

“The Medication always Reminds Me”. Living with Perinatal acquired HIV-Children and Parents’ View Points

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Abstract

As a result of the increased availability of antiretroviral treatment, children infected with HIV can expect to live to adulthood and even to have long, productive lives. The aim of this qualitative study was to describe how children aged 8-18 with perinatally-acquired HIV and parents living in Sweden view the child’s overall life, future and medical treatment adherence, and to find out if their views and expectations differ from one another. Data were comprised of written answers to open-ended questions from two questionnaires. The participants were 50 parents of HIV-positive children and 29 children aged 8-18. Data was analyzed with two content analysis approaches. The analysis revealed five categories. Three from children: *A good future*, *Future concerns* and *Challenging to remember medication*, containing five subcategories. Two from parents: *A good future* and *Future concerns*, containing four subcategories.

The results suggest that it is necessary to have tools to help children adhere to medical treatment, including tools encouraging dialogue between children and their parents.

Keywords: Children; HIV; Parent; Perinatally acquired.

Introduction

Estimates suggest that more than 1.8 million children aged 0-14 [1] and 2.1 million adolescents aged 10-19 are living with HIV worldwide [2]. The majority of these children are born with perinatal acquired HIV (PAH), and in countries where antiretroviral treatment (ART) is available they can expect to live to adulthood and to live long, productive lives [3]. Despite this, 120,000 children (aged 0-14) died in 2016 [2] and 38,000 adolescents (aged 15-19) died in 2017 from AIDS-related illnesses [4].

Present study takes place in Sweden, a small Scandinavian country with a population of 10.02 million, of which 2 million are children aged 0- ≤ 18. As a consequence of international migration, 27% of Sweden’s inhabitants are foreign-born with a variety of nationalities [5]. The prevalence of HIV is currently estimated at 7,000 individuals, of which approximately 150 are children aged 0- ≤ 18. Of those diagnosed, almost all were foreign-born and were infected with HIV before arriving in Sweden [6]. A majority of children and young people are reported to have been infected through mother-to-child transmission [6]. All children living with known HIV infection in Sweden have access to medical treatment [7]. The organization of care varies and children can receive medical treatment at pediatric clinics, infectious disease clinics or both.

In this study, we had access to written viewpoints from children and parents, and strived to understand how children and “parents” consider aspects of life in relation to the

acquired chronic disease. Notable is that the concept parents are used but we are aware that it refers to a variety of adults who are responsible for and legal caregivers of the minor children. In this case parents can be biological, adoptive or foster parents, or relatives such as aunts and/or uncles.

Background

HIV is somewhat different in children than in adults. Children living with HIV normally have much higher CD4 cell counts than adults living with HIV and in some cases children tend to have higher viral loads than adults. In children HIV attacks a developing immune system. As a result, children living with HIV - even those on ART - are more likely than both HIV-negative children and adults living with HIV to get bacterial infections [8]. Children living with HIV who are not taking ART may also experience more learning problems than children in general [9].

UNICEF (2017) reports that mortality among children aged 10-19 with PAH is increasing and that one reason might be related to difficulties with adherence to treatment in this age group [2]. Further, it has been found that treatment sometimes makes children feel worse than the virus itself, which in turn entails children with PAH to have low expectations for outcomes of HIV treatment. Likewise, the secrecy surrounding HIV makes it complicated for children to fit their medication into daily life [3]. Childhood is a time of thoughts of existential questions about life and adulthood. For a child with a chronic disease, as HIV, adolescence can become difficult and be a cause to non-adherence to treatment [4,10].

Adolescents with PAH tend to have difficulties with treatment adherence, and have an increased risk of mortality [1]. Adolescence is a turbulent period in life. Peer and romantic relationships become vital, and with this associated normative challenges such as negotiating and managing relationships, risk-taking behavior and likelihood of sexual activity which could potentially increase infection rates. Therefore, treatment becomes essential. The phenomenon of non-adherence is known from other groups of children and is often related to not wanting to be different from their peers [10,11].

Other factors affecting adherence to medical treatment among adolescents are family structure, psychosocial and socioeconomic characteristics, treatment regimen, and access to healthcare services [12,13]. Another factor is that even after initiating medical treatment, some adolescents are unaware of their HIV serostatus and the actual reasons for taking medicines daily [13]. Non-adherence is also connected to the child's development stage, psychological distress and loss of a parent [14,15]. Since medical treatment is essential for PAH children's survival, the child's adherence to medical treatment is crucial for their parents. Research has shown that parents must be aware of children's barriers to medical treatment adherence and be conscious of which barriers are the strongest [11]. Furthermore, parents' own anxiety related to disclosure [10,16] and stress related to the child's treatment influences adherence to treatment [14,16]. It emerged in an

Indian study that children and parents experience several daily challenges, and many of these challenges are unmarked but relevant expectations [17].

There is a knowledge gap regarding children with PAH and their parents' thoughts about medical treatment and what impact medical treatment might have on the child's future.

The aim of this study was twofold: (1) to describe how children (aged 8-18) with PAH and parents of children (aged 0-18) view the child's overall life, future and adherence to medical treatment, and (2) to discover if children with PAH and their parents have differing views.

Method

Study design

This study used a qualitative approach. Data was gathered using open-ended questions from an earlier study based on two self-administered questionnaires in a Swedish cohort study. The open-ended questions were analyzed using a two-pronged content analysis approach [18].

Data collection

Earlier study: During 2011-2012 a Swedish nationwide cohort study was performed in which children with PAH and their parents were invited to participate. In Sweden at that time a total of 148 children aged 0- ≤ 18 were registered with a PAH diagnosis (INFCARE 2012). All Swedish hospital clinics providing health care to and responsible for the children's check-ups were contacted and informed about the study. Registered nurses or physicians working in these hospital clinics were asked to identify and recruit children and parents who met the inclusion criteria.

Inclusion criteria for children: aged 8- ≤ 18 years, diagnosed with PAH, informed of their HIV-positive status, receiving (medical) treatment, and sufficiently fluent in Swedish to partake in the study. Inclusion criteria for parents: parent of a child aged 0 - ≤ 18 with PAH and sufficiently fluent in Swedish to partake in the study.

Of those fulfilling the inclusion criteria, a total of 82 children aged 8- ≤ 18 and 148 parents were identified and invited to participate, 58 children (71%) and 56 parents (61%) agreed to participate (Table 1). Children and parents who consented were informed by a nurse how to fill in and complete the study questionnaires. Additionally they were informed that children and parents should answer the questionnaire separately and could choose to do that at the hospital clinic or to take it home and return it by mail. If the questionnaire was not returned within three weeks, the nurse reminded the participant twice.

Present study: The qualitative data in present study are written answers to open-ended questions, for an example see appendix 1. Of the total number of participating children (58) and parents (56) written answers were provided by 29 children (50%) and 50 parents (89%) (Table 1), their characteristics are shown in table 2. Data on parent characteristics is limited and information about their HIV status was not collected.

Table 1. Recruitment of participants.

Year 2011-2012	Children aged 0-≤18		Parents	
Proposed number of participants (n)	148		148	
	Children aged 0-7 (n=41)	Children aged 8-≤ 18 (n=107)	Parents of children aged 0-7 (n=41)	Parents of children aged 8-≤ 18 (n=107)
Matched inclusion criteria (n)	0	82	29	62
Accepted participation n, (%)	NA	58 (71%)	19 (66%)	37 (60%)
Gave written comments n, (%)	NA	29 (50%)	19 (100 %)	31 (84%)

The number of children living with PAH was collected from INFCARE, a decision-support and quality registry for Swedish HIV care.

See definition; NA: Not Applicable.

Table 2. Characteristics of participants.

Participants		Children aged 8-≤ 18 (n 29)	Parents of children aged 0-≤18	
			Parents of children aged 0-7 (n 19)	Parents of children aged 8-≤ 18 (n 31)
Age	range	8-≤18	No available data	No available data
	mean	14.5		
Sex	Female	17 (59%)	12 (63%)	24 (77%)
	Male	12 (41%)	4 (21%)	3 (10%)
	Unknown	0 (0%)	3 (16%)	4 (13%)
Foreign origin	Non-European ¹	23 (79%)	No available data	No available data (Presumed to be the same as for children aged 8-≤18)
	European	4 (14%)		
	Unknown	2 (7%)		

Data regarding the legal guardians' age, origin, social background and HIV status was not collected.

¹Asia and Africa.

The length of written answers given by the 29 participating children ranged from 6 to 147 words (average 25 words) and from the 50 participating parents from 2 to 265 words (average 40 words).

Data analysis

Qualitative content analysis was applied using two approaches: *conventional* (inductive codes and category development derived from data) and *summative* (quantifying certain content or words in text) [19]. The analysis processes comprised three phases as shown in table 3.

To ensure trustworthiness, each analysis phase was critically reviewed and discussed until all researchers in the present study reached a consensus [19].

In line with Sandelowski's recommendation, quotations are presented with clarifying comments in brackets to increase the clarity of the meaning without changing the content [20].

Ethics and procedure

Ethical approval was obtained from the Regional Ethical Review Board of Stockholm, Sweden (2011/1120-32). Children and parents who were willing to participate received written information about the study and signed an informed consent form in conjunction with filling out the questionnaire. After the survey was completed, the participant placed it in an envelope. The sealed envelope and the signed consent form were then given or sent to a nurse or researcher. For children under 15, consent was obtained from the child him or herself and from one parent. Children age 16- ≤ 18 do not need parents to sign a consent.

Table 3. Data analyzes phases.

Phase	Analysis method	Description
1	Data set preparation	The handwritten answers to questions were transcribed verbatim, compiled into separate documents for children and parents, and read several times. The three groups of participants;parents of children aged 0-7, parents of children aged 8- ≤ 18, children aged 8- ≤ 18 were analyzed separately. Answers were identified relating to positive and/or negative words and phrases.
2	Conventional	The perceived positive and/or negative words and phrases were marked in text units as answers to the two-fold aim. Codes and categories relating to positive and/or negative descriptions were derived from these text units. Tables were used to give structure to the process of this inductive analysis (see tables 4 and 5 for example). A total of five categories and nine subcategories emerged here. For children, three categories (a good future, future concern, challenging to remember medication) and five subcategories (receiving understanding, keeping healthy, non-disclosure, poor health, forgetting) emerged. For parents, there were two categories (a good future, future concern) and four subcategories (bright, healthy, worrying, poor health). In this phase quotations representing the results were consistently noted, selected and translated into English.
3	Summative	Positive or negative words and phrases were quantified. This was done in order to obtain numeric results to describe whether children's and parents' descriptions differed regarding overall life, future and medical treatment. In total, children gave 39 and parents gave 53 answers that related to positive and/or negative answers. Tables 4 and 5 show the results from this quantification.

Results

Children's descriptions of overall life, future and medical treatment

Thirty-three (85%) of the comments written by children mainly contained words which were negatively phrased. Furthermore, children's comments mostly focused on aspects of their future and future concerns relating to poor health. Challenges in relation to medical treatment were also described (Table 4).

Table 4. Children's descriptions of their overall life, future and medical treatment displayed by categories, subcategories, and number of positive and negative words and phrases.

Categories	Subcategories	Number of times the word is used	Number of positive and negative words and phrases
	Receiving understanding (perceived loyalty)	1	
A good future	Keeping healthy (poor health not visible, survival, good medical treatment, like other children)	5	Pos. (6)
Future concerns	Non-disclosure (living with a secret)	2	
	Poor health (nausea, stomach ache, fatigued, psychological stress headache, dizziness)	22	Neg. (24)
Challenging to remember medication	Forgetting (forget to take medication, do not take medication all the time)	9	Neg. (9)
Total positive and negative words and phrases used			39

A good future

The majority of children wrote in their comments that treatment was something good which enabled them to keep healthy and thereby be like their peers, and have the possibility to live an ordinary life. Furthermore, they comment that in the future it will probably be possible for them, as well as for their non-HIV infected friend, to work with anything of their interest. With effective treatment, the children stated that they had the same future opportunities as all other children and young people. The participating children commented that medical treatment gave them the opportunity to have a future.

"Treatment is good, I believe in it" (9 year),

"I believe I am like all others" (10 year)

"The medicine makes me live a normal and long life" (15 year).

Future concerns

Children wrote that they were worried about living with a lifelong infection influencing their mental and physical health relating to medication side effects, like dizziness, nausea and fatigue.

"Nausea, wants to vomit. Getting headache, everything is spinning around" (16 year).

The medication was in some cases the only thing which reminded the child of his or her HIV infection. *"The medication always reminds me that I have HIV even though I sometimes try to forget it"* (16 years).

Children expressed it was troublesome to live with a secret and worried that their friends would reject them if they found out that they had HIV. *"If you tell someone you have HIV it might result in friends leaving you. I think several people (living with HIV) have that experience."* (16 year).

Children also made comments regarding life, death related to HIV and described being afraid of dying. *"I do not feel that I want to die because I have HIV or to tell a friend"* (14 years).

Challenging to remember medication

Some children wrote that forgetting to take their medication was a way of avoiding thinking about HIV and avoiding the negative side effects of medical treatment, such as feeling sick, nauseous and dizzy.

"Sometimes you just forget (to take the medication) or think about other things. The treatment sometimes makes me feel bad – I feel tired and I just want to go to bed" (16 years).

Parents' descriptions of their children's overall life, future and medical treatment

The majority (79%) of the words and phrases used by parents were positive such as a good and bright future, or a healthy and not worrying future, due to medical treatment getting better and being easier to manage (Table 5).

Table 5. Parents' descriptions of their children's overall life, future and medical treatment displayed by categories, subcategories, and number of positive and negative words and phrases.

Categories	Subcategories	Number of times the word is used		Number of positive and negative words and phrases
		Parents of children aged 0-7 (n 19)	Parents of children aged 8-<18 (n 31)	
A good future	Bright (hopeful, positive, good, optimistic although challenging, life like other children's)	12	27	Pos. (42)
	Healthy (not worrying good medication)	2	1	
Future concerns	Worrying (uncertain, feel very worried)	5	5	Neg. (10)
	Poor health (side effects of medication, mental difficulties in relation to disclosure, stress, anxiety)	1	0	Neg. (1)
Total positive and negative words used in text		20	33	53

A good future

The participating parents wrote that things have changed due to treatment and new knowledge. They felt that their children would be able to have a good future with the same opportunities as their peers.

"We believe she has a future, with an ordinary profession and not a celebrity as she always talks about. To be HIV infected is not an issue in most professions. But our mission is to guide her to an ordinary profession" (Parent of a 13 year old child).

Parents of younger children expressed in their comments that they believed their children had a bright future and the possibility to live like any other child.

"He feels well and I can't see any reason why he won't feel well both physically and mentally in the future. I have a bright view of his future, and he can become whomever and whatever he likes in the future and do things that make him feel happy" (Parent of a 5 year old child).

Parents also believe their children have the opportunity to have whatever profession they want. Some also trusted in God and believed that God would be a guide and protect their children in the future and guide their children to a good life. Further, parents relied on knowledge regarding HIV increasing in society, making it easier to live with HIV.

"I'm sure his future will become better and better due to new and increased knowledge regarding HIV" (Parent of a 16 year old child).

Future concerns

Even if parents had a positive view on their children's future there were some worries. An issue of concern to parents of younger children (aged 0-7) was that point in the future when they would have to disclose the HIV diagnosis to the child. They also see a risk that the child might risk to experience psychological stress in life due to HIV and treatment. How the medication will influence the child and his/her body in the future was also a concern, together with the fact that children sometimes felt side-effects from medication, like dizziness, nausea and fatigue.

Some parents express worries that the lifelong medical treatment might not working the long term, will have side effects, might injure the child and might even cause the child's death.

"Very worried. I don't know how long he can live, I can't stop thinking, may be his body can't handle the medication. His body is full of medicine" (Parent of an 8 year old child).

Some mention that their children have difficulties at school that might affect their future.

"Hoping for the best, but he has difficulties at school and is a bit behind (his friends)" (Parent of a 14 year old child).

Comparing children's and parents' descriptions

Results from the quantification of words and phrases suggest that parents generally seem to have a more positive view of their child's future. Consequently, positive words and phrases are in the majority and could be related to a good, bright and healthy future. However, children's descriptions mostly relate to future concerns such as poor health and the challenge of remembering to take medication. Children expressed concern that living with a chronic condition requiring lifelong medical treatment may impact their health negatively in the future. This was a conflict since they understood that medical treatment was necessary for them to live a long life.

Discussion

Main findings

The main finding of this study are that parents seem to generally have a more positive view of their children's lives and a more optimistic view of their future than the children themselves do. Children worried more than the parents about lifelong adherence to medication.

There are few studies on how adolescents and young adults with PAH and their parents describe thoughts about their children's future [21-23]. In some studies children say that HIV causes them negative feelings both mentally and physically [23], while other studies show that children with PAH seem to have a positive view of life [21,22].

Access to treatment might influence both children's and parents' views of children's overall lives and futures. The results in this study showed that the majority of parents seemed to have a mainly positive view of their child's future related to treatment being available.

One possible explanation for children's more negative views is that they in addition to the disease-specific problems have to deal with existential thoughts that are a part of the normal development of children and adolescents. Having to deal with a chronic illness such as HIV might simply add to the worries and concerns that they share with their healthier peers. Studies have found that the presence of a chronic disease during adolescence can interfere with different developmental stages [24-28]. If the condition is a stigmatizing disease such as PAH and the child has to keep a secret to avoid stigma [22], the stigma might have an impact on the

child's development and be a cause of the child's future concerns. Furthermore, insecurity about the future might be a factor that leads children living with PAH to expose themselves to more risky situations than their peers [24-27,29].

One issue that might be related to risk behavior is non-adherence to treatment. Strict adherence to ART is necessary to enable the child to have a long life [30]. As children sometimes say that they deliberately forget their medication, this might be a reason why they are more worried and express themselves more negatively than their parents. The non-adherence might also be an indicator of disclosure concerns, as treatment is the only visible indication that the child has HIV [10]. Furthermore, children sometimes deliberately forget to take the medical treatment as it is often the only reminder of their PAH [22,31,32] and they want to avoid being different from their peers [31,32]. This kind of non-adherence might also be a factor that causes concern for the future. Likewise, feeling different from one's peers' leads to poor self-esteem, and poor self-esteem has been shown to have negative effects on treatment adherence [30,33,34]. It is crucial to be aware that adherence depends on multiple factors such as the family's social and economic situation and stigma. These factors also influence the individual's future beliefs [35-37].

Children who participated in this study seemed to think that treatment is a burden even if they express a belief in the future in other respects. These findings are similar to findings in other studies [22,23,38-40]. Furthermore, the views of the children's futures differ between parents and the children themselves even if the parents have an understanding of how the children experience health-related quality of life and stigma [10]. The divergent thought regarding the future might be related to the fact that children sometimes prefer to talk about sensitive issues with professionals.

Among children living with other chronic diseases it occurred that they developed strong relationships with caregivers, on established routines and shifted responsibilities for treatment between parent and child was essential to the child's adherents to treatment [41].

Talking about negative issues, such as not taking medication, might lead to the child making their parents worried, and causing them to have negative thoughts of the future. Therefore, children with PAH might sometimes find it easier to talk to their counsellor, with whom they have had a long relationship, as it has been found that children sometimes prefer to discuss sensitive issues with a neutral party rather than with someone emotionally close [29].

However, even if children with PAH seem to struggle with several difficulties, studies have found that these children can have a positive view of the future [21-23].

The results from this study could therefore be an indicator of how children and parents describe their thoughts regarding children with PAH's future and medical treatment, and such knowledge could support the development of interventions to help families struggling with medical adherence.

Methodological considerations

There are some potential limitations of the study. It is a limitation that we do not know the parents' HIV status. However, a criterion to participate is early acquired HIV and the majority of the participating parents are women, we only can assume the majority of parents are HIV positive. The generalizability of our findings is limited due to the small number of participants. Strength is that the participants are from a national cohort where all those fitting the inclusion criteria were invited to participate. Furthermore, it is a limitation that the results are based on short comments from a survey and the questions to children and parents are not phrased in exactly the same way. Moreover, the result from this study is just an indicator on how children and parents experiences child's overall future and medical treatment. In order to gain a deeper understanding of how children and parents think about the future and medicine adherence of these aspects more research is required. To elicit a richer subjective knowledge it would be of interest to interview both children and legal parents on these specific subjects.

Conclusion and Implications

The results from this study indicate that children and their parents have partly divergent views regarding the child's overall life, future and medical treatment. Parents believed their children should be able to have similar lives to their peers due to medical treatment. Children on the other hand had concerns about their future and contradictory views of their medical treatment. It is seen as a burden, but also as their lifeline – keeping them healthy and enabling a rather normal life. Our findings support a need to develop interventions to help families struggling with concerns about the future and adherence to medical treatment. In order to provide high quality healthcare to children with PAH the following recommendations are given:

- Development of guidelines to facilitate an open communication between children, parents and healthcare professionals.
- Provide healthcare professionals with pedagogical and communication skills in order to manage open discussions on sensitive topics, such as stigma, future concerns and adherence to medical treatment.
- Provide opportunities for older children to discuss sensitive topics and medical challenges in privacy with healthcare personnel acting as a neutral party.

These recommendations are important since high quality interventions can contribute to positive effects on children's overall life, health and wellbeing.

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Author Contributions

Two of the three authors (L.R., L.E.) collected data. L.R. with help from A.B. analyzed and categorized data. L.R. drafted the manuscript, A.B. and L.E. critically revised the manuscript and approved the final manuscript.

Disclosure Statement

No potential conflict of interest was reported by the authors.

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Appendix 1

Data collection by open-ended questions in two questionnaires.

Children and parents gave written answers on the following questions:

Open-ended questions targeting children aged 8- ≤ 18 years

1. Have you at any time this week not taken your medication? If so, what was the reason for not taking it?
2. Have you at times felt unwell? If so, describe in what way;
3. How do you view your future?
4. Is there anything else you want to tell us in addition to what we have already asked?

Open-ended questions targeting parents to children 0- ≤ 18 years

1. Has your child at any time this week not taken his/her medication? If so, what was the reason for not taking it?
2. Has your child at times felt unwell? If so, describe in what way;
3. How do you view your child's future?
4. Is there anything else you want to tell us in addition to what we have already asked?