

Caregivers' knowledge and perceptions of HIV/AIDS



DR TINA YARONG

CHILD HEALTH

MMED 2 THESIS PRESENTATION

22nd September 2021

Introduction

- Families play an important role in HIV education. This was demonstrated by Dimbuene in his study in 2015. [1]
- In an earlier paper Dimbuene ZT et al [2] found significance in the role of family environment as source of accurate HIV knowledge transmission route and prevention strategies.
- HIV burden in PNG [3]:
 - 52,000 people living with HIV
 - 28,000 women
 - 3,200 (<15years)
 - 3,300 new infections
 - 62 per cent ART coverage
 - 610 report AIDS related deaths

What do caregivers' of children living with HIV understand about HIV?

Objectives

Disease

- What it is
- Transmission
- Prevention

ART

- What it does
- Purpose

Social

- Future
- Disclosure
- Difficulties

Methods

- Cross sectional qualitative
- Site : Port Moresby General Hospital, wards and well-baby clinic (WBC)
- Study Period : June 2021 – July 2021

Interviews Wards/WBC
Informed consent
Audio recording
Semi structured questionnaire
WBC patient files

Transcribing Typing out interviews
Tabulating the demographics
Categorizing texts in the transcribed interviews

Analysis Simple statistic analysis
Analysis of the themes to form a conclusion

Results

INTERVIEWEES

INTERVIEWS (27)

CHILDREN

Relationship to Child:

- Mothers (n=17) 62.9% (16 on ART)
- Fathers (n=3) 11.1 %
- Aunt (n=3) 11.1%
- Grandmother (n=3) 11.1%
- Sibling (sister) (n=1) 3.7%

Residence:

Urban 18 (66.7%), Rural 9 (33.3%)

<u>Educational Status</u>	N =27
None (7.4%)	2
Primary (29.6%)	8
Secondary (37.04%)	10
Post-secondary (25.9%)	7
<u>Employment Status</u>	
Employed (14.8%)	4
Unemployed (77.8%)	21
Student (7.4%)	2

HIV Status

- 25 confirmed Positive
- 1 False positive
- 1 Presumptive Rx

Recruitment Sites

Consultation Clinic (3.7%)	1
Ward 1Bb (7.4%)	2
Ward 1C (7.4%)	2
Ward 1D (22.2%)	6
Well Baby Clinic (59.3%)	16



Themes identified

UNDERSTANDING HIV AND TREATMENT

- The disease
- Thoughts on ART

THE EMOTIONS OF HIV

- Thoughts about child's status
- Acceptance

THE CHILD

- Disclosing HIV Status of child
- Caring for the child
- Future hopes

SOCIAL IMPACT

- Stigma and judgment
- Financial challenges

UNDERSTANDING HIV AND TREATMENT

- The disease
- Thoughts on ART

"... em wanpla virus em stap insait lon blut system..Em i save burukim immune sistem bilong yumi na wokim bodi i wik na drainim up olgeta system blo bodi. Pikinini kisim sik taim ol partners ol i no faithful lon ol yet. " (AT10WBC23)

"Sapos mama no stap lon marasin taim baby stap insait lon bel or lo taim lon karim na tu lon susu em ken tranferrim sik." (ME18WBC19)

"So taim marasin save go, em save kilim dispela binatang we em i save go hait lon wanpela hap na bai yu stap olsem nomol man. Taim yu lusim marasin nau, dispela binatang save maliplai go na kamap bikpela. " (SA122D10)

"Mi save hamamas bikos, mi ken stap yet wantaim ol pikinini bilong mi na livim laif osem normal person." (AT10WBC23)

THE EMOTIONS OF HIV

- Thoughts about child's status
- Acceptance

"Just for her to learn that she is like this (HIV positive). I just hope that she'll understand and she'll forgive us as her parents for what she has to go through. (DS202D02)

"Mi sa wari yah, why na mi no laik go lo hausik na find out na kisim marasin na em bai orait. (DJ06CO05)

"...mipela tupela fogivim mipela yet na hamamas olsem God givim pikinini na mipla tenkim God lo disla. Wanem kain sik kamap, mipela bilif osem God em stap lo side blo mipla." (AT10WBC23, Both parents positive)

"...mi skelim olsem i no luk orait sapos mi lusim ol, na mi (go) raun ken. Pikinini tu i bon pinis na disla na mi tingim bai mi stap wantaim ol tasol na traim lon lukautim mama na pikinini wantaim." (AA192D06, Negative father)

THE CHILD

- Caring for the child
- Future hopes

"Olgeta (femili) save mi no putim wanpela han lon skin blong em. Wanem samfin em laikim, mi laik mekim mindset blon em i bai hamamas lo kisim dose so mi mas bihainim laik blo em. Wanem samting em laikim, mi mas givim lo em so em bai hamamas lo taim blon drin marasin. Stronpela koros, bagarapim toktok em mi no save mekim kos mi mas sowim love lo em so em ken stap longpela taim. (BD09WBC18)

"So priority blo mi sa go lo em. Bai mi mek sure em kaikai gut, marasin em kisim lon taim tu." (ME18WBC19)

"Since baby blo mi sa go kam lo hausik, em future blo em, em laik kamap dokta. Lo sait blon mi papa, mi mas mek sure olsem em disla dream bilong em i mas kam tru lo laif blo em." (AT10WBC23)

"Mi laik em kamap nomol pikinini. Mi stap olsem na mi save lukautim em gut na go kam lon follow up lo marasin blo em so det lon future em mas stap nomol." (BT15WBC17)

THE CHILD

- Disclosing HIV status to child

"Mi wok lon tin olsem, em liklik yet taim mi save karim em go kam. But taim em 9 o 10 yias nau, mi tin olsem em bai askim mi "Mummy why yu woklo karim mi go lo hausik?" Nau mi bai tokim em." (EM19WBC26)

"When he is old enough to understand why he is taking medications daily. Then I will tell him that you have lived long enough to know your status you are just as I am, a normal being." (JS202C07)

"Maybe when his old enough to understand and know properly then it will be okay to sit him down and explain to him, but it will be a challenge to accept the fact that he has it." (BN19WBC08)

THE SOCIAL IMPACT

- Stigma and judgement
- Financial challenges

"Nau yet mipela les lon tokim narapela man bikos yu no skelim gut na yu wokim rong disisen na nau dis deis ol man ol bai toktok baksait na bagarapim, ino yu tasol but pikinini blo yu kamap nau yah bai ol haitim em bihain taim, taim mitupla no moa stap...(AT10WBC23)

***"..mi yet mi dai, ol narapela bai ino inap lo lukautim dispel tripla pikinini blo mi. Olsem sampela ol no save lon dispela sait blo stori blo sik. So sampela bai tok pikinini nogat tu but ol bai tok olsem em pikinini blo meri i gat sik na dai pinis."
(SA122D10)***

"Sampla taim, osem nogat busfare or nogat money,... mi sa wokabout, because mi save tingim marasin blo em. Na mi sa tokim em, yu noken kam wantaim mi, yu stap..... nogut em kam bai em tok lo kaikai so mi sa lusim em lo haus. ... Because mi sa tingim life blo em so mi sa...wokabout kam."(DJ06CO05)

Discussion

- **Thematic Analysis of this study showed:**
 - **Sound knowledge of HIV/AIDS**
 - **Non-curable**
 - **Modes of transmission**
 - **ART was important to prevent MTC transmission**
 - **Good understanding of how ART works**
 - **Compliance was important for viral suppression**
 - **Viral suppression would allow for a normal life**
 - **ART is lifelong treatment. Social challenges included;**
 - **Stigma and discrimination**
 - **Financial issues**
 - **Lack of family support for some**

Discussion

- ▶ **Caregivers strived to fulfil their responsibility to the child by**
 - ▶ **Maintaining clinic reviews**
 - ▶ **Ensuring adequate supply of and adherence to ART**
 - ▶ **Desire to provide a conducive environment for child growth**
- ▶ **Other significant issues identified include:**
 - ▶ **Maternal regret (MTCT)**
 - ▶ **Fear of blame**
 - ▶ **Fear of how child would accept disclosure of status**

Recommendations

- Important that adults and carers have a sound understanding of HIV/AIDS in order to have a positive impact on living with HIV within families.
- Orelly's study [4] proved that information improves care for children with HIV, but it also highlighted that the disclosure rate was still quite low (7%) in Port Moresby as most of the caregivers believed the child to be too young.
- To better evaluate the quality and amount of HIV knowledge taught within families, a further study can be done also involving perspectives from;
 - Those who have had their statuses disclosed and
 - Those that have transited to the adult clinic



➤ Limitations

- Time, no proper counselling rooms, technical issues with interviews and transcribing.

➤ Acknowledgements

- Professor T Duke
- Professor J Vince
- Dr G Vali
- Sr Kalebe and staff of Well Baby Clinic – PMGH
- Paediatric Unit Staff : Colleagues and Nurses
- Family

Reference

1. Dimbuene ZT. FAMILIES' RESPONSE TO AIDS: NEW INSIGHTS INTO PARENTAL ROLES IN FOSTERING HIV/AIDS KNOWLEDGE. *J biosci Sci.* 2015 Nov;47 (6): 762-79. Doi: 10.1017/S0021932014000406, Epub 2014 Sep 30. PMID: 25268460.
2. Tsala Dimbuene Z, Kuate Defo B. Fostering accurate HIV/AIDS knowledge among unmarried youths in Cameroon: do family environment and peers matter? *BMC Public Health.* 2011 May 19;11:348. Doi: 10.1186/1471-2458-11-348. PMID: 21595931; PMCID: PMC3123591.
3. HIV/AIDS Data Hub for the Asia Pacific. <https://www.aidsdatahub.org/country-profiles/papua-new-guinea>
4. Orelly T, Welch H, Machine E, Pameh W, Duke T: Human immunodeficiency virus status disclosure and education for children and adolescent in Papua New Guinea. *Journal of Paediatrics and Child Health* **54** (2018) 728-734
5. UNAIDS data 2020. Geneva: joint UN programme on HIV/AIDS, 2020. https://www.unaids.org/sites/default/files/media_asset/2020_aids-data-book_en.pdf
6. National Department of Health, Papua New Guinea National Guidelines for HIV care and treatment, 2019.
7. Working to achieve an HIV-free generation in PNG. <https://www.unicef.org/png/press-releases/working-achieve-hiv-free-generation-png>
8. Sherr L, Cluver LD, Betancourt TS, Kellerman SE, Richter LM, Desmond C. Evidence of impact: health, psychological and social effects of adult HIV on children. *AIDS.* 2014 Jul;28 Suppl 3:S251-9.doi: 10.1097/QAD.0000000000000327.PMID:24991898.
9. Rujumba *et al*: Challenges faced by health workers in providing counselling services to HIV positive children in Uganda: a descriptive study. *Journal of the International AIDS Society* 2010 **13**:09.
10. Campbell C *et al*: A 'good hospital': Nurse and patient perceptions of good clinical care for HIV-positive people on antiretroviral treatment in rural Zimbabwe – A mixed-methods qualitative study. *International journal of Nursing Studies* 48 (2011) 175-183.
11. Fetzer BC *et al*: Barriers to and Facilitators of Adherence to Pediatric Antiretroviral Therapy in a Sub-Saharan Setting: Insights from a Qualitative Study. *AIDS Patient Care STDS.* 2011 Oct; 25(10): 611-621.doi: 10.1089/apc.2011.0083.



Thank you

Comments ? Questions ?