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Utilising Abandoned Leprosarium for HIV & AIDS Hospice Centre

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Abstract
The purpose of writing this paper is to understand the issues related to People Living with HIV and AIDS (PLWHA). The issues are often related to health, social and economical. Health issues gave a certain limitations towards the HIV patient which leads to social issues such as stigma, discrimination and marginalisation. Consequently, these social issues give an impact towards the economy of an individual and the country whereby PLWHA loses their job and becoming a burden towards the family and government. Despite that, there are still some non-government bodies such as Malaysian AIDS Council who concerns with this group of community and the future of the country. They have provided shelters and organising a lot of HIV/AIDS related campaigns. However, the issues arised is that the number of shelters is too minimum compared to the number of PLWHAs in the country. Moreover, shelters provided are mostly bungalows or terrace houses which has a small compound to have any form of activities. Since there is available land of abandoned leprosarium in Johor, it could be utilised and turn it into a HIV/AIDS Hospice Centre. Characteristics of the site and designed environments for PLWHA are discussed in order to understand the desired and suitable environment to assist people living with HIV/AIDS in reducing depression, negative emotional, stigmatisation and other miserable symptoms.
Keywords: Hospice, HIV, AIDS, Stigma, Leprosarium

1.0 Introduction

'Architecture should defend man at his weakest.'
Alvar Aalto

In the usual situation, hospitals with doctors and nurses have the responsibilities to help their patients recovers from their illness or injuries. However, those whose illness is uncurable including HIV or AIDS would generally be discharge from the hospitals as the hospitals feel that they could not do much about the illness. They felt that the beds can be more bennificial to other needed patients (Hospis Malaysia, 2011).

Relievingly, hospice care has been introduced. Hospice care is basiclly referred to end-of-life care with a team of health care professionals and volunteers. These cares includes medical, psychological and spirtual support. The concept of hospice is treating the patients rather than the disease so that a patient's last days could be spent with dignity and quality, surrounded by their loved ones. The misconception of a hospice care is that it only takes place in an instittutions or centre such as hospitals, hospice centres and nursing homes. On the other hand, hospice care could also takes place at a person's home.

Hospice Care has existed since the 11th century where it was historically provided inside a home. The word ‘hospice’ was derived from a Latin word ‘hospes’ which gives a meaning of to host a guest or stranger. Hospice care has been evolving with times. Modern concept of hospice has includes palliative care given for the incurable patients in institutions such as hospitals and nursing homes and also at homes for the people who wanted to spend their lifes at home (Robbins, J., 1983).

Palliative care is a therapy which helps in lessening pain and suffering by providing patients with medications for relief of symtoms and with comfort and support for the terminally ill.

Hospice care is still considered new in Malaysia. It began in August 1991 where a charitable organisation named HOSPIS MALAYSIA was formed by a group of dedicated individuals from various professional backgrounds who feels the need of having Palliative Care services for Malaysian society. In 1998, Malaysian Hospice Council was set up by eleven founder members from all over Malaysia. Up to this date, there are about nineteen hospice and palliative care organisations has been setup throughout Malaysia.

These hospices in Malaysia are open to anyone with any uncurable illness. The services given are free provided that there must be a main guardians at home or hospice centres. Main guardians in a hospice care are the family caregiver and a hospice nurse who comes regularly at interval times.

2.0 People Living with HIV / AIDS (PLWHA)

Human Immunodefficiency Virus (HIV) is a type of virus. Meanwhile, Acquired Immunodeficiency Syndrom (AIDS) is a medical condition or syndrome causes by the entity of HIV infections if it is untreated. All people with AIDS will eventually have their immune sysem weakened, leaving them vulnerable to numerous viral and bacterial infections known as opportunistic infections and uncommon cancers. There is no linear progression to

this disease and the stages of this disease have been identified as apparently well, acutely ill and terminally ill (Scheitinger, 1986).

PLWHA are a group of community with incurable disease. HIV was discovered in 1981 on five homosexual men in Los Angeles California followed by 26 young, homosexual men in New York and San Francisco (T.L. Zborowsky, 2008). The first HIV case reported in Malaysia was in the year 1986 (Rozaidah T., 2006). Since then until the year of 2012, the total number of people living with HIV in Malysia is 81, 209 people (Ministry of Health Malaysia, 2012).

HIV infection ratio of male to female has shifted from 1:99 in 1990 to 1:10 in 2000. At the end of 2011, the ratio of male to female bacame 1:4. From the annual report of Malaysian AIDS Council (MAC), this is due to the increasing trend of heterosexual transmission of HIV. The highest HIV infected group belongs to the age of 30-39 years old.

HIV can be transmitted in a three basic ways such as sexual transmission (heterosexual, bisexual) , perinatal transmission (mother to child) and blood transmission (Injecting drug users (IDU's,blood donation, organ donations). Injecting Drug Users (IDU's) record the highest mode of transmission in Malaysia which is 70%.

Classifications of uncurable disease is given to HIV or AIDS because of its unfounded treatment up until today. Despite that, antiretroviral therapy (ART) may help slows down or stop (not remove) the progression of HIV disease. Generally, highly active antiretoviral therapy (HAART) which are made up of combinations of antiretroviral (ARV) drugs are used to produce a maximum effects of preventing the virus from spreading in the body. (World Health Organization, 2013). These ART treatment is permanent and lifelong taken at a regular schedule.

3.0 Issues and Challenges

Alongside with the virus that causes sickness and death (which is already a bad condition), the person diagnosed with HIV or AIDS are also attached with something worst which is stigma. Stigma can be explained as a quality that functions to discredit an individual or a group in the eye of others. Basic foundationa of stigma is 'differences'. The differences can be in the form of personality, physical appearance, illness and disability, age, gender or sexuality (Matson, Carlisle, Watkins & Whitehead, 2001). The differences that HIV positive patients inherits is the confirmation of knowing that they will die because of the virus and the health issue that comes before ot such as severe weightloss, extreme weakness, high recurring fevers, profuse night sweats, loss of consciousness, severe headeaches, fungal growth on tongue, skin rash poor memory, reduced ability to concentrate, depression, tuberculosis (TB), diabetes, stroke and ovarian cancer.

Stigmatisation, descrimation & marginalisation actions towards PLWHA begins at the family & community settings and institutional settings. In the family & community settings, PLWHA may experience osracization, where thay are forced to leave home and being ignored. Apart from that, family or community shuns and try avoiding everyday contact. Some would give a hard time by verbal harrassment, physical violence, verbal discrediting and blaming, gossip and denial of traditional funeral rites.

On the other hand, institutional setting such as healthcare setting starts the action of stigma by reducing standard of care and breaching the confidentiality of HIV positive patient to their relatives and outside agencies. Besides that, in a workplace, stigma begins when there is denial in employment based on HIV-positive status or exclusion of HIV-positive individuals from pension schemes or medeical benefits. For teenagers, stigma are felt when HIV positive teenagers are denied to enter the schools, while teachers with HIV are dismissed. In institution like prison, mendatory segregation of HIV positive individuals and exclusion from certain activities contibutes to stigma.

Stigma, marginalisation and discrimination has given a lot of impacts on individuals, families, communities of Malaysia over the past few years. Stigma has caused an impact towards the economy. Based on a survey, two-third of PLWHAs are unemployed. A majority decides to stop working as a result of incapacitated by illness caused by the virus and forced to resign or leave their job. Thus, they cannot support for themselves to pay for medical bills let alone their family. These does not only affect the individual itself, but also their families. Family members could not receive their rights of education and working normally despite their HIV family member's illness. As a result, some are being disowned by families and became homeless. Consequently, these people has bacame a government burden when government has to support their medical, provide living place, create awareness and giving education on HIV.

The situation of marginalising the HIV patient is a waste because some PLWHAs can still contribute to society and not becoming a government burden. It does not mean that when a person is jobless, they are not skillful. According to a research on the 'Study of the Impact of HIV on People Living with HIV, Their families and Communities in Malaysia', 52.6% of PLWHAs are employed and self employed. They range from managers & executives to middle management works such as clerks, technicians, nurse and general workers in restaurant and minimarts. The self employed includes those occupation ranging from electricians, designers, tailors,

hairdressers, musician and sales personnel. This shows that they have skills such as teaching, nursing, waitressing, designing, hairdressing, repairing electrical and electronics and much more but hard to contribute due to lack of programmmes and concentrated places.

Based on the key figures from 2012 MAC annual report, 471 PLHIV were served by the shelter homes and 327 gets the beneficiaries on ARV, giving a total of 693 beneficiaries. However, the number of PLHIV in Malaysia is 81, 209 people. The beneficieries are only 0.8 percent out of the total number of PLHIV. The question is where does the other 99.2% went? Have they seek for help? Did they get any medications or any form of support and information or education? These could be the reason of the increasing number of infected person every year where these people is not well educate or well informed about the disease and thus they kept on doing their HIV-contributing activities. National Commisions of Aids (1993) stated that one-third to one-half of persons with AIDS are homeless or has a high probability of becoming homeless. Homeless people with HIV has a higher death rate than those in stable housing, , insufficient transportation to receive or follow up medical care, lack of awareness of services available and challanges to access help with daily activities (The Healthcare for the Homeless Clinician's Network, 1999).

4.0 Care and Support Programme for PLHIV in Malaysia

In 2012, under the Shelter Home Programme, the ministry of Women, Family and Community Deveopment (KPWKM) has primarily funded 17 shelter homes under the care of MAC and Partner Organisations throughout Malaysia. Services provided by this shelter home programme includes basic nursing care, palliative care, medical refferals, bereavement, counselling and psychological and spiritual service.

Name of Organisation	Client					Name of Shelter Homes	Location
	Men	Women	Women & Children	Children	Transgender		
KLASS	✓					Faith Helping Centre	Kuala Lumpur
DIC Pahang	✓					Casa Villa	Pahang
DIC Pahang	IDU					Casa Non Kasta	Pahang
DIC Pahang			✓			Casa Harapan	Pahang
DIC Pahang		IDU				Casa Femina	Pahang
CASP	✓	✓				Rumah CASP	Penang
PPIM			✓			Rumah Solehah 1	Kuala Lumpur
PPIM			✓			Rumah Solehah 2	Kuala Lumpur
ILZ	✓					Rumah Dignity 1	Johor
ILZ		✓				Rumah Dignity 2	Johor
WAKE				✓		WAKE 1	Kuala Lumpur
WAKE		✓				WAKE 2	Kuala Lumpur
WAKE					✓	WAKE 3	Kuala Lumpur
CWS	✓					Welcome Community Home	Selangor
Cakna			✓			Baitul Cakna	Terengganu
Kelab Rakan Melaka	✓					Rumah Perlindungan Lelaki	Melaka
KASIH			✓			Rumah Kasih	Sabah
Positive Living Community	✓					Rumah Perlindungan Lelaki	Selangor
Pertubuhan Harapan Kasih			✓			Rumah Perlindungan Wanita & Kanak-Kanak	Johor

Table 1: 17 shelter homes throughout Malaysia under the care of specific organisiations serves specifics clients. (*Source: Annual Report 2012 MAC & MAF, 2013*)

Besides shelter homes for PLWHAs, Hospis Malaysia also provides care for terminally ill patients who are at the end of life. However, the services are general and not specific for one types of illness. The clients could be old folks, cancer's patient or PLWHAs.

Based on the services provided by these shelter homes, it can be seen that the concept of shelter homes for PLWHA are the same as hospices. It can be concluded that shelter homes provides the same services as hospices. The difference between these two is the types of patients served and occurance or the placement of the PLWHAs and complexity of the services. Shelter homes focussed are to care and served for specific clients of specific illness while hospice serves for various clients. Besides that, shelter homes are basicly a place such as bungalows or housing units where the clients are placed whereas Hospice is an institute with complex services and bigger environment.

In Hospis Malaysia, many clients are old folks compare to patients with illness. PLWHAs are placed in shelter homes provided by the government and NGOs bodies. It is a good initiative that they are provided a

shelter. However, these shelters is not enough to accomodate these patients. Other than that, shelters has small compound to have activities that are organised by NGOs for the PLWHAs. Using a housing units instead of a customised building may cause lacking in facilities for the PLWHAs.

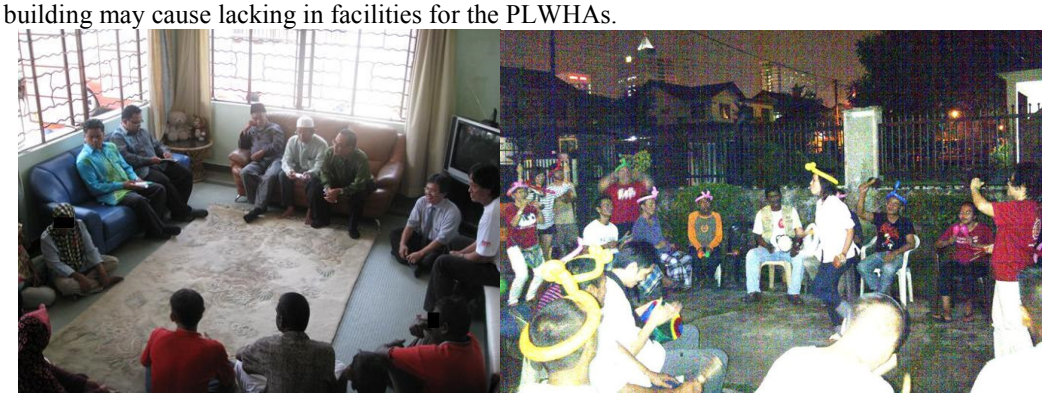


Figure 1: Activities in the housing compound for PLWHAs
(Source: MAC & MAF 2011 Annual Report, 2012)

5.0 Idea of Converting a Leprosarium into AIDS Hospice Centre

An abandoned leprosarium in Johor has characteristics that could be suited and utilised into a HIV/AIDS Hospice Centre. The idea of Hospice design by Stephen Verdeber and case study of Kalien Hospice Centre and Maitri Hospice for Aids could be implemented to build a hospice for PLWHAs in Johor.

5.1 Tampoi Leprosarium

Lot 46685 owned by Kementerian Kesihatan Malaysia is historically a site for leprocy settlement since the year 1929. The settlement was planned in a way that the lepers will be settling in a house instead of wards. In addition, this lot has a large area which allows the lepers to do farming and rearing of poultry and pigs. The location of the site by the Skudai River also allows the lepers do fishing activity.

Initially, in 1929, there are 10 housing blocks which are separated into two clusters of five blocks each. Each block consist of three rooms to accomodate three patients. In 1930, four villa type houses were built which can accomodate 8 patients for each villa. Three years later, four Chengai Huts has been built which could accomodate four patients. Two years later, they added up a marrieid quarter. Eventually, the places grew with two new sick wards, two concrete buildings and a barrack for watchman.Thus the settlemets has been providing a place for 250 leppers patient. The area are divided into three zones which are adminstration zone, quarters zone and facilities zone.

The location of this site is within 15-20 minutes away from Hospital Sultanah Aminah, Hospital Sultan Ismail, Johor Specialist Hospital and Hospital Permai Tampoi. It has a big compound that can provide a place for governments or NGO's to organised their activities for PLWHAs or awareness activities for the public. Besides that, the site is surrounded by residentials and basic facilities. Thus, PLWHAs could integrate with the community and increase social interactions to decrese stigmatisation. The existing Skudai river on the south gave a serene environment as water is one of healing elements.

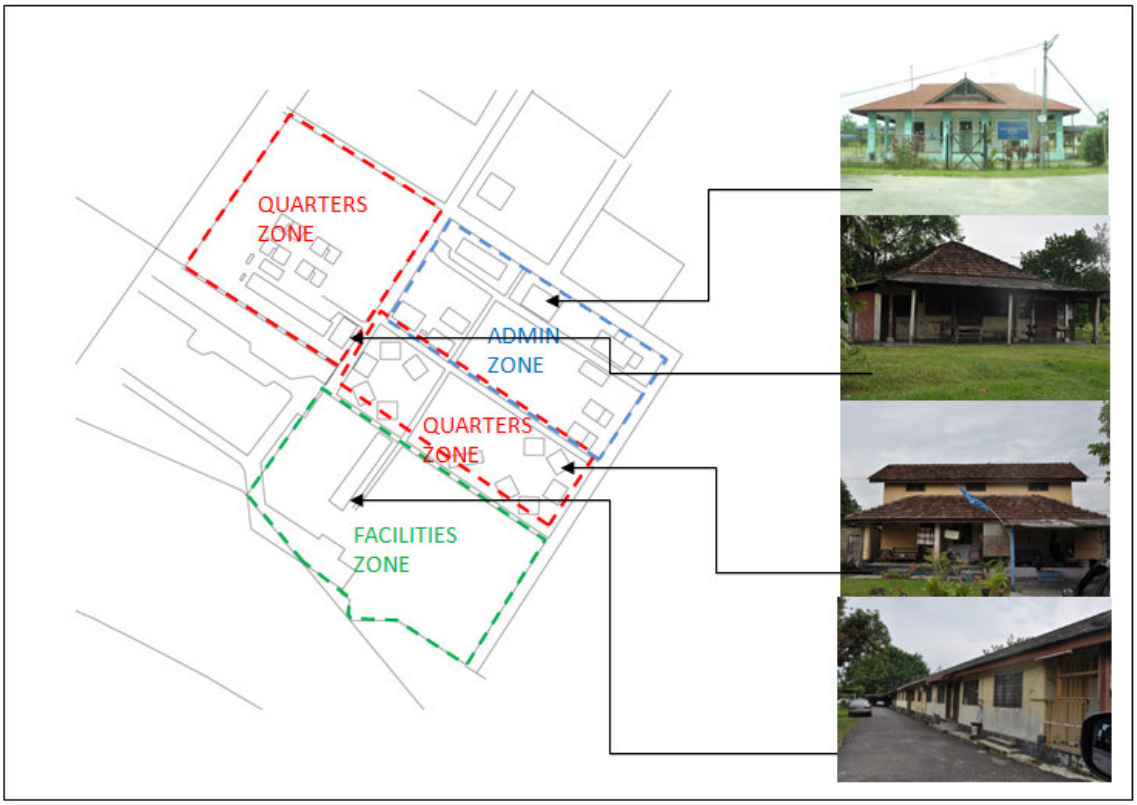


Figure 2: Zoning of the site & existing building on the site
(Source: Measured Drawing – Pejabat Pentadbiran Hospital Kusta Tampoi)

5.2 Space and Services Required

In Hospice Architecture written by Stephen Verdeber, there are seven different areas that should be taken into considerations when planning a hospice. The seven components include site & context, arrival spaces, common spaces, private spaces, transitional spaces, connection with nature and administration.

	Components	Spaces	Functions / Specifications
1	Site & Context	A distance away from hospital care	Easier n faster tranportation of patients.
2	Arrival spaces	External entrance Reception Ambulance Bay	-It is the first point of contact for members of the community and should display clear directions informing people where to proceed. should be well lit at night. -Likely to be part of larger facility. May include space for unit clerk. -Ambulance bay is important to allow emergency cases and the route should be in non traffic zone.
3	Common spaces	Family rooms kitchen/dining room resource library art therapy room aromatherapy room dayrooms activity rooms for children	For visiting families to spend quality times with patients -To provide a refreshment area where PLWHAs and family/visitors can prepare drinks and meals. outpatient faclities To provide apropriate space either externally or internally for children of all ages.
4	Private spaces	Bedrooms Bathrooms Nurses stations Staff kitchen Drug room Laundry room	To accomodate patients of any age, including a child in an environment which resembles a residential bedroom, while at the same time allowing for the necessary medical and nursing functions. There could be assisted bathrooms or ensuites(attached to bedrooms) Stores and Services
5	Transitional spaces	Circulation paths Elevators Maditation room/ surau/chapel /temples	-As a spiritual area
6	Connection with nature	Garden Courtyards Large windows	Provide a pleasant setting for the building with adequate sittings, clear and non-slip pathways, and desirable for outdoor activity.
7	Administration	Sluice room Cleaners cupboard Storage Offices Bereavement counselling room Backup power generators	Provide a place to manage the whole hospice

Table 2: Seven Components in Designing a Hospice

5.3 Case Study

1. Kalien Hospice Centre

Kalien Hospice Centre were design with a concept of campus featuring primary components of Hospice Care facility, Centre for Dialogue & Education, courtyard, private patios & gardens and public gardens.

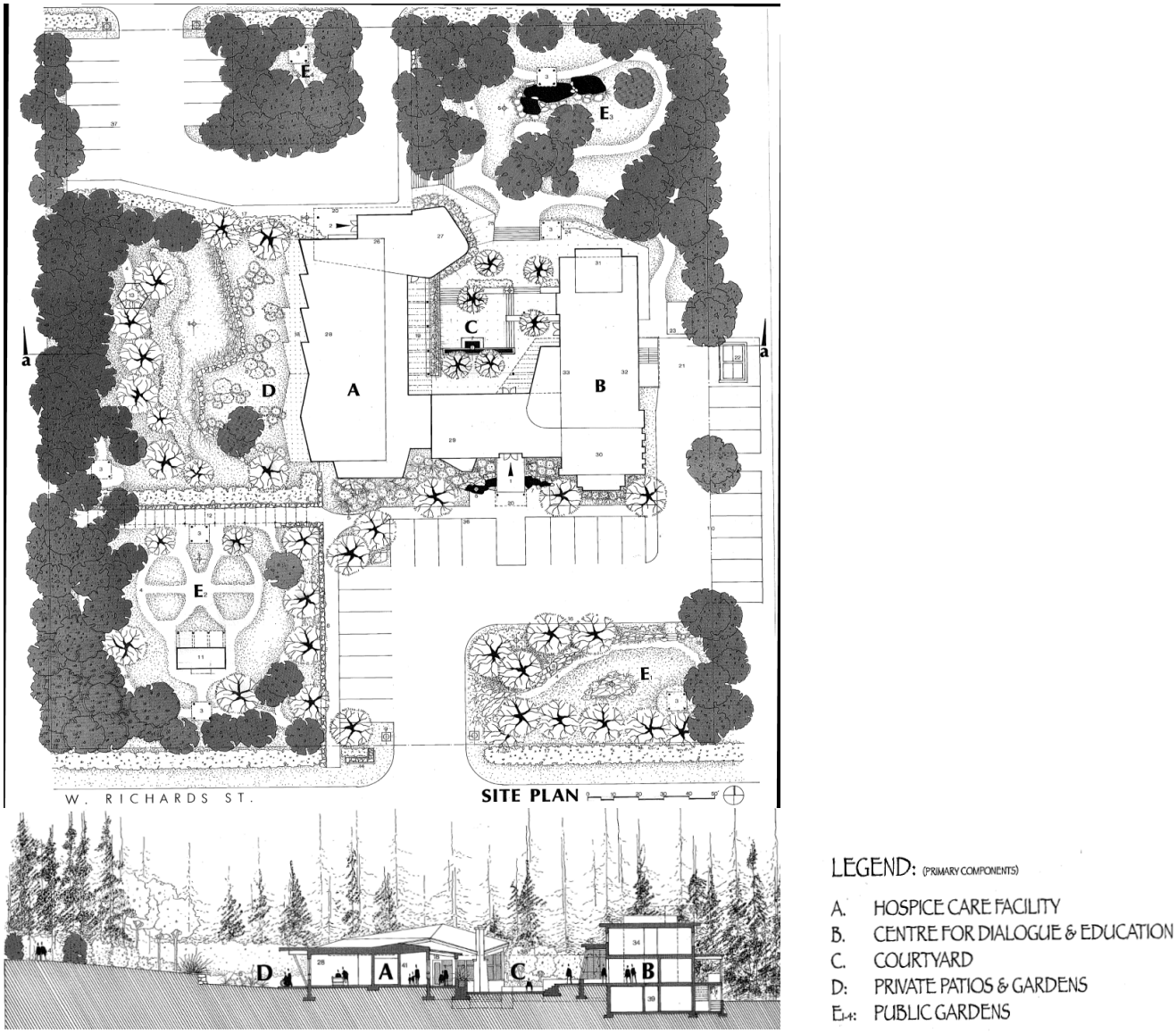


Figure 3: Planning of the Primary Components and Sections of Kalien Hospice Design

(Source: Kalien Hospice Centre Society, 2013)

The centre was build with existing site features and structures where a new building (Hospice Care facility) is connected with existing building (Centre for Dialogue and Education) and created a courtyard in the between. The planning creates efficiency in sharing functions and services while still maintianing adequate separation for privacy.

The primary components in these Hospice Centre is suitable to be adapted into the master palnning for AIDS Hospice Centre because the community basiclly needs a hospice facility while the supporting organisations need the Centre for Dialogue and Education to organise activities, creating awareness and educate people on HIV and AIDS and PLWHAs. On the other hand, courtyards are important as a transitional space and also acts as public spaces for outside community and PLWHAs to interact.

2. Maitri Hospice for AIDS by Kwan Henmi Architecture

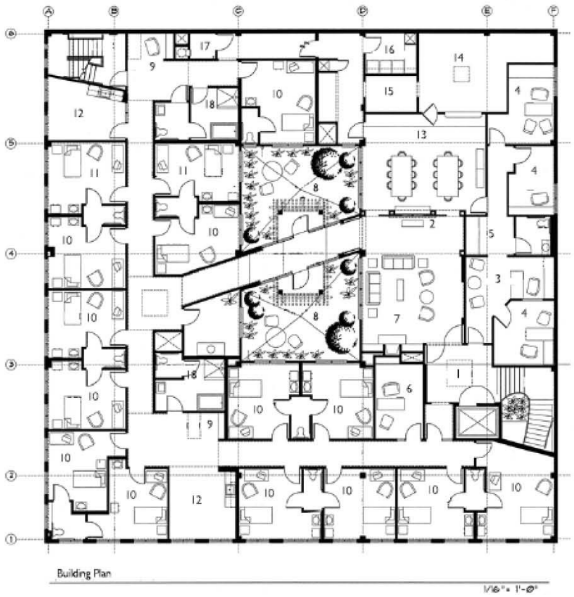
Maitri is a recognised leader in residential care for PLWHAs and served as a model programme. Maitri which is pronounce as "MY-tree" is a Sanskrit word that means compassionate friendship. Maitri started its operation in 1987 by Soto Zen teacher, Issan Dorsey. Maitri offers six components programme including nursing & attendance care, comfortable accomodations, food and nutrition, social work care environment, resident activities and volunteer programme.

In the explosion of AIDS epidemic in 1980's, Issan Dorsey started taking in homeless AIDS victim which eventually openned an 8 bed hospice in San Fransisco. In 1997, Maitri moved to a custom made building

with 15 private rooms. AIDS has become the common thing in the hospice over 25 years of persuing the treatments.

In order to enter or admit into the this hospice, the person must be diagnosed with HIV or AIDS. This HIV patient must be a san Fransisco residents and be 18 years older. The patient must also have an annual income of less then $31, 950. Maitri rooms are always full with waiting list of needed patients.

Kwan Henmi Architecture has designed the hospis to be revolving around a central courtyard. Meanwhile, the interior is designed to have residential feeling with lots of soft furnishing. Besides from the provided furniture in the hospice, patient's personal items and own furniture are allowed in the hospice (Allayne, H., 2012).



The programmes and the design considerations in Matri Hospice as shown in Table 3 can be sampled and applied into the proposed Hospice AIDS Centre.

Spaces	Design Considerations
	Light earth tones That helps in the vision Non skid flooring helps in the ability to walk without falling
	Replicating Buddhist aspects for spiritual purposes

	Private spaces with comfortable furnitures that compforts those who have bony prostusions which leads to painful skin breakdown
	Access to nature as a part of healing elements. Natural daylighting are used to give an adequate lighting into the building to assist their lack of vision.
	Communal meals room acts as a place for social interactions

Table 3: Design Considerations in Maitri Hospice

6.0 Conclusion

It is vital to know that one's last days are lived comfortably. The comfort can comes from a soft bed, time spent in the garden, one's favourite music or a loving touch. Despite all those comfort, the most important thing is that the patient and their family will feel being cared for under the environment that is calm, peaceful and comforting which we can call it a shelter from the storm.

6.1 Discussions

Role of Design environment for PLWHA

For PLWHA, designed environments provides more than a shelter. It also provides a setting to meet their physical, social and psychological needs (Zborowsky, T.L , 2008). PLWHA has a better oppurtunity to provide themselves with proper nutritions, hygiene and rest. A national study suggets that there may be a strong relationship between the provision of Housing on both transmission of HIV and the health of PLWHA. (Housing and Urban Development & Centers of Disease Controls, 2005).

The designed environment also acts as a setting for health and hospice care. Today, there have been an increase in the medical treatment in the home or home-like settings rather than hospitals because of current medical technology. It is suggested that PLWHA receives the care in these environments which provides them with maximum independence and dignity as well as allowing family members and significant others to

participate in their caregiving and reduces healthcare costs (Ungvarski, 1987). These includes of having some recreational area, gardens, gyms or places for them to go out for exercise or just to get some fresh air.

Moreover, social interactions can be improved from the design environments. Social interactions can occur between the PLWHA and formal or informal social groups. Formal social groups may include the skilled nursing facility and hospice care agencies while informal social groups are family, friends and volunteers or the non-HIV community itself. These interactions is important in giving support emotionally and spiritually.

Last but not least, by having a designated environment just for the PLWHA's can provide them with safety and security. This place could help them look out for each other because they share common needs. Moreover, in a homeless shelters, people with HIV/AIDS can became the victims of abuse (D'Adesky, 1992).

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