



**THERAPEUTIC EDUCATION :
RECOMMENDATIONS REGARDING DISCLOSURE OF HIV STATUS
TO CHILDREN UNDER ARV
IN MSF PROJECTS**

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SUMMARY

A. CHILD OBJECTIVES.....	3
B. PARENT OBJECTIVES	5
C. HUMAN RESOURCES	9
D. IMPLEMENTATION.....	11
E. STRATEGIES.....	15
F. EDUCATIONAL TOOLS.....	17
G. EVALUATION.....	21

Therapeutic Patient Education (TPE) in the context of chronic childhood illness is care characterised by continuous personalised support and by a process of progressive and evolving education. The child's, emotional and cognitive development will influence his reactions to the disease. Depending on the child's age, his reaction to disease might differ. In annex, a table proposes a schematic (though hopefully usefull to the teams) the different ages of child development in relation to illness and possible actions for health care workers.

TPE is integrated into medical care, which permits the family and the child to adapt to illness, to plan life projects and to acquire knowledge and competence with respect to the illness, so as to permit a level of autonomy in the management of the child's medical treatment (45).

Taking care of a child in the context of paediatric HIV infection means taking into account and being interested in the familial environment. TPE is centred both upon the child and his family (34). This is why some general objectives of care proposed below are child specific, some parent specific and without neglecting the siblings.

This work then focuses particularly upon the objectives and means of disclosure of paediatric HIV. Disclosure is not an end unto itself, but more a means through which the child lives better with his illness. It is integrated within the care package offered to the individual. It is an obligatory stage in the life of the child, in his journey with his disease, and part of continuing care.

A. CHILD OBJECTIVES

The general objective in the care of HIV in the child could be defined as the following:

To help the child to grow and develop despite his illness, and to live as well as possible, through a structured and structuring care environment.

To do this, certain key principles must be respected:

- To consider the child patient a partner and an interlocutor of the care team in the same way as the adult responsible for him.
- To establish and maintain the child's participation in his treatment that is adapted to his development.
- To permit the child to be both the subject and the actor in his health.
- To ensure carer-child relationships based upon respect, confidence and openness.

1) Specific Objectives

The general objective will be attained if more specific objectives are worked upon such as:

- To help the child to develop, to live and to project himself into the future through a life project and according to his own norms of "health"; not to reduce the child to his illness (46),
- To help the child manage his emotions in the face of his disease, to develop a positive attitude.
- To liberate the child's thoughts and speech in the absence of his parents, to offer him the possibility to express his fears, anxieties, to talk about his seropositivity. The presence of parents may block such expression (24),
- To bring up undermining secret, unsaid and "forbidden" subjects in consultations,
- To act as intermediary between the child and his parents; to facilitate communication between them,
- To tackle and permit the expression of death anxiety¹,
- To help (older) children to make choices and to take decisions to improve their quality of life,

¹ Of course, children may be anxious about the idea of their own death but they may also worry about the death of their parents. Any physical manifestation or illness in the parents or adults in charge of the child (re)activates separation and death anxiety.

- To help the child to understand his health status, his illness and the necessary treatment,
- Once his cognitive development permits it, to involve the child in the taking of his treatment and thus to render him partly responsible for his adherence to treatment,
- To work with the child upon his self-esteem, issues of stigma, and his place in society,
- To evoke the question of secrecy: should he tell others that he is on treatment or not? If so, to whom ? ²

2) Educational Objectives concerning disclosure

The process of disclosure of HIV disease must be constantly repeated and as such there is no end to it. All the objectives listed below may and must be repeatedly worked upon. An objective attained at a specific moment in the life of a child does not signify that it will not be necessary to retackle the question at another age or taking into account new elements brought to the child's knowledge.

This means that educational assessment must be continually performed with the child but that it must also be supple and come from what the child wants. Where is he at? What does he want? What is he worrying about at the moment? The child is the best indicator as to when to start disclosure. One is able, through pertinent specific and non-aggressive questioning, and without overwhelming the child with questions to evaluate his knowledge or preoccupations:

- To evaluate and identify the child's representations and knowledge of his disease,
- To identify his preoccupations,
- To leave the child space for questioning so as to bring out the child's preoccupations at that time (to let him know that his questions are welcome and will always receive honest and frank answers).

During disclosure, some desired objectives will also "serve" as objectives to increase adherence to treatment. The explanations that give the child bearings in his disease and help him to take treatment converge with those maximising adherence. One may distinguish objectives that are specific for partial and complete disclosure³.

² The question of secrecy is one of the key elements in parents' reticence in announcing the illness to the child. This objective is thus essential and must be brought up early, at the moment of partial announcement.

³ See annex for definitions of disclosure

Disclosure	Specific Objectives (the child should be able to.)
Partial Disclosure	<p>Explain the question of immunity</p> <p>Explain the importance of treatment to be taken and its effects upon microbes and the organism</p> <p>Explain the disease and the fact he is not necessarily feeling sick</p> <p>Explain prevention of illness (taking a treatment)</p> <p>Identify the symptoms he suffers or has suffered and to link them to his disease</p> <p>Describe his sensitivity to microbes and his lack of immune defence</p> <p>Explain the medical and biological follow up imposed by the disease</p>
Complete Disclosure	<p>Name the disease</p> <p>Explain the general modes of transmission</p> <p>Tackle the questions of sexuality and prevention (condom use)</p> <p>Distinguish between contradictory messages received in school education sessions on health, HIV and AIDS and the educational messages heard during consultations</p>

B. PARENT OBJECTIVES

The support of children living with HIV implies interest in the parents as people and in their relationship with their child. The general objective with respect to parents could be described as the following:

To help the parents to support the child in his disease and to exercise their parental role in a manner that is as structuring, positive and reassuring as possible for the child.

1) Specific Objectives for parents

Parents are often going through difficult situations themselves and living with the seropositivity of their child is in no way a minor event in their lives. Time should be specifically allocated for parents without the presence of the child. The creation of room for parental expression allows us to:

- Tackle their worries and their anguish with respect to the health and the future of their child, and with respect to treatment,

- Permit the expression of the death⁴.
- To take the drama out of the notions of the disease and treatment⁵.

When seropositivity is discovered in pregnancy the mother requires accompaniment. Consultations can be determinative in future mother-child bonding. The more the mother will have been able to speak about her suffering, the more comfortable she will feel with her child, and the higher the chances that bonding will take place between them (23).

Subjects to be discussed with the mother from the moment of disclosure of her seropositivity:

- The acceptance of her disease (getting through the shock and initial trauma and turning towards the future that the pregnancy represents),
- Early discussions about bonding,
- Sharing of the secret within the family.

2) Parent support during initiation of anti retroviral treatment in their child

As soon as the child is put on ARVs:

- Tackle the issue of the carer-child therapeutic relationship for which parents can not go against (tacit contract):
 - For the carers the child will be an interlocutor exactly in the same manner as the parents are,
 - Without naming the disease a minimum of information must be provided to the child (partial disclosure),
 - The parents' confidentiality will be respected in the same manner as that of the child during individual consultations.
- Educate the parents about treatment
- Discuss the distribution of roles and tasks concerning treatment between the child and the parent. The child's level of responsibility should be situated between the two extremes of overprotection and too much responsibility. The former, where the child does nothing and is

⁴ Parents and grandparents often fear their own death. They are often relieved to be able to envisage the eventuality and to plan solutions in case of their death. This reassures them and relieves their guilt: in the event of their death their child will not have to face his disease alone, there will be continuity in the care of the child.

⁵ Sometimes the parents themselves have fixed ideas, representations with respect to the disease. They may not have succeeded to live with it and some may be in denial for example.

responsible for nothing, is contradictory with his inexorably growing need for autonomy. The latter, giving too much responsibility to the child too young, does not take into account his development and his need for a parent as a reference point (45).

In annex, a questionnaire can be used to evaluate the degree of parent's capacity to deal with the treatment of their children.

3) Objectives relating to disclosure:

- Identify and evaluate the dominant modes of communication in the family,
- Envisage realistic solutions to re-establish and improve it (dialogue is often blocked due to the impact of secrecy),
- Prepare parents for disclosure, evoke together its modalities: what? who? when? where? What is planned after disclosure?
- Recognise that disclosure will be difficult but re-affirm its necessity and try to gauge parental motivation,
- Work with the parents on the necessity of announcing the disease to the child ⁶,
- Decide with the parents what exactly will be said to the child; re-negotiate at each stage what to say in response to the child's questions,
- With respect to secrecy, discuss with parents what they will say to the child:
 - With whom the child may speak about his disease if he so wishes, both within and outside of the family.
 - Be clear with the child as to why they may not wish the child to speak about his disease. This brings meaning to the request for secrecy, and instead of the child becoming a prisoner of his secret, structure is brought to the family (18).
 - Speak with the parents about the distinction between telling all and telling what is necessary for the child's understanding. All must not necessarily be revealed. Clarify which information is the domain of intimacy.
- Propose specific help to the parents for disclosure:
 - Anticipate the difficult questions that the child may well ask (14, 30) : "Why did it happen to you? How did you get it? Are you going to die? Is it my fault that

⁶ For instance, it is probably best not to argue, emphasise on achieving therapeutic goals (eg: having high Cd4s) but emphasise more on both the child's and the parents' psychological, emotional and affective well-being due to disclosure.

you are sick? Who else knows that I have the virus? Why do I have the virus?
Am I going to die?»

- Propose role plays to practice disclosure, the words they will use and how to answer difficult questions,
- Be present on the day of disclosure to support the parents,
- As a last resort, perform disclosure on the parents' behalf⁷.

4) Special considerations in child HIV testing

The question of disclosure of results must be addressed when parents request HIV testing of their child. If the child is aged 8 years or older it is appropriate to ask the parents about the pertinence of involving the child in pre and post-test counselling.

If the child turns out to be positive, personalised support and follow up should be offered immediately.

5) Objectives with respect to other family members, brothers and sisters (13, 14)

The disclosure to the child of the realities of his disease is obligatorily accompanied by discussions on the subject with other members of the family. It is a logical continuation, a cascade effect. This disclosure within the family is another challenge to parents. The carers should have the objective to help the parents and the child to announce their status within the family.

Adults in the family. There is no lack of reasons to tackle with parents the subject of disclosure to other adult members of the family:

- They may become additional supports for the parents. If the parents become sick themselves, they will need to find someone to take over the care of the child.
- The death of the parents needs to be envisaged and who could potentially look after the child.
- If the child becomes unwell the medical care may require the involvement of other adults.
- The child may find other verbal outlets for how he is living with his illness and may be able to share his secret with others outside the restrained circle of his carers and his parents.
This is even more important when communication is inadequate with the parents.

⁷ The last resort: always to be done in the presence of the parents; everyone hears the same thing at the same time and thus the discussion may be continued in the family circle if thus desired.

Siblings: the disease affects every member of the family and each one deals with it in his own fashion. There is a risk of isolation, of aggravated guilt and other feelings that may make exchange difficult in the family. Family links are affected on all levels: between parents, between the parents and the affected child, and between children. Children are very sensitive and will feel dramas that are played out under the cover of secrecy: they can feel guilty and responsible for others' illness there is no explanation as to what is going on. The reality is better, even if it is tough to spell out, than vagueness and uncertainty.

The objective is that each member of the family is able to make some sense of what is happening thus promoting an emotionally healthy and balanced environment.

C. HUMAN RESOURCES

Ideally a pluridisciplinary team working together with the parents and the child should provide HIV care. This care typically involves three types of professionals in MSF programs: the clinician, the counsellors. And the nurse delivering ARVs. In some programs the nurse also performs the role of counsellors.

1) A specific team for child follow up

From the moment when the child is being followed in the HIV clinic it is important to organise care so that he is always in contact with the same clinician, dispensing nurse and counsellors :

- To improve child follow up: the child and his family will be better known (personality, familial and social environments) and thus the care will be better adapted,
- To know where the child is up to in the process of disclosure,
- Having the same interlocutor will also permit the child to be at ease and to have confidence and thus to construct a privileged relationship with his carers,
- The carer himself develops specific communication abilities,
- To ensure coherency of educational messages and thus to avoid confusion due to contradictory information.

2) Required Skills

Even if the different health providers' missions are distinct and complementary, each must nonetheless possess the following specific skills so as to offer efficacious care to the child and his family (45) : psychological skills, educational skills, interpersonal communication skills, listening and reformulation skills, the capacity to negotiate with parents, the capacity to manage a group of adults, and finally and more challengingly, to manage a group of children.

In addition, each professional working with children should:

- Enjoy teamwork. All team members needing to be conscious of the importance of the pluridisciplinary dimension of the care provided,
- Enjoy working with sick children,
- Like children and feel at ease working with them, be creative, enjoy playing,
- Have enough knowledge about the disease,
- Know a minimum of child psycho-affective development landmarks,

Specific Roles

ARV Dispensers	Educators	Clinicians
<p>Focalise the relationship upon adherence</p> <p>Involve the child in his treatment: ask him if he knows the names of the drugs he is taking, how many he must take per day and how?</p> <p>Involve the child also in what to do in the case of forgotten doses, vomiting, etc.</p>	<p>Accompany, support, and follow up the child and parents over time</p> <p>Work on adherence to treatment (parents and the child)</p> <p>Work on disclosure to the parents and the child, and also to other adults and siblings</p> <p>Depending on the age of the child, to bring up sexuality and prevention of transmission.</p>	<p>Consider the child as a care partner and privileged interlocutor during consultations</p> <p>Involve the child in his follow up and treatment</p> <p>Respond to the child's questions or send the child to the educator for appropriate follow up</p> <p>Be the link for educators as to the child's key questions and to transmit them in written form</p>

Common roles for all team members

- To provide the child with accurate and age appropriate information,
- To answer the child's questions honestly but not necessarily specifically (e.g. "the drugs will keep you well and strong"), not to lie,
- To provide time specifically for parents so they are able to express in private their worries about their child's health and treatment, and both theirs and the child's futures

To evaluate the child's knowledge regarding his prescribed treatment,

To listen to the child's questions,

To observe the child's reactions (or the absence of) and parent-child relationships,

To be attentive to any sign evoking that the child might be worried about something or have unanswered questions. Signs of a child's worry may include the reduction in adherence to treatment, bad school results, changes in appetite or mood, retreating into himself, new fears, sleeping or concentration difficulties, tics, or the reappearance of bed wetting.

To reassure the child about his health (without demagoguery or lying).

To encourage the child to participate in his care and treatment

D. IMPLEMENTATION

1) Follow up: Consultation rhythm according to stage of disclosure

Disclosure of HIV disease is not trivial. One must adapt the rhythm of follow up consultations so as to be able to observe reactions to it.

Phase preceding complete disclosure	The frequency of consultations is no more than required for medical follow up and ARV delivery. Partial disclosure does not require more intense follow up as it is understood that the door is always open between planned consultations.
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Phase immediately after complete disclosure	Weekly consultations for one month: to answer the child's questions and evaluate his reactions to disclosure
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Later phase after complete disclosure	Monthly consultations for 6 months, then adjust to every two months if feasible
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2) Dedicated days for child consultations

Will permit the same health carers see the children (continuity in the relationship),

Will make it easier to start up group activities when this becomes a necessity.

3) A dedicated room

A room equipped with appropriate furniture, games and decorations. The place should be convivial for the child so that he is not afraid to come to the clinic, and hopefully counterbalance the discomfort of clinical examinations and blood taking.

4) A single medical file

A single child-specific medical file should be used that notes the key points of each discussion: the child's questions, advances in discussions with the parents, what the parents and the carers have agreed to tell the child (and how, by whom, when, etc.).

All carers who see the child should fill out the file. The key points to be recorded in the file concern the following areas:

Cognitive: what the child and his parents know about HIV disease and treatment

Emotional: how the child is, interacts, does he ask questions? and his parents?

Social: what are the family and social environment and living conditions like? sexual activity yes or no?

Behavioural: patterns of taking ARVs. At home, away from home, adherence problems and envisaged solutions. Problems with taking medications and the solutions proposed by the parents and carers.

5) Pluridisciplinary Meetings

These meetings should take place with the aim of consulting the files and to know which children will be coming on a specific day and where each one of them is up to in the process of disclosure of HIV disease. A single common file and pluridisciplinary work practices are essential to ensure continuity of care (41) : the words used during disclosure should be known by all members of the care team so as to maintain coherency. The same arguments should be used and the same points brought up at the same time. Notably if some specific questions have provoked significant emotion in the child, this should be transmitted so the other members of the care team can respond in later consultations if required. The team must plan the educational objectives for the child and his parents, and then share the corresponding tasks.

6) Initial evaluation

The child will evolve constantly, therefore the evaluation will have to be brought up to date regularly. The following information needs to be kept in the file ⁸:

Child	<p>How was the child's HIV status discovered? Prevention of mother to child transmission program? Suspicious symptomatology?</p> <p>Clinical state of the child at diagnosis: asymptomatic or symptomatic</p> <p>Age of the child at diagnosis</p> <p>Child on ARVs? since when?</p> <p>Date of birth</p> <p>Stage of cognitive development (language, writing, etc.)</p> <p>Was the child involved in the process of pre- and post-test counselling?</p>
Parents	<p>Are they the biological parents? Did the biological parents die? when?</p> <p>What family ties unite the non-biological parents and the child?</p> <p>Have the parent(s) been tested for HIV?</p> <p>Is/Are the Parent(s) HIV +ve? Asymptomatic? On ARVs? Treatment similar or different to that of the child?</p> <p>Is the adult unwell, does he or she need help either for themselves or to look after the child or children?</p> <p>Which adult is the main focus of bonding for the child?</p> <p>What arguments have been brought up against disclosure of HIV disease if any?</p> <p>Does the health status of the parents affect their parental capacity and if so how?</p>
Family	<p>Who knows about the child's seropositivity?</p> <p>Are there other adults in the family known to be HIV infected?</p> <p>Are there other siblings in the family known to be HIV infected? If so, who knows about it?</p> <p>Who takes ARVs in the family?</p> <p>What is the family like: cohesion, communication modes, living under the same roof?</p>

⁸ Adapted from resource N°15 and 27 and file currently in use at Brussels hospital

E. STRATEGIES

1) Individual consultations

For children

Individual consultations may be offered from the age of 4-5 years. A meeting with the parents usually allows the definition of objectives: give the child an opportunity to speak about his disease, how he lives with it and what he thinks about it (47).

This kind of meeting is often well accepted by parents. The child will be able to confide in someone who is neutral and is not anxious, stressed, sad or depressed about the child's illness, and will thus speak more freely. The child feels "negative waves" very strongly, and often does not speak or ask questions as freely as a result (27).

Individual consultations are preferred to group sessions for small children (less than 8 years of age) and those in the starting ARV treatment.

For parents

Essentially, individual consultations with parents permit to negotiate the process of disclosure of HIV disease to the child. Nonetheless, as said above, parents need time to be able to express themselves, and this must not be neglected for the child's equilibrium. They are one of the key factors of the child's overall well being and more specifically in his adherence to treatment.

Working with parents includes the possibility of role-plays to help prepare them for questions that the child will ask them.

Joint child and parent consultations

As the parents and the child are partners in treatment, educational work and follow up on treatment and adherence are always done with both parents and the child present.

With respect to disclosure, consultations with parents and the child present will permit to say the same thing to all at the same time. Thus everyone will have heard exactly the same information, which helps promote communication and discussion in the family. The carer may also be a role model for parents in how to discuss, explain, and speak honestly with the child.

2) Group sessions

For children

Group sessions are particularly pertinent post disclosure around 9-10 years of age.

These groups allow support and sharing of experiences, but also permit sharing of concerns (26).

Moreover, given that children are generally unable to announce their disease in their environment (school, friends), participation in support groups is an opportunity for them to speak with HIV affected peers and, why not, to participate in social activities. The groups thus serve as emotional supports.

Group sessions also permit to tackle the questions of adherence and the difficulties in taking drugs every day when one isn't feeling unwell.

In older children it is an appropriate environment to bring up questions in relation to sexuality and the use of condoms.

- Group size: maximum 8 children of roughly the same age (all aware of their status).
- Short highly interactive sessions are preferred (maximum 1 hour).
- Use life experiences. For example, on the subject of adherence: "and you, how do you manage at home to remind yourself to take your treatment?"
- Role of the animator: consists in ensuring that each participant is able to formulate his own ways of thinking and doing things. He reformulates issues that are brought up so as to stimulate awareness, synthesises the debates, and refocuses the discussion back to the theme where necessary.
- One must be careful when animating and managing groups of children as it is not as easy as groups of adults. Children's attention needs to be held, their participation incited, educational objectives need to be attained and adapted methods need to be used. Children are sometimes turbulent and difficult to "control", and in such cases the animator may feel to have failed and that the session was useless. Animators working in these sessions must be able to self evaluate and self criticise, and also be capable of analysing situations encountered from an educational point of view and subsequently readjust interventions. There is a temptation to attribute responsibility to the child "that one's a horror, not interested, not involved".

For parents

Group sessions for parents have the aim of permitting parents to realise that they are not alone in living with their situation and that there are other families asking themselves the same questions.

They should help them to accept problems they encounter such as those they think will be posed by disclosure. Parents will reassure each other through the sharing of life experiences.

These sessions should be animated by a counsellor. Of course disclosure is not their only aim and other themes may be proposed. Propositions may be at the request of parents or suggested by team members. Team members are privileged witnesses in their work with the families and children, and accordingly observe the difficulties that families are experiencing.

Diverse discussion methods may be employed two common examples being the round table and role-plays. Any method favouring participants' free expression is potentially useful in group sessions.

F. EDUCATIONAL TOOLS

1) Games (34, 48)

Games play a fundamental role in the development of children. Paediatric TPE is generally based upon the use of games; they are powerful vehicles for children's understanding. The game and what it carries with it serve as mediators for the information that we hope to transmit, but also serve to learn what the child knows about or is worried about regarding his illness. Games help children to acquire knowledge and know-how about their bodies, the disease, and the treatment, but also help them "live with HIV".

The game must be able to stimulate curiosity about the body and health, whilst inspiring the will to learn. Games may also be more simply a means of exchange and of communication with children (whether in groups or individually).

Educational games

Each game or educational tool must have a specific aim and apply itself to a specific age group, taking into account the child's development. Games should be used for precise educational intentions and not only according to the tastes and interest of the children. Games need to have a double purpose to really be appreciated and used, firstly to please the child (essential to him), and secondly to help in his cognitive development with respect to his disease.

Educational games may be constructed with the aim of transmitting knowledge to the child about the body, health, health care, so that the child can come to terms with his disease through game. Games may also prepare children psychologically and impart real health education. Amongst the

tools seen during visits to specialised services the "Jeremy and his medications" puzzle and the "learning whilst having fun" card game answer these criteria. Educational sheets are also available that fulfil educational objectives in a very simple fashion (see annexes).

Games in the clinic waiting room

Games in the consultation waiting room give pleasure and joy to children in an environment that the sick child may perceive as hostile. They also reduce anxiety. Games are a useful auxiliary tool for health personnel because of these positive effects upon the child's mood and the impact upon treatment.

Games as a means of observation of emotions, worries and the child's experience

Games are natural activities for children, the symbolic function of games (according to Piaget) permits them to recreate and reproduce past events, past situations, and the emotions experienced in their "real" lives. They may recreate their own attitudes or those of their parents or any other person. They reproduce, play at being, imitate.

Through games one may explore the feelings and emotions being experienced by children. Children with or without toys will play. Any object can be used, even the most simple. Children do not need elaborate toys to have fun or for educational purposes.

For example, when a child plays with a doll, we can ask him to demonstrate or to tell about the chapters of his life. The counsellor does not participate in the game as such, but observes, follows, makes comments, and asks the child questions to be sure that what he observes or hears is what the child is trying to communicate or imply. Similarly, communication techniques may keep the child playing and prolong the game:

- Repeating the child's comments without interpretation,
- Using open questions so the child expresses his feelings (how were you feeling that time when... ?)
- Evaluating the child's perceptions, knowledge, and understanding concerning his health or disease ("tell me, why did dolly come to see the doctor?")

2) Stories (48, 49, 50)

Stories are commonly used in health education in general and are of proven efficacy in children. The child may identify himself in one of the characters. The parents may also be indirectly involved if

present when the story is being told. The context of the story must be close to the reality in which the people are living, there should not be any "intellectualisation", nor is there need for logical, structured or scientific information. On the contrary, the story have links with life experience and reality, as such abstract ideas can be expressed in simple, concrete, everyday terms. In this way stories permit children to discover and learn themselves, through the tale. Stories like "Bekhi" proposed in annex work if:

One ensures that the children can understand the language used

The story is funny, exciting, has scenes of action.

The child is able to identify with the characters.

The subject is important to the child.

The story is pertinent with respect to the lives of the reader.

3) Drawings (24, 34, 51)

Drawings allow us to explore the child's emotions, his representations and his worries. Drawing can be a powerful educational tool. Children may in this manner communicate their emotions without having to verbalise them. They can thus "open secret drawers" that the counsellor may take into account later on. In addition, most children at all ages love to draw.

To do drawings on the themes of "health" and "family" gives the child an opportunity to express himself. One may then ask him to talk about the drawing and to explain the images so as to learn about his worries at that point in time (which may or may not have to do with his illness or treatment), his life and his family environment. The carer must always be in active listening mode and ask open questions.

To make the child draw the virus permits him to distance himself from it, gives it meaning, and gives him the impression of mastery over it. The virus is always drawn as a spiky ball but the important question is where the child thinks it is physically and how the child imagines such an "object" circulating within his own body.

In annex, an article on the use of drawing in therapeutic education.

4) Tools proposed in a Therapeutic Patient Education program

Having different tools is precious help for carers. These tools have been used and validated, and have demonstrated their importance and pertinence. The recommended ages are only rough guides and should take into account the individuality of the child and his personal development. Any tool used in partial disclosure may equally be used for complete disclosure.

PURPOSE	TOOLS	RECOMMENDED AGE FOR USE		
		3 - 6 years	7 - 9 years	10 - 12 years
Educational Assessment	The "Jeremy and his medications, how do you do it?" puzzle			
Partial Disclosure + Educational Assessment	Educational sheet: "Health and Illness"			
	Use of drawings about health			
Partial Disclosure	The story "Bekhi"			
	Card game "learning whilst having fun"			
	Educational sheet: "the secret"			
Complete Disclosure	Educational sheet: "transmission of the virus"			
	Educational sheet: "daily life"			
	Educational sheet: "the epidemic"			

G. EVALUATION

1) Evaluating the program

It is easily conceivable to follow indicators so as to evaluate the program and its success such as:

- The proportion of children 10 years old and older knowing their status (goal close to 100% of course),
- The proportion of children 6-10 years old having started the process of disclosure (ongoing partial disclosure)
- The proportion of children attending their appointments (attendance rate: number attended /expected number)

2) Individual child evaluation and follow up

The child is continually evolving; one cannot rely upon a single evaluation. Thus the evaluation process is continual.

One may envisage the measurement of acquired knowledge about the disease and its treatment immediately after education. However, it is important to regularly re-evaluate knowledge at regular intervals.

Improvements in signs such as anxiety may be observed as indicators of emotional improvement. Adherence to treatment can be an indirect indicator of family functioning.

In terms of behavioural aspects the child's gradual taking of responsibility in his treatment can be observed. As mentioned above, a "balanced" parental attitude is one that is neither overprotective, nor imposing too much responsibility on the child.

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ANNEXES

Annex 1 : Child development ; cognitive and psycho-affective development, the child's perceptions of disease and what carers should do

Annex 2 : Definitions of disclosure

Annex 3 : Questionnaires used for parents

Annex 4 : "Jeremy and his medications, how do you do it?" puzzle

Annex 5 : "Learning while having fun" card game

Annex 6 : The "Bekhi" story

Annex 7 : Drawing health : an instrument for establishing an educational diagnosis

Annex 8 : Educational sheets from Brussels

Annex 1 : Child development: Cognitive and psycho-affective development, the child's perceptions of disease and what carers should do⁹

Age < 18 months

Cognitive and psycho-affective development, perceptions and impact of the disease

The child does not know how to communicate or to express what he feels. We do not know much about how he lives with his disease.

The child does not understand the disease, he lives it.

The child can feel pain. His suffering will be expressed through crying and agitation. If pain continues the child will avoid looking at adults. The child can quickly go from crying to laughing as soon as the pain stops.

What carers should do

Carers cannot make the child understand the reason for treatment nor the physical manifestations of disease.

Facilitate the continual presence of a parent or main attachment figure.

Be attentive to, evaluate, and treat pain.

Put into place all means likely to reassure the child. Take into consideration that he cannot express himself in words. Look at him, smile at him, speak to him and wrap him up physically.

⁹ Sources : N° 8, 9, 13, 15, 22, 53, 54, 55

From 18 months to 3 years

Cognitive and psycho-affective development, perceptions and impact of the disease

The child perceives the disease as an external constraint that he can oppose. He can react strongly to the consequences of his illness and the disruption to his routine.

The causes of the disease are invisible and causal links are not understood. For example, pulmonary physiotherapy is interpreted as stopping the child from playing and not clearing his lungs.

The child does not anticipate future deterioration or treatment.

With the progressive acquisition of language, the child becomes capable to express pain in other ways apart from crying, although the latter is still the main mode of expression.

When disease occurs early in the child's life he lives with it without asking questions, it's like "wearing glasses".

Death is linked with sleep and the child thinks that dead people are going to wake up. Fear of separation from his parents.

The child's thoughts are very egocentric, everything revolves around him.

What carers should do

Install routine and ritualise treatments

Respect the child's routine as much as possible

Explaining the disease is not useful, as the child does not understand what is happening to him. Adult explanations are irrelevant to his understanding and perception of disease.

Put into place all means likely to reassure the child

Give the child as much autonomy as possible to take away as much as possible the constraints of disease. Give him choices such as "would you prefer a story before seeing the doctor?"

Help parents to resist the control the child tries to impose upon them; parental anxiety and guilt often express themselves through excessive permissiveness. Saying "no" is necessary in certain situations as for all children of this age. The psychological development of the child will be harmed if all is permitted because of his illness.

Be attentive to, evaluate, and treat pain.

From 3 to 6 years

Cognitive and psycho-affective development, perceptions and impact of the disease

The child is able to name his external but not his internal organs. He sees his body from the outside and is unable to represent the interior.

The child's vision of his disease is fragmented (limited to painful areas) and from time to time (when he has pain).

The child is not susceptible to rational explanations and is satisfied with vague notions.

From 3 to 4 years the child has animist thoughts, things around him are alive and "that chair hurt me". There is a causal and artificial reason for everything: for example, the world is man made, and "the mountains where the man put the stones" or the "river that the man filled up with water". A period of incessant "why".

The child has no notion of time and lives his disease from day to day. He does not project into the future.

When disease occurs early in the child's life he lives with it without asking questions, it's like "wearing glasses".

The causes of disease are invisible. The child does not think in terms of "what, why how" but will simply associate disease with any other phenomenon "X". This is in no way trying to look for a cause or to understand what is happening to him. The developmental stage is that of magical thoughts and no causal links are established. He is a victim of events that master and triumph over him. He may feel guilty about his disease and feel that he is sick because he did not obey, that he was naughty, or because he didn't eat all his dinner. He thinks that his disease is punishment for his bad behaviour or thoughts.

When we tell the child that he "has to take treatment to stop getting sick" he retains the "has to" and cannot anticipate what "getting sick" means. From four years of age he may understand preventing symptoms that he has already experienced; "take the horrible medicine so you don't cough any more". The child does not understand the medical care and follow up. Being weighed, measured and having blood taken may be interpreted as menacing and disturbing acts. The child confuses fear and pain and expresses them in the same fashion (crying).

The child thinks of death not as something definitive but as a temporary separation. Given his powerful imagination, the child may feel responsible for the deaths of others.

The child's thoughts are egocentric and he only can envisage things from his own point of view. If he knows he has HIV he thinks that everyone else knows it, can see it and is aware of his disease.

The child tries to please the parents and carers. Having been brought up to respect adults, he generally adheres to what he is told by them. He is generally confident and obeys without doubts. This is even truer when there is a good quality parent-carer relationship and when the parents adhere to their prescribed treatments.

An action is good if satisfying a felt need or rewarded and bad if punished.

From 3 to 6 years (continues)

What carers should do

Install routine and ritualise treatments and respect the child's routine as much as possible

Reassure the child and relieve him of guilt if necessary.

Take away the constraints that the disease represents by giving the child a sense of autonomy. Offer him choices such as "would you prefer a story before going to see the doctor?"

Use imagination to transmit ideas about the disease and treatment (stories).

Respect the child's imagination and lack of concept of limits that are helping him to grow. For example, never say to a handicapped child "you will never be able to walk" when he talks about the desire to run and be a sportsman.

Give information relevant in the short term, as at this age it is difficult to think more than 3 or 4 nights ahead.

Establish a carer-child relationship. Even if the child does not understand everything he should be the centre of the therapeutic relationship.

The adult's word is "truth". Do not lie to the child.

Help parents to resist the control the child tries to impose upon them; parental anxiety and guilt often express themselves through excessive permissiveness. Saying "no" is necessary in certain situations as for all children of this age. The psychological development of the child will be harmed if all is permitted because of his illness.

From 6 to 9 years

Cognitive and psycho-affective development, perceptions and impact of the disease

The concepts of being sick and having to take treatment are accepted. The child can understand the disease affecting him. Schooling helps the child to organise his thoughts and his reason.

It is useless to speak of the concept "for the rest of your life" that does not yet make any sense to the child. Shorter term temporal landmarks may be given that have meaning such as the fact that next Christmas he will still be taking his treatment or next holidays, or on his next birthday etc.

Up until around seven years of age the child will continue to be marked by colourful and representational thought processes. "Will the little beasts in my body wake up while I'm asleep?"

The child has some capacity to imagine internal human organs. However, he thinks that the brain is only for thinking and his arms and legs move on their own.

The child's desire for mastery and understanding ensure good exchanges with his environment and help him understand what he is going through. The child starts to question his surroundings (parents and carers).

The representation of HIV disease is complex for asymptomatic children. As the child cannot feel the HIV in his body and has no symptoms the disease lacks landmarks. It is difficult for the child to understand his disease and treatment given the abstract nature of the disease. Treatment may be problematic.

Significant protective factors predicting the way the child will adapt to disease in adolescence include; the acquisition of self-esteem through social activities, games and sports, putting some distance between himself and the family (investing elsewhere), and notions of autonomy.

The first real fear of death is felt. The child understands three very important things about death; it is universal, irreversible and its cause is not linked to (imaginary) thoughts.

What carers should do

Give the child information about his disease, as he needs landmarks. Analogies should be used to explain bodily functions that he can understand; the heart is a pump, the stomach is a breadbasket, cells are like bricks.

Bring up the potential gravity of his illness whilst keeping up realistic hopes.

Without provoking them, answer or encourage the parent(s) to answer the child's questions about death. Encourage the parents to disclose.

Help the child to get organised in his daily routine, integrating the disease.

It is important to consider the child as an active interlocutor.

Promote contact with other young people with HIV disease if the child so wishes.

From 9 to 12 years

Cognitive and psycho-affective development, perceptions and impact of the disease

Abstract thought occurs around 10 to 11 years of age. Therefore the mechanisms (physiopathology) can be understood.

Concrete thought. The child can understand causal links and that several causes can act synergistically to have a specific effect.

The child can describe and explain the symptoms of HIV disease on different organs and their function. He can express hypotheses as to the causes of the disease.

The child is more and more conscious of the control he can have over the disease. He has desires of mastery and of autonomy that allow rich exchanges and the slow and progressive taking of responsibility.

The representation of HIV disease is complex for asymptomatic children. As the child cannot feel the HIV in his body and has no symptoms the disease lacks landmarks. It is difficult for the child to understand his disease and treatment given the abstract nature of the disease. Treatment may be problematic. Divisions in representation of his disease and denial with respect to his disease complicate the child's care.

If HIV disease limits the child's ability to invest in relationships outside of the family circle then it will affect his acquisition of autonomy.

Significant protective factors predicting the way the child will adapt to disease in adolescence include; the acquisition of self-esteem through social activities, games and sports, putting some distancing between himself and the family (investing elsewhere), and notions of autonomy.

Time spent with friends is a source of pleasure.

The child gradually becomes conscious of the chronic nature of his disease through daily treatment and the repetitive aspect of his care. Ideas of the temporality and disease "for life" that can't be cured are only completely understood at around 15 years of age.

What carers should do

Give the child information about his disease. From around 11 years of age we can explain in detail and using physiology. Illustrations of the body should be used to explain physiological mechanisms from around 11 years of age.

Bring up the potential gravity of his illness whilst keeping up realistic hopes.

Encourage the parents to perform disclosure if it has not been already done.

Help the child to get organised in his daily routine, integrating the disease.

Encourage investment in activities outside of the family circle. Promote contact with other young people with HIV disease if the child so wishes.

It is important to consider the child as an active interlocutor.

Provide temporal landmarks that make sense such as "to enter into adult life"

Annex 2 : definitions of disclosure in HIV / AIDS

2 types of disclosure may be considered: partial and complete disclosure. Both are strongly influenced by the children's age and psycho-cognitive-affective developmental stage, as well as by parents' reticence to speak about HIV/AIDS. The two kinds of disclosure are to be considered as a continuum and are part of the progression in providing information to the child.

Partial disclosure

Partial disclosure is defined as fragmented information that never divulges the name of the disease despite providing elements and landmarks of what is happening in the child's body and the need to take treatment. It is simply and prudently initiating dialogue with the child.

"Partial disclosure has the advantage of being a compromise between the necessity for the child to have a minimum of reference points of what is going on in his body, and the concern at the same time to show consideration for parents' reticence to name the disease early" (28).

Complete disclosure

Complete disclosure consists of naming the disease and the virus. But it is much more than that as:

- It means also evoking the modes of transmission and thus will lead to discussions about the family history as the child will ask "how did I get sick and why?>>
- It is accompanied by discussion upon sexuality, as the child needs to take responsibility with respect to the risks of transmission.
- It often triggers rapid maturation in the child giving him the possibility and the capacity to confront the difficulties he faces as a result of his disease. The child will become more autonomous with respect to his parents, displaying a will to look after himself.

"to know the name of his disease and the connected elements of his life becomes an indispensable need for the child to be able to grow and structure himself whilst sharing the therapeutic program" (28).

Annex 3 : parents' questionnaires

The Robert Debré hospital in Paris uses these two questionnaires, which are inspired by the recommendations of C. Tourette-Turgis (52). The first prepares parents for treatment and evaluates their capacity to manage treatment. The second anticipates and tries to minimise adherence problems.

1) Parental adhesion to their child's ARV treatment questionnaire. The parents answer yes, no or I don't know to each question.

- I think the treatment is good for my child
- I don't like giving my child his treatment
- I'll give the treatment because I have to but I don't like doing it
- I believe this treatment will help my child to be in better health
- I am not ready to give my child this treatment as he is currently well
- I am afraid of what I have heard of these treatments
- In my community we do not give treatments to children who aren't sick

2) Parental questionnaire evaluating feelings of their capacity to manage ARV treatment in their child. The parents answer yes, no or I don't know to each question. More

- I think that I will manage to keep up with the rhythm of the doses taken in my child's treatment
- If I have problems with my child's treatment I will ask the educators, nurses, and doctors for help
- I think it would help if I could speak with other families giving ARVs to their children
- I don't feel capable of giving all these medications to my child
- It would help me if my child participated further in taking his drugs
- I feel bad about the idea of forgetting my child's treatment doses

Annex 4 : The Nantes "Jeremy and his medications, how do you do it?" puzzle¹⁰

The particular interest of this game is that it allows us to work on several themes. These themes include education for starting treatment, adherence to treatment, and educational, social and familial assessments. The playful character of the puzzle incites discussion over and above the simple fact of taking one's medications. The carers are then able to furnish necessary explanations and information. According to those that use the game, "revelations" are often brought to light, such as a child that eats alone, or goes to bed without stories or a goodnight kiss from his parents. It is a way of evaluating the family and social environment and possibly the mode of communication between the child and his parents.

Educational objectives

This game may be used in initial learning during treatment initiation but also during changes of drug regimens.

The child and parents should be capable of:

- Recognising the drugs to be taken

- Take them correctly (how and when)

It also allows one to:

- Perform an educational, social and family assessment, which aims to bring out previous knowledge, evaluate needs, evaluate the child's preoccupations, and to identify obstacles to treatment.

- Perform a learning assessment (follow the child's educational progress)

It also leads to working on the following secondary but important objectives:

- To bring the child and the carer closer together through the child talking about his life and unveiling his day-to-day existence. To build the relationship with the child.

- To de-dramatise treatment and to improve how treatment is experienced. Some children and parents have the impression to live only for and through their medical treatment. The game shows them all the day-to-day activities of a person on treatment, and demonstrates the actual influence of taking medications.

¹⁰ Designed by Eliette Vinet, paediatric nurse, Hotel-Dieu University Hospital, Nantes

Target audience:

The game principally targets children but the parents also participate. They need to be involved in the information their child is receiving. The parents-children-carers exchanges allow the carer to be sure that the messages have been well understood.

This game is particularly well adapted to MSF type contexts as both illiterate parents and children may participate, and the fact that parents learn at the same time as the child.

Age: In Nantes around 6 to 7 years as it does not require abstract thought.

Time needed to do the puzzle: 30 minutes minimum

Number of sessions: 3 to 4 sessions are usually required to achieve the educational objectives although this is very variable.

Description of the game:

The game is based upon playing card-sized cardboard cards. The cards have different drawn images (20-30¹¹) on them and the child selects those that best represent his daily life.

The drawings show:

- ARV treatment: drawings of capsules, pills, syrup, drug bottles and boxes
- Different daily moments linked to treatment such as waking up, breakfast, lunch, after school snacks, dinner and bedtime. These moments are represented by symbols, for example an alarm clock for waking up or dinner plates for meal times, or the moon for bedtime, etc.
- Family, lifestyle, food, school, leisure time and holidays are some of the themes represented. Thus there are drawings of activities children playing football, working in the garden, brushing their teeth, riding a bike, listening to music, writing and doing homework; but also family life images such as the family meal, the parents together alone, a pregnant woman, a family walk, etc.

The child chooses the cards himself and then it is up to the carer to ask questions and to direct the discussion from this departure point. The secrets and confidences must be allowed to surface on their own and questions should be asked without giving the impression of being inquisitive.

¹¹ The drawings on the cards have evolved and been enriched by the children's suggestions over time

The child projects himself into the situations represented by the cards and then talks about the what has happened during his day, the bother it is to take the medications, gives information as to how he perceives his illness and how he and his family live with his disease.

Practical use:

Depending on the subject that we are aiming to explore with the child, the cards that the child will have to choose from may be pre-selected showing specific themes. But when we are trying to conduct an educational assessment (that is to know what the child knows about his treatment, how he lives with it, what his representations of his disease are, what he is worried about and what his family environment is like) we will present him with all the cards.

Example using the game for ARV treatment education:

Initial session:

- 1) After the child has chosen the cards among those representing his usual daily activities, we arrange them in chronological order from morning to night-time. When we want to talk about treatment, we ask the child to choose the images that show what he does during his day. Sitting either on the ground or on a table we put them one under another. If he knows them, we ask the child to tell us the times that he takes his medications, if not we involve a parent. Then we ask the child about the regularity of his daily activities and try to learn more about what he does on "non classical" days, for example when there is no school.
- 2) Next, we bring out the cards that represent ARV treatment. If required we go over the conditions of treatment, for example taking the treatment away from mealtimes.

During the 2nd session we repeat the above activities but we give the child more freedom to put the cards where he wants to see if he has understood when he should take his treatment and which doses. This is finally a learning evaluation of the taking of treatment.

Practical constraints of the game's use:

When all the cards are displayed the number and the surface area required may render the game impractical.

Annex 5 : The Nantes "learning while having fun" card game¹²

This game has been simplified to a card game so it may be used in resource poor settings. It was originally played interactively using a CD-ROM.

The child progresses in his knowledge of the disease through a mix of "information" and "question" cards.

Teaching objectives:

The specific teaching objectives are the following:

- To know where the lymph nodes are
- To say what the role of Cd4s is
- To explain how the virus lives in the body
- To say what the medications are for
- To say what the blood tests are for

Type of disclosure:

This game is particularly well adapted to the process of **partial disclosure**. The aim is thus that the child establishes reference points with respect to his disease and treatment WITHOUT EVER NAMING THE VIRUS OR THE AIDS DISEASE.

Children that know their status may also want to play this game to refresh or enrich their knowledge.

Target audience:

Children 7 to 8 years and older. At this stage of concrete operational thought the child understands the causes of the disease, the terms microbes and germs, and is capable of representing the insides of the human body.

How to use the game:

The child may play this game repeatedly; he will not understand everything the first time around. The carers should ask him if he wants to play it again, particularly keeping in mind that information that appears to be assimilated at a certain time in the child's life may be put in question later, and thus should be revisited.

¹² Design: Lydie Gilardeau, paediatric nurse, Production: Sylvain Dibon, Hotel-Dieu University Hospital Production Unit, Nantes.

Game duration:

The game comprises 19 cards of which 13 are informative and 6 are "question" cards. Around 15 to 20 minutes are required to play the game during a séance.

Precautions for use:

This game was conceived for use in France, as such it needs to be assessed and potentially adapted before use with children in countries where MSF intervenes. The texts and images may not be appropriate to the culture or audience in some places. It is advised to perform the following steps before use:

1. The health educators should play the game amongst themselves to discover it, get used to it and see whether modifications should be envisaged.
2. The very European images and words used in the game that are potentially nonsensical to African and Asian audiences should be critically reviewed according to the target audience.
3. A local artist may be identified to reproduce in colour appropriately modified images.
4. If modifications are made, it is important to keep the practical A5 format so as to facilitate its use and minimise the room needed to play.

Annex 6 : The "Bekhi" story¹³

This story was originally created on CD-ROM for interactive use and has been restructured as a book of images for use in resource poor settings. The little lion that is the hero of the story also has a disease and must take treatment every day. The story is very similar to that of a HIV affected child including similar negative themes such as a chronic illness, secrecy and taking treatment every day that isn't nice to take. At the same time it also talks about hope for the future and has the classic "happy ending".

Teaching objectives:

The therapeutic and teaching objectives of the story are the following:

- That the child acquires a sense of meaning of his situation and his disease; the symptoms, treatment (not always nice) to be taken every day, secrecy, deaths of people close to him,
- To initiate discussions with the child about what he is going through and what his preoccupations are,
- To help the child understand what he feels,
- To sooth his worries.

Type of disclosure:

This game is particularly well adapted to the process of **partial disclosure**. The aim is thus that the child establishes reference points with respect to his disease and treatment WITHOUT EVER NAMING THE VIRUS OR THE AIDS DISEASE.

Children that know their status may also want to hear or read this story.

Audience:

Children 4 years of age and above

How to use the story:

The story may be used in either individual or group consultations.

Both the educators and the psychologists use the story in Brussels each to his own ends (therapeutic or educational).

¹³ Design: St Pierre University Hospital Paediatrics Department, Brussels, Media animation, asbl, www.media-animation.be

The story may be read all in one go or split into parts according to individuals. There is no point in going on if the child is tired and losing interest, it is more prudent to stop and to offer to recommence at the next consultation.

Children may ask for the story to be told over and over again, in which case it should and the carer should let himself be guided by the child. Perhaps one part of the story interests the child particularly and the child will ask to go back to it and to skip over the other parts.

When telling a story one should:

- Use expressive speech and play different characters to make the story "truer" and more attractive. Tone and voice intensity should be varied according to the passages, emotions and action.
- Seek to implicate the children regularly, asking them for example "what do you think will happen next?". The involvement of the children maintains their attention, but also demonstrates whether they identify themselves with the characters and what they understand about the story. Furthermore it is a form of educational assessment.
- Stop regularly to give the children time to think about the story and its meaning.
- Let the children ask any questions they want.
- Help the child to make connections between the story and their own experiences without rushing them, letting it come.
- Get parents involved. They may read the story, if they know how to read, and their presence will mean that they hear the questions asked by the child, which may act as a catalyst or developer for future discussions.

Duration: 20 minutes minimum

Precautions for use

This story, despite being written in Belgium, does not pose any problems for use in MSF programs. Given that it is about animals it is culturally acceptable in all countries and cultures.

The only precondition for its use is translation into local language so that carers can tell the story in their own language without worrying about translation and so that older children can read it on their own. The tool then becomes even more attractive as it combines learning to read and learning about the disease.

Annex 7 : Drawing health: an instrument for establishing an educational diagnosis? (51)

By Béatrice Ginières¹⁴

Graphic representations have always played a major role in psychological work with children, they can be used as an evaluation method, a method of studying personality or even as a way of relationship mediation.

Drawing is a natural method of expression and a mediator facilitating communication for most children. It is also a space where they can project their feelings and express their view of the world, by making spontaneous comments or answering adult questions. This gives us good reason to believe that drawing can be used to help us establish an educational diagnosis.

Key words: patient education, asthma, image of health, needs survey, educational diagnosis, multidisciplinary, France

Educational diagnosis

In the first phase of the educational diagnostic process we conduct one or more interviews to identify the patient's needs. Once the broad spectrum of information has been obtained, the team can meet to evaluate the learner's characteristics and potentials and develop a personal plan that is most likely to motivate them to learn.

If the interview is just a verbal exchange it can be rather brief for various reasons: the child's age, inhibitions or, more generally, problems with answering the questions they are asked *"I would like to talk about you, about your asthma, but also about what you do and what you like"*.

Yet, this meeting is essential to give the child an active role, at the centre of the educational process. Drawing health actually facilitates and enriches verbal exchanges because it will be used as a basis for the exchange process.

Drawing health

The child is encouraged to draw two little people: one Healthy and the other Unhealthy. They have two white pieces of paper (21 x 29.5 cm), crayons, felt tips, a pencil, a pencil sharpener and a rubber. The child is free to use one or two sheets of paper, to choose the order of the drawings and the way round the sheet of paper is used. When they have finished the educationalist then asks the child to talk about them by showing the difference between the two people and how they show the difference between them. The educationalist takes notes of the child's spontaneous comments, of the order of the drawings, of the answers to the two questions asked, of the sex of the little people and of their own questions.

There are two requirements for the theme of health, it needs to remain centred on the reason for the meeting whilst also being sufficiently flexible so that the child can communicate freely. A survey carried out by the French National Institute for Educational Research¹⁵ on children's representations of the concept of "Health" showed a polyvalent image of health, a term which was widely known by five-year-old children.

¹⁴ Psychologist, Centre d'Asthmologie du Col des Maroux, F-09000 Foix. Tel: 00 33 561 65 75 08

¹⁵ Les représentations du concept "santé" chez l'enfant, CFESINRP study, 1984/1986

Health drawn by asthmatic children¹⁶

Children communicate a very varied view of 'health' in their drawings.

The 'Healthy' little person has a body in glowing health; sturdy, well-muscled, emphasised by clothing details. The surroundings also play a part in this positive image, there is sunshine, flowers, nature.

The children's comments concentrate on the physical form, the affective nature of the feelings suggested (being happy). The Healthy little person is systematically represented standing up in a position that symbolises physical exercise, the children also talk about this frequently. The children give importance to games, physical activity is often a characteristic of good health.



Girl, 9 years 4 months. "He is standing up, he's playing football, he's isn't wearing many clothes"



Boy, 8 years 1 month. "The person is happy, the sun is shining, the sky is blue"

The children often talk more when they are describing the Unhealthy person, as if this situation needs to be justified in relation to 'Healthy' which would be the normal, usual situation. More numerous comments, redundant, but they also express feelings about the physical and affective nature.

Unhealthy is not a synonym for ill, although as children get older the references to the medical world tends to become more systematic. The comments are more extensive; an illness, symptoms, a pain, a wound, hospital, the doctor, asthma, and so on.

Unhealthy is connected with not being allowed to do things (not going outdoors), impossibility (play); it deprives the child of many of the most important things in life: playing, going outside, friends and so on.

Drawing health: a space for projection

The drawing only has meaning for the artist so, by asking questions, the educationalist will seek to learn and clarify the hints that the child will give. Several points should attract our attention - the child's remarks from the time the instructions are read to them will show the effects of our request. They may spontaneously tell us things, make associations with their personal experience,

¹⁶ This was a study of drawings by forty-four asthmatic children who were staying at the Col des Maroux Asthma Centre, France

start a dialogue. We should offer reassurance when they hesitate, find it difficult to express themselves or get bogged down.

The order of the pictures very frequently agrees with their identification with the subject. The order chosen by the child can reveal hesitations which the educationalist will be able to verbalise with them.

Even though the term little person (*bonhomme* in the French), is often interpreted as masculine, the sex of the person drawn is often a function of the sex of the child doing the drawing. However, in some cases the child draws two people of different sexes. This process has been used either to reinforce the identification of the person of the same sex as the child, or to highlight an important element connected with the illness. So this boy drew a woman having an infusion which represented his mother who died during an acute asthma attack.

"What makes the difference between the Healthy Person and the Unhealthy person?" By describing each drawing the child will be telling us about their own experiences. To produce their drawings they will be subconsciously referring to all the images of the 'other' who populate their spirit. The interior perceptions of the human image will be added to the external perceptions.

"Do you feel more like this person here or more like that one?" The identification is often directly invoked, the child says "I" when talking about their drawing. With this question the child must make a choice as it shows that he has put something of himself in each of his drawings.

Most of the children say that they are healthy, a response that is frequently associated with further explanation of the current character of this feeling ("right now", "at the moment"). In other cases the child says that they cannot choose ("between the two", "a bit of both").

All these answers and the comments that reflect identification with the drawing of the unhealthy person should be talked over with the child. Does he understand the chronic nature of his illness? Does he feel disabled when performing activities of daily life? Does he feel fitter at some times than others?

The educationalist's interventions will direct the interview, re-centering it on the themes that they want to discuss with the child, helping the child focus their thoughts.



Girl, 9 years 5 months. "He stays inside, he doesn't play with toys which are too dusty, he takes pills"



"He does what he likes, he can play with what he wants, he can go outside"

"He does what he likes, he can play with what he wants, he can go outside"

Drawing health: an instrument for establishing an educational diagnosis?

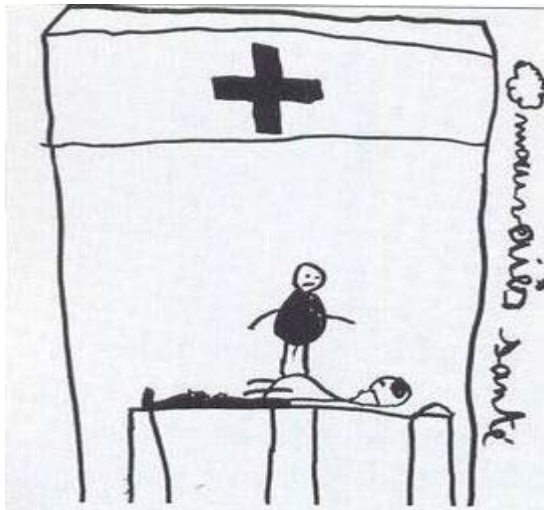
Yes, insofar as the drawing is going to help us gather information about the child. It is a means given to the child so that they can share their own ideas with us, but is not systematic or obligatory.

Yes, if the drawing is used within the framework of relating to the child, having a conversation where the child can talk about the drawing, guided by the educationalist's interventions.

Yes, if the elements gathered are related to the rest of the data available to the other contributors (doctor, nurse, relations etc.)

Yes, and drawing health can be used in addition to the educational diagnosis, throughout all the educational process; symbols can be reused in the learning phase, drawing can be a point of departure for a teaching method.

Other questions remain; can it be an indication of the child's general development? Can it be used to measure the effects of education? There are only subjective answers to these questions at the moment, directly influenced by the enthusiasm that this experience brings.



Boy, 9 years. "He felt bad when he was running, he goes to the doctor for treatment"



Boy, 7 years 3 months. "He's miserable, he's got chickenpox."



Boy, 9 years 2 months. "He's got a runny nose, he's not happy"

These 13 teaching cards gradually give the child necessary information about his disease and treatment. They are used in logical and chronological order. They are useful in the passage from partial to total disclosure and bring up many questions that are essential for the child.

Teaching objectives:

The teaching and therapeutic objectives are the following:

Explain the concepts of health and illness (card 1)

Explain the immune system, how the disease attacks immune defences and how the treatment acts against the virus (cards 2 to 8),

Give meaning to older children about the situation they are going through with respect to their disease (cards 9 to 13).

Type of disclosure:

These cards are adapted for use in both **partial and complete disclosure**.

The cards numbers 1 through 8 explain disease landmarks without naming the virus or the disease. The remaining cards are to be used once disclosure has been performed and bring up other objectives and themes such as secrecy, modes of transmission, condom use and feeling alone in the world.

Target audience:

Children from six years of age, although the references to body landmarks only become obvious from 7 to 8 years. The cards may be used until complete disclosure at pre-adolescence (around 10 years of age) and beyond.

The cards may be also be used by parents (alone or with the child) and siblings.

¹⁷ Design: St Pierre University Hospital Paediatrics Department, Brussels, Media animation, asbl, www.media-animation.be

How to use the cards:

In Brussels the cards are available to be used by all health carers and thus employed from the doctor to the educator during consultations. Each team member follows the child's evolution and team meetings help to anticipate which cards should be brought up in the following consultations.

If the child is up to the card number 6, the carer will systematically go back over older cards so as to evaluate previous teaching, what the child has retained and assuring himself that it is appropriate to go further in the current consultation.

The carer asks the child questions about what he sees on the cards and what he understands. He then corrects, adds, and explains using analogies the child will understand. "the human body is like a house made of bricks; oxygen is compared to water needed to make the bricks and platelets fill the holes in the house".

Duration:

Highly variable. Getting through one card may require 3 or 30 minutes depending on the individual. The cards are also variably complicated and some need more explanations and time spent on them than others.

A carer can "get through" four or five cards in the hour of consultation time which is the maximum before the child loses concentration.

Precautions for use

The cards give relatively complicated explanations on subjects such as immunity and HIV treatment. The explanations include speaking about DNA, different classes of ARVs and their modes of action, for example. The complementary explanations required are complicated and do not necessarily help much with respect to the treatment to be taken. Other cards explain the immune system in a simpler fashion. All the same it seems logical either to use them all or not at all given their logical and chronological progression. Given this, the card game developed in Nantes seems to correspond better to children's cognitive stages and also is globally easier to use for educators who have to explain to children their disease and how treatment works. It is important to remember that not all health educators have a medical background.

The cards proposed below are selected as those that are independent of knowledge presented in others and bring something to the child's education not proposed in the other educational tools in these annexes.

Each card has on one side an image and on the other the teacher's manual and notes for the user :

Card	Explanations
N°1	This card helps to perform an educational assessment of perceptions of health and illness
N° 9 and 10	The number 9 and 10 cards are used together. After complete disclosure these cards help to reassure the child that he is not a danger to others and to work on his real, imaginary and erroneous ideas of how transmission takes place
N°11	This card brings up secrecy once complete disclosure has taken place. Even before complete disclosure it may be used to ask the child for example what he thinks about "does everyone have to know that he is taking treatment?" This card is also used with parents in Nantes to bring up the question of secrecy.
N° 13	This card helps to bring up issues such as "not being alone in the world" and the progress in treatment.