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Paediatric Hospice in Palliative Care

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Introduction

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO definition of palliative care is appropriate for children with life threatening or chronic disorders and their families: (WHO; 1998a)

- Palliative care for children is the active total care of the child's body, mind and spirit and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- Health care provider must evaluate and alleviate a child's physical, psychological and social distress.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

South Africa is currently in the throws of an HIV epidemic that has produced a great number of children with chronic non-curable disease. The quality of life of these children (whether infected or not) in that they deal with the bereavement issues faced by this vulnerable population.

HIV-1 infection is a chronic manageable disease. The prognosis is better that childhood leukaemia 40 years ago. And will continue to improve as new therapeutic modalities become available. There has been rapid progress in the development of anti retro viral therapy (ART) in children and adults. In particular, triple therapy, as known as highly active antiretroviral therapy (HAART).

Even where children are able to access anti-retroviral treatment (ART), there will still be a need to control distressing symptoms; (that may include the side effects of ART) and to provide these children with the often neglected, psychological support that is a crucial component to palliative care.

A primary objective in paediatric hospice programs is to create a special place for children and their families where the care is family–focused and where all family members, not just the ill child, receive the attention of paediatric health care providers. Consequently, a full understanding of the experiences of all family members is crucial to any program's success.

Maintaining a family focus in paediatric palliative care necessitates the inclusion of siblings in care programs. In Paediatric hospice suggest that siblings may experience more distress than ill children in end–of–life care settings. Encouraging sibling involvement in paediatric end–of–life care validates their relationship with the sick child and lessens their feeling of helplessness.

Psychologist Roger Hart wrote, children are undoubtedly the most photographed and least listened to members of society. According to United Nations (UN) however, children have the right to a voice. Without addressing children perspectives directly, we are denying them their right to a voice and furthermore are missing out on much valuable information they have to offer.

Patient's background

Our patient Dlkeledy is a 5 years old girl and AIDS orphan too. Se is living with her aunty and lives with many other different age group people.

Her aunty also running a she been to get some income for daily living and the uncle is unemployed. According to case details of Dikaledy seem she abused by adult sometimes in her life and that's why she is very much afraid of adult people.

Dikaledy currently is on TB medication and suffered from few episodes of diarrhoeal disease. Also has eczematous lesion on body which may be very painful.

Palliative care for Dikeledy

Recent years Paediatric Palliative Care has improved a lot and there is new development for management of terminally ill non–curable disease in children.

In paediatric palliative care multidisciplinary team approach is essential to manage a patient. The main focus of PPC is to maximize the patient's quality of life by providing relief from distressing symptoms. PPC is also concerned with the provision of good end of life care and ensures that dying children in whom death is unavoidable die comfortably and with dignity.

Multidisciplinary team consist as follows:

- Hospice care.
- Family members (eg; aunty here).

- Social worker.
- HIV/AIDS counsellor.
- Religious practise and rituals (eg; pastor).
- Medical management (eg; doctor, nurses etc).

Discussion with family/caregiver's (aunty of Dikeledy)
I will discuss with her aunty about the admission in hospice and possible management of Dikeledy's ailment. How Dikeledy's parent died and what were the consequences before their death? Also, I would like to explore that how old was Dikaledy when her parent died? Is she knowing anything about their death etc?

I will also inform the aunty that I need to involve multi disciplinary team to manage Dikeledy's condition. I will discuss about the HAART treatment; the side effect of the medicines and she will be going to drink/take many medicines a day. After everything informed to caregiver, I will make a management plan for Dikeledy.

Predominant symptoms occurring in HIV infected children include:
- Pain
- Cough
- Dyspnoea
- Excessive secretions
- Odynophagia
- Nausea and vomiting
- Chronic diarrhoea
- The constitutional symptoms: Anorexia, Cachexia, and asthenia.
- Depression and anxiety.
- Pruritis and other painful dermatological conditions.

We should assess properly what is Dikaledy's needs here and how to manage her according to palliative care principles.

General principles for palliative care are as follows:
1. Determine and treat underlying cause including non-physical causes.
2. Relieve the symptoms without creating new symptoms, unwanted side-effects.
3. Consider different types of interventions: drug and non-drug.
4. Consider whether the treatment is of benefit to the individual patient.

Treatment of the underlying cause of distressing symptoms in HIV/AIDS includes the treatment of infection and use of anti retro viral therapy to improve the quality of life.

In case of Dikeledy few key points we need to consider for her total management such as follows:
- Dikaledy is 5 years old.
- AIDS orphan.
- Staying with aunty.
- Staying with different age group children and people at home.
- An abused child by adult.
- Her fear to adult people.
- Malnutrition.
- Chronic diarrhoea.
- On active TB treatment.
- Pain due to eczematous lesion on her almost whole body.
- Not getting any grant.

Pain assessment
To manage her pain, I will use QUESTT acronym and which was developed by Wong et al. in 2001.

Q: Question the child + parent/caregiver in both verbal and non–verbal child.
U: Use pain rating scales if appropriate. E: Evaluate behaviour and psychological changes.
S: Secure parent/caregivers' involvement.
T: Take the cause into account.
T: Take action and evaluate results.

By definition pain is an unpleasant sensory and emotional experience associated with potential or actual tissue damage or described in terms of such damage (Merskey 1986: International Association for the study of pain). As pain is a subjective symptom it may be difficult in pre-verbal children to determine whether or not pain is present.

There are four key concepts in treating pain. Pain should be treated:
1. By the clock: regular dosing prevents the child from having to first experience pain before it is treated. Regular dosing has also been shown to decrease the total daily analgesic requirements.
2. By the WHO ladder: Using the steps of analgesics use.
3. By the appropriate route: the oral route is best for the children.
4. By the child: each individual child's experience of pain is different from the next and even with the same pathology children may have different experiences of pain.

I will ask few questions to Dikaledy and the aunty that the site, radiation, aggravating factors, relieving factors of her pain. According to history her pain is due extensive eczematous skin condition of her body.

Therefore, I would like to control her pain by using WHO analgesic 3 steps ladder as follows:
Step 1: Non–opioid (e.g. paracetamol or NSAID) +/- adjuvant.
Step 2: Weak opioid + non–opioid (as in step1) +/- adjuvant
Step 3: Strong opioid +/- adjuvant.

The WHO pain ladder is a useful tool in the management of pain it was designed for the management of pain in cancer patient, although it is also useful in case chronically ill HIV infected patient those who suffer from recurrent infections.

Management of chronic diarrhoea in this situation a patient like Dikeledy
Chronic diarrhoea is distressing not only to the child experiencing it but also to the parent or caregiver looking after the child. Chronic diarrhoea in HIV is caused by the virus itself, by other infections of the GIT (eg: cryptosporidium, giardiasis, mycobacterium avian complex) as well as infections outside GIT (eg urinary tract infections). Treated underlying causes should be diagnosed and managed where possible. Anti retroviral treatment usually indicated in most children with this stage – 3 AIDS defining illness?

In chronic diarrhoea nutrition rehabilitation is important in Dikeledy's case in order to break the malnutrition–diarrhoea–malnutrition cycle. I will organize rice or maize based oral rehydration solutions for better outcome.

(A maize based ORS can be made at by boiling 50 grams of mealiemeal in 1 litre of water while stirring for 5–8 minutes, add one tea spoon of salt it has cooled, mix well)

If diarrhoea persists after using ORS (Oral rehydration salt), then loperamide can be used in her case and also alternatively codeine

phosphate.

In Dikeledy's case we have to correct malnutrition as well, because she needs to be prepared for HAART.

Management of extensive skin lesion that is eczema in her case
Skin infection is very common in children rather than bed sores in adult. Eczema also can cause pruritus. I will encourage Dikeledy's aunty to improve hyiegine status of her and at same time I will give anti histamine to control itching condition. Aqueous cream or calamine lotion also very effective in this condition.

Management of stress/depression/fears of Dikeledy
According to history every possibility Dikeledy was abused by adult and that's why she is very much afraid of adult people surrounding. Due to that fear, probably she is distress, depress and withdrawn. Because at her age suppose to be busy with toys and play with other same age group children. This thing needs to be sorted out as well by involving social worker or welfare officer. I will also inform child protection about the child abuse.

Children hospice is the best place for her as an orphan, because she will feel much more secure there then aunt's home. At hospice she will be able to play with toys and other same age group children.

Also, social worker can organize common grant for her which government gives to AIDS orphan and chronically children. Also, I will organize a place for at local pre school, where she can mix with other children with out any discrimination.

If necessary, I can also involve the pastor of Anglican church where may be she was baptised. At her own understanding level pastor can give knowledge about what happens after death etc or what happens to her mother/father etc.

Management of HIV/AIDS itself
Antiretroviral therapy (ART) started as mono therapy with significant short–term gains. With the advent of newer drugs management has been become more complex, but with significant gains in quality and quantity of life.

According to WHO staging of HIV/AIDS Dikeledy stands for stage–3 and if she qualifies for HAART treatment programme then I will start on her.

She needs few investigations to qualify for HAART as follows:
- Full blood count.
- Liver function test.
- Blood urea and electrolytes.
- Chest x–ray.
- RPR or VDRL.
- CD4% and viral load.
- Stool MCS.

Dikeledy is only 5 years old, to her with will not be an easy task. Because also needs to be counselled by AIDS counsellor at different sittings obviously at Dikeledy's own understanding level. Repeated counselling is very important because of the adherence of medicine (HAART). Also, she needs to be informed that now she going to take many medicines every day for her ailment.

Even after well informed to the patient and the caregiver both still adherences are poor, also sometimes patient deny or refuse to take medicine anymore. In that case after proper assessment I will respect the patient wish as well.

As I know Dikeledy is also taking TB treatment, therefore I will find out, she is on intensive or continuation phase of treatment. According to my assessment I will start Ia regime HAART treatment for Dikeledy.

Conclusions
It is a challenge in South Africa now because there are many AIDS orphan and they are neglected by other relatives. Therefore, government and non–governmental organization both should come forward to rescue or help these children, otherwise a big population in the community will suffer and in there will be a generation gap in the community as well.

Also, the most pressing concern with ART is it lack accessibility to the majority of the patients that need it. Other important issues are how and when to use it in ways that promote durability of response but avoid unnecessary use.

However, as a health professional we also need to come forward with heart as well to help these groups of people in the community. Dying children and adolescent may differ their ability to take part or participate to make decision at the end of their life care, that's why we as a health professional has to listen the voice of children and adolescent attentively to improve the quality of dying young people's life.

Foot note
HAART: Highly Active Antiretroviral Therapy.
PPC: Paediatric Palliative Care.
WHO: World Health Organisation.
ART: Anti Retroviral Therapy.
TB: tuberculosis.

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