

Original Article

RUMAH SOLEHAH - MALAYSIA

Half Way Home For Women And Children With HIV/AIDS

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Abstract

Rumah Solehah (RS) is a half way home for women and children living with HIV/AIDS. Since July 1998, more than 100 women and 50 children have "graduated" from RS. Presently, we have 22 children, 3 months to 9 years old and 8 women.

We bought our own home in Kampung Pandan in 2007. We have a second home in Cheras and started a third home in Kuala Terengganu in August 2007. The home and family ambience of RS has offered our women and children the opportunity to cherish the joy and happiness of family life and caring for each other.

RS received the Tun Dr. Siti Hasmah Special Mention Award 2004 for excellence in care and support at the grass-root level. With the inevitable surplus of HIV/AIDS infected and affected children, the challenges to RS will continue to be a daunting and awesome one. Together we can make a difference to the lives of these little and innocent souls.

Introduction

Some 26 years into the syndrome complex, the WHO estimates 39.5 million people living with HIV/AIDS (PLWHA), 4.3 million new infections in 2006 alone. About 530,000 HIV-positives in 2006 were children under 15.

And to address the "missing face of the child in the AIDS pandemic", UNICEF in 2006 launched Unite for Children, Unite Against AIDS. The 3 key strategies being prevention of mother to child transmission, ensuring treatment for HIV-positive children and caring for the inevitable surplus of AIDS orphans.

Since HIV infection in children mirrors closely the prevalence of women acquiring the disease, keeping mothers free from HIV/AIDS and preventing the transmission of HIV from infected mothers

to their offsprings is of paramount importance.

From 2001-2005, there were 6-7 thousand new HIV cases annually in Malaysia, 17 - 19 cases per day; 2 of whom were women. There is a worrying trend in heterosexual transmission, 22.1% in 2005 vs 4.8% in 1990. More alarmingly, the proportion of women being infected had increased ten fold, 1.2% in 1990 vs 12% in 2005.

The Ministry of Health (MOH) initiated antenatal HIV screening in 1998.

Till the end of 2005, 865 (0.034%) mothers were confirmed HIV infected. In 2005 alone, 107 (14.5%) out of 737 HIV-positive women were pregnant mothers. About 4% of babies delivered to these mothers were found to be infected.

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In 1998, the Islamic Medical Association of Malaysia organized a half way home for HIV/AIDS Rumah Solehah (RS). Our experience with the 100 women whom we have sheltered in Rumah Solehah showed that the majority acquired the virus heterosexually from their IVDU (intravenous drug users) husbands or partners. All of the HIV-positive children in our care acquired HIV vertically from their mothers. This unfortunately is the domino effect of the heroin culture, which contributes 75% of the HIV/AIDS data base and which needs to be expeditiously addressed by the respective government agencies which to date has been a dismal failure.

The first reported case of pediatric AIDS in Malaysia in 1986 was a 6 year old hemophiliac boy who had received contaminated blood products. Till Dec. 2005, a cohort of 424 HIV positive children were followed up in specialist pediatric clinics throughout the country with 49% reviewed in KL, Johor and Kelantan alone. Some were diagnosed HIV-positive in late infancy when they were investigated for recurrent infections or failure to thrive. Their mothers were often not screened antenatally. 302 (71%) of the cohort are on antiretrovirals. Globally, only one in ten children needing antiretrovirals has access to treatment.

With newer anti-retrovirals and aggressive management of opportunistic infections the survivals of these children have improved tremendously. We have yet to lose a child in Rumah Solehah to AIDS or its complications. Vigilant supervision, medications 3-4 times daily, scheduled visits to the Pediatric Institute and the occasional ER visit keeps the virus at bay.

Eleven children are attending school ferried by an MPV donated by Big Tree. The teachers and school administrators are fully cognizant of their condition and have been most supportive. The children know exactly what to do should a blood related

incident occur. There was a sole protest from a member of the PTA which was diffused with tact and understanding.

Fifty one (59%) of the HIV-positive children in Klang Valley are cared for by their parents or extended families. Twelve (14%) have been adopted legally by couples oblivious of the babies' HIV status at birth. Twenty two (25%) are in foster homes managed by NGOs. Only one child is nursed in a government social welfare home.

Amin, now five years old was found wandering the streets of Chow Kit, abandoned at the age of two. He is street wise, bright and studies well. His other house mates in our home were either abandoned in the streets or at birth or orphaned. It is estimated that some 6-10 thousand children had been orphaned because of HIV/AIDS. Their long-term survival and a near normal quality of life would depend largely on their immediate or expanded family support. Failing this, the next best would be foster care in a dedicated home with trained and live in care givers, simulating a home and family ambience, cherishing the joy and happiness of family life and caring for each another.

When Rumahh Solehah was initiated in 1998, the national mood on HIV/ AIDS was shrouded with fear, hostility and indifference. The Ministry of Health gave us a grant whilst the then Ministry of Social Welfare did not want to know. We sourced further funds from the embassies of Britain, New Zealand, Canada, Japan and Australia since Malaysians then were not quite forthcoming. These extra funds were invested in various financial initiatives to ensure some form of long term fiscal independence. Our economic projects include coin operated laundry and drying machines in various universities, housing estates and in our shop lot, which doubles as our office. The supervisor along with the other ladies runs this business.

Well over 100 women have "graduated" from Rumah Solehah. Many have returned to their families and the wider society. Others have found decent jobs and are self supporting. The eight women currently resident continue the family traditions of our home and help to care for the 22 children with the other caregivers.

The demand for shelter and homes for HIV-positive children and AIDS orphans far outstrip the numbers available. Not infrequently, our two homes in Cheras have to refuse requests for placements. Our third home in Kuala Terengganu will soon foster children from the East Coast, thanks to a grant from a corporate body.

The following is a brief outline of RUMAH SOLEHAH, its operations and accomplishments:

1. Whilst a few homes of similar intent mooted in the 1990's have failed, RS has braved the difficult circumstances and passed the test of time.
2. Well over 100 women infected or affected by HIV/AIDS, of all races and religions, have "graduated" from RS. These women came from the streets and engaged in high risk behaviors e.g. commercial sex workers, intravenous drug users (IVDU) or were abandoned and ostracized by their families and communities. Many have now returned to their families and the wider society. Others have found decent jobs and are self-supporting. A few have died. Currently, there are eight residents.
3. RS is not a hospice. On the contrary, RS has provided a home for these women to rejuvenate their self esteem, and feelings of self worth; to rediscover the joy of life and living. The home and family ambience of RS has offered these unfortunate women the opportunity to cherish the joy and happiness of family life, caring for each other and sharing in the upkeep of their home.
4. Many of these graduates of RS are now actively involved in creating awareness on the dangers of HIV/AIDS. They have become champions of the HIV/AIDS cause traveling across the country to disseminate the message of HIV/AIDS and healthy lifestyles.
5. The activities of RS have been featured in many TV programs and write ups in the mainstream press and magazines.
6. Many university students, both under and postgraduates have taken up the RS project as their field study.
7. RS has attracted many individuals, NGOs, professional organizations, student organizations to volunteer their services in the home. MERCY Malaysia regularly sends teams to volunteer their services to RS.
8. With the inevitable surplus of HIV/AIDS infected or affected children and orphans, RS opened their home to the first HIV child in 2001. Since then over 50 children have been cared for in RS. RS gets referrals from all over the country, from doctors, the welfare homes, Pengasih and the Malaysian AIDS Council. Currently there are 22 children in RS.
9. A second home was opened in 2004 to cater for the increasing number of children. They have taken on board a most challenging

- task to address not only the daily sustenance of these children but also their educational needs and to ensure their optimal physical, emotional, spiritual and cognitive development. A TALL ORDER BY ANY STANDARDS!
10. A third home was started in Kuala Terengganu in August 2007 to cater for the surplus of HIV/AIDS cases in the east coast of Peninsular Malaysia.
 11. In our humble beginnings only the Ministry of health provided us with a decent but regular grant. This was however insufficient to meet the every growing number of residents and activities of RS. And especially with our expansion to a child shelter home in 2001.
 12. In the late 1990s, when the national mood was one of "indifference to persons living with HIV/AIDS" (PLWHA); RS sourced funding from the foreign embassies. The British, Canadian, New Zealand, Japanese and Australian embassies donated generously.
 13. The monies were invested in various financial initiatives, to ensure some form of long term financial independency. Some of the economic projects include coin operated laundry and drying machines in various universities and housing projects; photocopying and book binding services, sewing services. RS now owns a shop lot which has a self service laundry and drying services; which also doubles as the office of the supervisor.
 14. More recently, the generosity of fellow Malaysian have been forthcoming.
 15. The Islamic Medical association of Malaysia has kick start a project called "TAKAFUL WAQF RUMAH SOLEHAH". Currently about 250 members have deposited monies each month (deducted from salaries/credit cards) to be made as waqf (endowment) to RS. This is expected to increase further as the nobility of these contributions is marketed widely.
 16. Whilst many have failed, Rumah Solehah is now into her 11th year of operations. RS continues to attract visitors nationally and world wide, as a model of a dedicated HIV/AIDS institution:
 - a. that has expanded from a shelter home for women to now addressing the needs of children with HIV/AIDS;
 - b. that has seen her residents "graduate" to be with their families and the wider society and some of the children have been accepted by their families/extended family members or fostered/adopted;
 - c. that has laid out concrete plans for their institution's viability, financially and human resource wise;
 - d. that has remained within the fraternity of the Malaysian AIDS Council and her election into the executive committee in 2004, further reinforces this resolve of sharing, caring and learning.
 17. Tax exemption is available to all donors.

“Do not think that We had created you in play (without any purpose), and that you would not be brought back to Us?” [Al-Quran 23:115]