescent:

- has the opportunity to gather emotional support - child/adolescent can access peer support groups
- may be more willing to maintain adherence to medication for HIV treatment
- can be better able to advocate for his/herself at school and within other social settings and can learn to deal with stigma and discrimination
- who chooses to engage in sexual activity is able to make informed sexual decisions – i.e. with full knowledge of the risks to both his/her partner and self

If the child is knowledgeable of his/her HIV status the caregiver:

- has an opportunity to control disclosure to the child/adolescent
- can gain emotional relief from secrecy around illness

It is our experience at Sinikithemba that:

- children/adolescents tend to have a sense of his/her health status even though they are not told by caregivers
- if the child/ adolescent is unable to speak about his/her illness openly, it often occurs that he/she blames him/herself for the illness and how it affects (or inconveniences) people around them. This self blame is likely to increase stress levels and increased stress levels can cause increased viral load
- if caregivers lie to children/adolescents about their status, children learn not to trust them
- A child should know that he or she is ill

At Sinikithemba, there is an appreciation of the challenges for disclosure and an understanding that there are instances where disclosure can be ill advised. The Clinic has a strong preference for caregivers leading the disclosure process, appreciating that

caregivers must be able to weigh the pros and cons of disclosure. For children under age 14, Sinikithemba is obligated legally to safeguard the caregivers' right to weigh the pros and cons and make an informed decision. However it is maintained that children have a right to know what is happening with their bodies. The following are challenges of disclosure which should be discussed with patients and caregivers in order to prepare them for disclosure.

Challenges of Disclosure

- Disclosure may decrease the ability of caregivers to control secondhand disclosure by others. Children/adolescents, even though secrecy is requested, may disclose their status and the status of caregivers to others – It has been the experience at Sinikithemba that social workers and psychologists can help children understand the difference between 'public information' and 'private information'. It is also more helpful to identify permissible persons whom the child can speak with about HIV – other family members, Sinikithemba staff etc. rather than forbid discussion of the illness
- There may be increased vulnerabilities for child/adolescents – depression, isolation are some difficulties which he/ she may experience as a result of learning of his/her status – the best way to help children/adolescents to deal with these vulnerabilities is to tell them about their status as early as possible and let them know that there are people who can help them deal with these feelings
- Caregivers who are having difficulties in coping with their own status and illnesses may experience extreme anxiety in the disclosure process – it is helpful to engage with caregivers about their anxieties about disclosure before talking about how they should disclose to their children

Common misconceptions about disclosure

Misconceptions about disclosure are rampant and I postulate that they persist because they are reinforced by anxieties and fears about internal and external stigma. These misconceptions are disempowering but they are consistent with debilitating discrimination in our societies.

- *'Disclosure will only be necessary if I get really sick, my child does not need to know.'* - Many people believe that disease progression is the marker for disclosure and that miraculously when they are very ill it will be easier to find the words to disclose to their dependants. It is suggested that HIV positive caregivers begin using an 'anticipated costs versus reward approach' to disclosure instead of waiting until they are extremely ill and less able to articulate their illnesses in an un-pressured manner. Illness may make disclosure exceedingly difficult; the HIV positive adult may have less control in the disclosure process – other family members may take over the supervision of the child, or illnesses may make one too weak to discuss the issue in a manner which is best for the child. It is advisable for caregivers to weigh the short-term and long-term costs versus rewards of disclosure rather than procrastinate about disclosure. Disclosure planning is necessary
- *'The child just talks too much, she/ he has no control over his/her mouth'* – Secret-keeping is especially difficult for children and there is often wisdom in this comment. However, children often learn of their status inadvertently and when caregivers are not open to dialogue they will be more likely to open discussion with other persons. Again, instead of telling the child who not to talk to about his/her status, it is more useful to identify for the child to whom he/she can safely speak about his/her status.
- *'My child will kill him/herself if he knew'* – Learning about one's HIV status is exceedingly difficult for adults and the same follows for children. The caregiver who feels this strongly about disclosure is aware of the stress that will be associated with this information for the child – this is more reason for the disclosure process to be done with caution. If the child were to discover his/her status on his/her own, the child would be left without the guidance and support of the caregiver to process the information. It has been the experience at Sinikithemba that children cope with their status better than caregivers expect.
- *'If my child asks if she/he has HIV I will tell him/her no, when he/she gets older they will understand why I did what I did'.* It has been the experience at

Sinikithemba that lying to children destroys the trust relationship between the child and caregiver.

- *'Children cannot understand death!'* Death is a reality which all children learn to deal with. Skilled social workers can help caregivers find words to explain death appropriately per the child's chronological or developmental age
- *'If my child learns that I gave him/her HIV he/she will hate me'* It has been the experience at Sinikithemba that blame and guilt are challenging issues for caregivers but honesty improves the relationship with the child/adolescent and can help that him/her begin to accept and cope with the illness

Age of Disclosure

Patients should be recommended for partial disclosure by age 10

It is recommended that all be fully disclosed patients must be disclosed by age 14.

- For children 5-10 years
 - illnesses are perceived as something which is “caught” – children may have difficulties understanding modes of transmission. This needs special consideration where HIV negative children in a household are knowledgeable about the positive status of a sibling, relative or house mate
 - “magical thinking” persists, children may not understand the chronic nature of HIV. Illnesses and death may also be perceived as punishment
- For children 10-13 years
 - the peer group has a strong influence on behaviour and decision-making. Children are knowledgeable about sex and drug use. They are also very keen to ask questions. Caregivers should be prepared to answer questions about transmission and risk behaviour which may have led to the child's infection. There may be blame and anger from the children
- For Adolescents: (in addition to the challenges above)
 - there is increased rebellion and risk behaviour among adolescents, it is absolutely necessary that they learn of their status so they can protect themselves and others

Who should disclose to a child

It is preferable that the primary caregiver(s) or a trusted, consistent adult(s) in the life of the child/ adolescent initially discloses to the child in a familiar non-threatening environment. Social Workers, doctors etc. should only disclose to the child as a last resort. Where primary caregivers request and require support, Sinikithemba staff may be present to support the process.

It may be ill-advised for professional health providers to disclose or lead the disclosure process:

- When this situation occurs the message may be received by the child that it is only permissible to speak about his/her illness with the Sinikithemba staff member. The caregiver is not empowered to begin coping with the illness and its psychosocial consequences. Instead, the illness may only be discussed at Sinikithemba and discussion of the issue continues to be forbidden.

The caregiver's preparation for disclosure

The Tasker (1992) conceptual model of the four stages of disclosure attempts to explain how individuals proceed through disclosure:

Ø Secrecy

Ø Exploration

Ø Readiness

Ø Final disclosure

The first step is normalizing this experience for the caregiver – helping the caregiver to realize that his/her feelings are normal and most if not all individuals in like circumstances experience similar feelings. The care provider must then attempt to support the caregiver through the phases of exploration (examining their feelings of guilt and shame), readiness (preparation and rehearsal for the disclosure process) and then to final disclosure (informing the child of the illness and continuing to provide support). Disclosure may require caregivers to address the mode of transmission of the virus to the child/adolescent. For many this is associated with guilt, denial, fear and shame. This may be pronounced for biological caregivers who may be experiencing internal stigmatization. Such internally directed feelings of guilt, anger and shame are not unique

to biological caregivers but may also be experienced by non-biological caregivers who may feel some responsibility for the circumstances under which the virus was contracted. As care providers we must aim to guide caregivers through this process of preparation for disclosure.

References

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