INFORMAL CAREGIVERS OF HIV PEOPLE IN MALAYSIA: UNMET SOCIO-ECONOMIC NEEDS AND RECOMMENDATION TO IMPROVEMENT

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Abstract

The consequences attached to the Informal caregivers (ICGs) of People Living with HIV (PLHIV) are numerous due to social sensitivity and the contagiousness of HIV. Therefore, this study aims to understand their perception of unmet needs and elucidate recommendations to improve their appropriate socio-economic resources. The qualitative study with four focus group discussions was conducted among IGGs caring for PLHIV in Kuala Lumpur, Kedah, Selangor, and Perak. A purposive sampling method was used to recruit n=23 female (n=14) and (n=9) male participants. The findings show that ICGs experienced complex perceptions in accessing social services and managing HIV-related crises. The low-income ICGs significantly expect the multiple support systems for their care recipients and children to enhance the well-being of care recipients and families instead of concerning their own self-care and personal development support. Their needs and expectations could be categorised into two primary forms: first, socioeconomic services such as financial assistance, employment flexibility, and stigma reduction intervention. Second, non-medical services such as emotional support and mental health services, caregiving training, medical transport services, and informational support. By drawing from their expectation of social support, holistic micro- and macro-level community-based strategies and supportive policy formulation are essential to enhance ICGs and the quality-of-care recipients.

Keywords: Informal caregiving, HIV/AIDS, socioeconomic needs, social support

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Introduction

Informal caregivers of People Living with HIV/AIDS (PLHIV) refer to someone who provides basic primary care, support, and services for PLHIV without receiving any salary or remuneration (Amaugo, 2019). Their caring role comprises home-based, either short-term or long-term. Usually, they help PLHIV in terms of caring for their personal health and hygiene matters, accompanying them to medical appointments, and providing emotional, physical, and financial support (Wilder et al., 2008). Meanwhile, the care recipient refers to someone who receives care regarding medication and requires assistance or comfort to perform their daily living activities, personalised care, and instrumental support to move around. This task may involve navigation of the health care; decision-making based on personal, family, or cultural and religious activities; managing and adhering to the treatment regime.

Stacey et al. (2016) noted that the prevalence surveys across countries Australia, the United Kingdom, and Canada have estimated that about one household out of twenty has a primary caregiver caring for their family member. Empirically, most literature shows that both men and women are involved in caregiving. However, women predominate the caregiving role as the nature of their contribution (Bastawrous, 2013; Kimemia, 2006; Prachakul & Grant, 2003; Swinkels et al., 2019). The multidimensional duties and responsibility workload encountered by informal caregivers may lead to multidimensional strain and socioeconomic burden (Folkman et al., 1994). Caregiving plays a routine and ongoing role. It arises from a relationship with the recipient in response to the need for support, which is greater than expected due to impairment in functioning.

Further caregiving among the HIV community is relatively invisible because the sensitivity of HIV issues and caregiving merges into the average relationship reciprocity; it is outside any formal agreements. The informal caregiver's burden is empirically categorised by four-dimensional strain as physical and emotional health, economic costs, and personal and social restrictions (Zarit, 2004). Interaction and connection between the caregiver and care recipient are described by emotional interaction such as loving expression, anger, stress and required adjustment in a relationship; for instance, HIV-related caregiving may demand a higher degree of patience in managing drug-user care recipients. The extension of burden may lead to mental disorders due to personal disadvantages of emotional coping, productivity loss, as well as disability due to perceived personal health problems (Alonso, 2013). In the local view, the data on ICGs is underrepresented. However, few Malaysian studies noted that family caregiving and its related research was primarily recognised in the late 1990s in child mental retardation, Alzheimer's, dementia, elderly care, and accidental injury or amputation caring (Ong et al., 1999). Providing informal caregiving for people living with HIV (PLHIV) is a newly explored topic in 2013.

The first study on family caregivers was conducted in the Malay community in Terengganu (Lua et al., 2013; Lua et al., 2014). The study pointed out that informal caregivers (ICG) - those caring for PLHIV, play an essential role in providing home-based care and moral support for their loved ones and thus experience various socioeconomic burdens.

Malaysia is far behind in terms of providing support and resources for informal caregivers of PLHIV. Although many countries are leading the way to improve the life quality of ICGs- those caring for PLHIV, Malaysia have limited policy provision in place to help carers. ICGs in Malaysia often shelter or share the welfare support provided to their HIV/AIDS family members. The first policies that included informal caregivers' wellness were the Community Welfare Policy 1990 and the Community Care Policy. This policy was initially initiated to address the needs and wellness of family/informal caregivers. This was later updated with the National Social Policy 2003. However, the provision and policy support for ICGs are unclearly described in this social policy (Siti Hajar et al., 2014).

Through a review of current literature in Malaysia, providing care for People Living with HIV/AIDS (PLHIV) may lead ICGs to encounter a wide range of burdens and deal with multiple coping strategies. The caregiving role is associated with physical, psychological, and socioeconomic challenges to informal caregivers (Fatimah Abdullah et al., 2016; Ong et al., 1999; Lua, 2014; Siti Norazah, 2007). The studies conducted by Siti Hajar et al. (2014), Lua (2014) and Zheng (2013) indicate that middle-income women or homemakers were the majority gender group performing resident caregiving roles instead of male ICGs, yet, reported multi-level workload caregiving commitment than those ICGs who live separately from the recipient of care (Siti Hajar et al., 2014). It is essential to emphasise behavioural medicine through multiple levels of social and ecological systems to reduce their caregiving burden and engage in self-care to maintain their well-being. The primary sources of first-degree social support (sorted by relationship affinity) are family, friends, neighbours and social groups that the individual is a member of. Second-degree social support includes civic groups and political and economic systems (Overholser, 1992). This study is pertinent to understanding the life needs of ICGs of PLHIV and their expectation of the social support system; from this study, we aim to provide fundamental information to the intervention framework and serve as a guide in enhancing the life quality of ICGs in Malaysia.

Methodology

There were 4 Focus Group Discussions (FGD) conducted on primary ICGs, those currently providing care for their HIV family member or partner, and those with higher to severe health impairment history or physical disability. A sample of 23 ICGs was recruited through the NGO network at Kedah (n=6), Kuala Lumpur (n=6), Selangor (5 participants) and Perak (6 participants), comprising male (n=9), female (n=14) ICGs of 25 years and above. The FGD interview schedule covers questions on their financial management, caregiving role, accessibility of social services, and social support expectations. Convenience sampling was utilised to encourage the ICGs to participate in FGD with a network of the abovementioned NGOs. The NGO introduced individuals who were screened to determine if they were eligible or fulfilled the criteria of lower income status B40 and below and their desire to participate in the study.

The ethical permission for conducting this study was obtained from the University Malaya Ethics Committee, No. UM.TNC2/UMREC-230, 2019. Participants were informed on the standard ethical practices involving participant's anonymity and confidentiality through a 'patient information sheet'. The FGD was conducted in Malay; all Malay audio was transcribed and translated to English by the researcher to protect the confidentiality and anonymity of the participants. The FGD time was, on average, about 60 minutes.

The data set was organised and analysed using QSR N-Vivo version 10. The responses to the questions were analysed using N-Vivo 10 Qualitative Software. The FGD and in-depth interview session were audio recorded; the audio was transcribed and translated from Malay to English. The translated transcripts were verified by researchers and read through again at least twice. Then, the key themes and patterns of subthemes were identified based on research questions. Afterwards, the data were searched to detect saturation of ideas and recurrent patterns of similar meanings and expressions. After the identification of core themes, each essential interview citation was coded, and the coding was grouped to construct the conceptualisation of the study.

RESULTS

Demographic background of participants

As depicted in Table 1, the median age was 41 for the participants who participated in FGD. They were predominantly (78%) Muslims, and nearly half were married or living with a partner (13%). The majority, around 13 (56%) of participants, were located in urban areas, which comprised townhouse areas, low-cost flats and urban slums. This is followed by 13 (43%) participants located in rural areas, and 3 (18%) reported having left semi-urban areas. The majority, 56%, reported earning an income below RM1000 (USD 232). Meanwhile, 8 participants (34%) were unemployed recently due to reasons of wanting to concentrate on caregiving responsibility alongside HIV-related health problems. The participants reported having worked as street cleaners, cleaners at orphanage homes, sales promoters at shopping complexes, and cleaners at fish markets alongside restaurant workers. Two of the participants were reported to be former drug users. Almost 80 per cent of the dependents relied on the participant's income for survival, especially children, palliative or physically disabled HIV spouses or cohabitating male partners, including unemployed injecting drug user (IDU) spouses.

Socioeconomic issues faced by ICGs

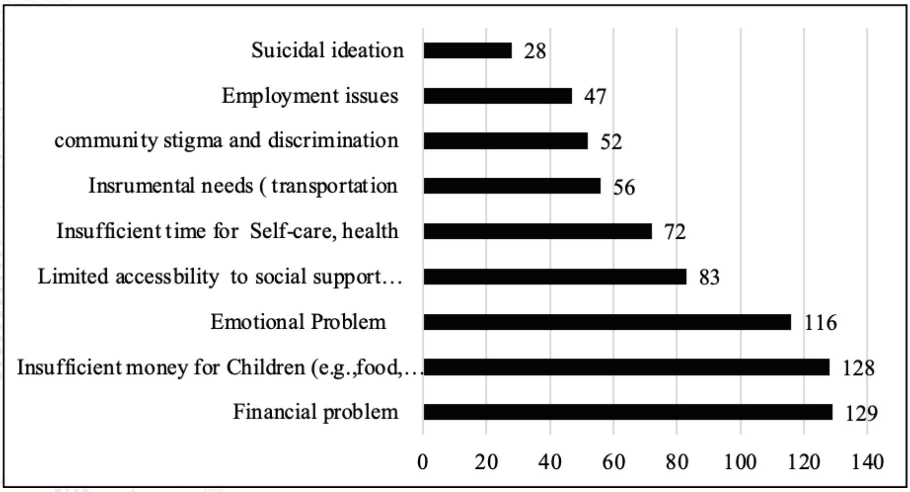
Figure 1 depicts themes discussed by ICGs in FGD. The thematic findings show that participants experienced various dilemmas due to heavy caregiving routines and surrounding socioeconomic circumstances such as impoverishment, health issues, and inadequate household income. The financial challenges of providing adequate caregiving support for their CR and family, including for children, were the most lamented themes. They were followed by the themes of emotional problems, such as living with anxiety, fear of the future, and suicidal ideation. Participants also mentioned their difficulties in accessing social services (e.g., issues in getting welfare funds, rejection of welfare fund applications, hassles in managing with public administration and getting a claim scheme for their illness or morbid condition from Social Security Organization PERKESO (SOCSO) as well as Baitulmal Funds (for Muslims). This discussion expanded to essential expectations and suggestions for improvement in the second phase of the FGD session. Their themes encompass support: (1) health and non-medical support needs, (2) social-economic support, (3) workplace support and employment policies change on flexible working arrangements, and compassionate leaves, which requires an interdisciplinary and macro level multidisciplinary approach, and (4) practical caregiving education and training.

Table 1 Participant's Background

	(N)=23	Percentage
Age		
25-35	4	17
36-45	14	60
46 -55	5	21
Marital status		
Married	11	47
Cohabitate	3	13
Single	1	4.3
Widow	5	21
Divorced/separated	3	13
Gender		
Male	14	60
Female	9	40

Ethnic		
Muslim	18	78
Indian	3	13
Chinese	2	8.7
Income		
0-1000	13	56
1001-200	8	34
2001-30004	2	8
Working status		
Full time/ part time Working	15	65
Not working	8	34
HIV status		
HIV positive	20	86.9
HIV negative	3	13
Welfare support		
Received monthly welfare fund	8	34
Living without any welfare fund	15	65

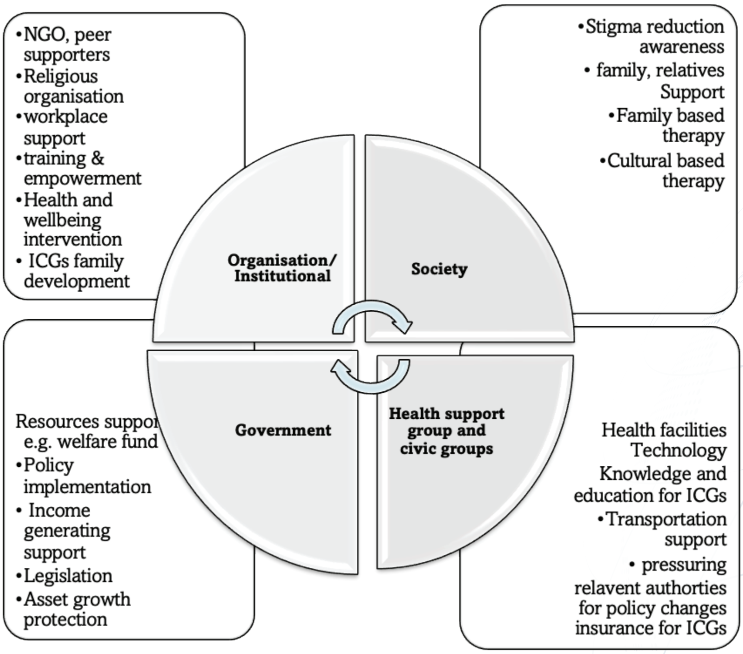
Figure 1 Socioeconomic Issues Faced by ICGs



First, the government and NGOs are expected to collaborate to support the HIV community, thus enabling them to live a more productive life. Such collaboration should provide ICGs with the opportunity to live healthier lives and ensure they have access to social services. The ecological perspective introduced by Bronfenbrenner

(2005) can be applied to explain environmental influences such as individual, community, societal, and organisational roles in enhancing the intervention on the life improvement of ICGs and reducing the burden to boost positive coping strategies. According to Bronfenbrenner (2005), studies related to ecological perspectives indicate how people live and interact within the environment. This infers that human beings develop according to their environment. Thus, the interrelation is divided into a microsystem, mesosystem, exosystem, and macrosystem. This also includes individual interrelated and changeable behaviours, which reach equilibrium and equality, such as relatives, family, friends, and teachers. Finally, it describes the extent of the interrelation with the government policy, culture, society, and global system. Further, ICGs engage in practice at all levels, including micro, mezzo, and macro, aided by an ecological approach. Thus, the ecological approach intervention at the community level is essential, as well as the government's involvement, organisations' and institutions' support, societal group intervention, and legal rights (e.g., legislation) NGO peer supporters. The recommendations to ease ICG's burden and enhance positive coping are demonstrated in Figure 2 and Table 2.

Figure 2 Intervention Recommendation



The needs for caregiving training and HIV related information for ICGs

Studies show that skills, counselling, and coping training for family members caring for a person with illness at home reduces burden and stress among the caregivers (Houts et al., 1996). The job-family caregiving balancing motivational programmes and stress management workshops should be given to ICGs. Based on participants in this study, NGOs such as the Malaysian AIDS Council and KLASS for PLHIVs, PT Foundation have conducted several workshops and empowerment programmes, particularly for the HIV people. However, the programmes needed to be covered by their ICGs. For instance, the COPE (Creativity et al., and Expert information) technique

Table 2 Recommendation of Strategy and Intervention Description

Strategy	**Description of interventions**
Managing emotional problem	• Increase social support system– e.g., education, motivational support training programs on the management of grief, management of stress, anger, counselling to accept the influence of the HIV course. • Religious institution support, spiritual meeting, training. • Regular suicide risk assessment (could be conducted by psychologist)
Managing financial problem	• Improving income-generating activities, improving small scale business skills, micro-finance loan, subsidies. • Increase welfare fund (government, private sectors, Hindu religious institutions, open channel for international donors). • Debt managing team to provide financial advice. • Legal protection on properties among HIV people (loose the bank loan default procedure to avoid withdrawal of their property, legal rights protection from their properties possessed by relatives or family.
Overcoming inadequate food	• Monthly or weekly food voucher • self-reliant programme- home garden farming skills e.g., farming adequate vegetables at home
Managing caregiving role	• Training on caregiving, medical care, and palliative care. Training on the knowledge of HIV /AIDS. • Training on managing relationship gap between ICGS and CR.

Continue Table 2

Technology and devices Improvise social networking and social services	• More efficient and sustainable use of resources. • Increased livelihood. • Smart mobile access- medical advice, caregiving Apps. • HIV and caregiving related knowledge and educational materials in their mother tongue e.g., Tamil newspaper articles, brochures, booklets, social media, short film, videos on caregiving and websites to offer information for HIV community in Tamil language. • Expand NGOs centres in urban poor and rural area. Sharing Message and knowledge
Policy changes	• Form national policies and plan of action plan particularly for ICGs. • Loosen welfare policy's tied requirements. • Employment policy, e.g., flexible working hours. • Policy changes on Children's Welfare Assistance Scheme to allow all HIV infected and affected children to get financial and educational aid. • Loosen the Social Security Organization (SOCSO) withdrawals.
Handling employment issues	• Anti-discrimination policy on PLHIV at Workplace. • Paid leave/ leave grants time away from work to care CR e.g., medical appointments. • Insurance scheme for PLHIV /ICGs. • Negotiation right with employers to provide non-tangible working. • Flexible working hours, flexible work task arrangement.

Continue Table 2

Stigma reduction awareness	• Education-involvement of social organisations and religious-based associations. • Social media broadcast (public and private media). • The campaign, awareness booth. • Self-stigma reduction programmes, such as one-to-one counselling of ICGs, and engaging PLHIV community in social activities. • Identify the degree of community stigma at organisational and institution level through conducting surveys, workplace seminars, and talks. • Faith-based organisation and social association's involvement – religious and spiritual teaching in helping the HIV community.
Caregiver's support group	• For medical knowledge as well as emotional support, channelling welfare/social support from government and NGOs.

to empower and enhance caregiving skills helped them to plan and react to caregiving challenges (Houts et al., 1996). Hence, it is recommended that, like COPE, other localised skills programmes should be carried out by relevant authorities to mitigate psychosocial problems and relevant training programmes such as individual counselling, workshops, and longer-term positive impact assessment.

Therefore, the training on how to care for PLHIV, such as first aid, medical care, palliative care, knowledge of HIV/AIDS, and ICG behaviour, changes the strategy to understand CR's emotional capacity to overcome the relationship gap between ICGS and CR. The training programmes also should emphasise HIV knowledge, improving medical care skill development at home. For example, based on findings, most of the participants felt that they have very little understanding of the medical and psychological problems being experienced by the CR, thus indicating the need for guidance from health professionals.

Mental health and motivation

Apart from that, the study shows that there is a suicidal risk among ICGs. Therefore, developing a plan to address high-risk ICGs and PLHIV, including those at risk for self-harm, is incredibly needed. Regular suicide risk assessment screening and interventions should be developed by NGOs, psychologist, and health care workers among the ICGs and care recipients. Furthermore, immediate action involving those at risk regarding suicidal prevention processes by giving counselling motivational and peer network support is needed (Schlebusch & Govender, 2015). Additionally, it is essential to understand that ICGs can also play an important role in motivating

CRs and providing emotional support for CR in preventing suicidal ideation among HIV CRs.

"When I asked, a lot of problem raised. At one point I consumed poison because of the problem "…sometimes we felt so down, I couldn't manage a lot of things…"

(Age 36, Female, widow, working as security guard, FGD2 Kedah)

"Maybe we need this kind of support, or treatment for calm our mind…usually doctors speak (advise) about how to take medicine [Continued by other participant], whenever we go for an appointment doctor more talk to them (talk to HIV patient instead of their caregiver) (motivation to medication adherence) instead of ideas how to relax our mind".

(Age 41, Female, married, factory worker, FGD1 Kuala Lumpur)

"Yes, it would be good, maybe we need someone can teach us to make emotionally controllable…maybe training".

(Age 32, cohabitate with partner, Male, executive, FGD1 Kuala Lumpur)

Managing employment issues

Besides the fact that caregiving affects their job performance, low job performance also affects their income and the depletion of financial resources and savings. Further, an anti-discrimination policy for HIV-positive employees in the workplace is needed in Malaysia to protect the labour rights of PLHIV and their ICGs. Limited supportive working environment policies for ICGs were implemented to protect their employment rights in Malaysia. Their stories illustrate their struggle to adjust to their employment needs and heavy caregiving workload. Due to the dynamic nature of caregiving over time, most of them stated that they only manage part-time jobs and stand to return home in any emergency cause instead of full-time jobs. A provision never covered their part-time job for compassionate leave. Therefore, they were often absent and took unpaid leave to manage it. Participants chose to use their unpaid leave rather than try to explain the situation to their employees. They rarely disclosed their own HIV status or the status of the care recipient, although they were asked for reasons to explain their poor performance before they were terminated from their employment.

"Hmm… income not even reached RM1000 (USD 228), the worst is last month, they ask me to stop coming work. I got around RM 600 (USD136) …hmm RM680 (USD155) only (last salary), because took leave for more 4 days, for send him for medical appointment and the other day…he was fall down, injured…stayed at home (absence to work) for 2 days to care him".

(Age 31, female, married, has 2 children, shopping complex cleaner, FGD2 Kedah)

“No! No chance…it is not allowed to come home and return work (time off) maybe for a while they allow, like 1 to 2 hours, if more than 2 hours…must take unpaid leave. I told him (supervisor) my husband falls down, rushed home I took him to hospital … he (supervisor) said ...if the duration more than an hour it considers as unpaid (falls under unpaid leave”.

(Age 48, female, married, factory worker, FGD3 Teluk Intan)

Evidence from various previous studies shows that workplace environment support for the HIV community and flexible employment policies for ICGS can be positive and practical (Ireson et al., 2018; Williams et al., 2017). Such measures include the establishment of workplace support such as groups to address the needs of caregivers’ families, opportunities to work part-time or share a job without loss of seniority or rates of pay, flexible working arrangements and a provision of annual entitlement to paid leave for family responsibilities, and ICGs support scheme.

In Malaysia, few high-profile companies have adopted policies for PLHIV employees. To date, companies such as PETRONAS, Sime Darby, and GlaxoSmithKline Pharmaceutical Sdn Bhd (GSK Malaysia) have adopted the code of practice on the HIV/AIDS workplace policy in Malaysia. Also, 42 government-linked and multinational companies have planned to accept these codes by the year 2019 to protect HIV/AIDS workers and eliminate discrimination at the workplace, such as not terminating an employee just because they are diagnosed with HIV. However, these policies do not include employees- those HIV-negative/normal ICGs who provide care for their HIV family member or partner. Further, based on this study, most ICGs and PLHIVs are from a lower income group (B40), working in Small and Medium Enterprises (SME) instead of high-profile companies. SMEs need to adopt these policies to benefit the most deserving group, such as the middle to lower-income or hardcore poor HIV community. First, the government and NGO’s mechanism for working with ICGs should lead them to live in a healthy working environment and ensure they generate enough income and sustainable livelihood.

Also, the legal rights of HIV caregivers at the workplace are an essential mechanism to guide them. Thus, they must also be allowed to negotiate with their employers to provide non-tangible working hours or schedules, caregiving allowance, and companionate leaves to manage their caregiving role. It could be one of the major strategies to reduce stress and ease their burden.

Social support needs for ICGs' children

Considering children as a coping factor among community volunteers, NGOs of HIV services and the Ministry of women welfare need to recognise the 'hidden' role of children in the HIV response. More community-based programmes should be initiated for HIV community Children's socio-psychology development. Also, the Ministry of Women, Family and Community Development and the Ministry of Education should increase more programmes and activities such as tuition classes, counselling, children's play, and therapy, as well as hold meeting for HIV affected children, provide knowledge on HIV/AIDS, computer classes and child development programmes. The Children Welfare Service Unit and Child Protection Service Unit under the Ministry of Health should include financial support in education, food, and health issues of HIV infected or affected children.

Furthermore, the Women, Family, and Community Development Ministry should include a special clause for HIV/AIDS infected and affected children in the National Council for Children. Thus far, the council covers the welfare for disabled children, underprivileged children, managing children abuse, deprived children, children with juvenile behaviour, as well as problematic children. Poor and disadvantaged children welfare policies due to HIV /AIDS or other illnesses should clearly be defined in this council's children welfare and children protection services.

"True also… children need food (food expenses), tuition fees, we are approaching December, school opening soon, all fees we must bear".

(Age 43, female, married, part-time house cleaner, FGD3 Teluk Intan)

(Interfered by another participant) "last time we got RM 100 per month for my son, later after few months …nothing, no money transferred in his account…I called the NGOs, they said no more fund to pay because no budget from management (discontinued with fund). No longer term support make us difficult … at least we need until they enter college or university".

(Age 33, female, married, housewife, FGD3 Teluk Intan)

"I got for my daughter, RM50…but not enough. Still have to pay school fees… she also wants to have maths tuition…"

(Age 46, female, widow, school cleaner, FGD4 Klang)

"You see…Now the teacher gave a letter to my daughter to wear spectacles. Because during exams, she couldn't see properly. It will cost about RM200-RM300, maybe more than that. I won't know with whom I can ask".

(Age 48, Male, married, lorry driver, FGD1 Kuala Lumpur)

Intervention to improve financial status

To manage the financial burden among the ICGs, household economic strengthening activities and social support intervention are essential according to five categories: (1) social, financial assistance, (2) income-generating activities, (3) asset growth and protection, (4) managing ICGs debt, as well as (5) managing inadequate food in the households.

The first intervention is that the government and non-profit organisation should raise their social financial assistance to ICGs to help them overcome their short-term financial problem. Only 34 per cent of participants of this study mentioned (As indicated in Table 2) received around RM 150-350 per month (Department of Social Welfare, 2016) as financial assistance from the government, which is considered relatively low for survival when weighed with the cost and Consumer Food Price in Malaysia (Department of Statistics Malaysia, 2023). Therefore, the government should consider increasing this fund for the HIV community, reducing the bureaucratic procedure, and loosening the participants' eligibility criteria to get financial assistance to allow more financial benefits.

It seems non-Muslims in Malaysia are not eligible for Islamic welfare funds; economic experts, social workers, and NGOs should strive to form specific social financial fund development mechanisms for pooling various forms of financial assistance for the poor non-Muslim population in Malaysia, similar to "Zakat" and "Baitulmal" which is specifically available for Muslims in Malaysia (Zahri Hamat & Hanapi, 2017). For instance, Singapore and Mauritius formed seed funds from the Singapore Indian Development (SINDA, 2017) to help poor and needy Indians in Singapore. Similarly, the Chinmaya Mission in Mauritius and the West United States focus on socioeconomic development for minorities (Chinmaya Mission, 2022). Therefore, more government funds should be created for marginalised minority community ICGs in Malaysia.

The study shows that the financial burden is a significant burden among participants in this study. Therefore, the income generation interventions might reduce the ICG's financial burden, which may also lead to a reduction in their economic dependence on others, feelings of self-confidence, and power within relationships, thus making ICG participants to be more able to cope positively, as compared to using negative or maladaptive techniques. In addition, this intervention can be of much effectiveness by accumulating savings to replace assets or properties that they have lost during periods of sickness or to build assets for the future (for instance, buy a house (based on our qualitative study, 75% of the participants in this study do not own a house), to pay for the education of their children, as well as saving for health and medical cost.

Medical transport services and other instrumental support

Based on findings from the study, poor participants from rural and semi-urban areas located in Kuala Selangor, Klang, Teluk Intan, Pendang, and Kulim mentioned that they encounter transportation difficulties in bringing their CRs to attend medical appointments in the hospital, as quite a number of them do not possess their transport and thus had financial lack of bearing the travel cost; which made them seek assistance to transport their disabled CRs. Therefore, the social welfare department and NGOs, with the government's support, should increase the door-to-door transportation support services to the PLHIV homes. The support should concern the rural, urban, poor PLHIV community, as well as the disabled PLHIVs. Further, it was requested subsidise the half-fare travel coupon or card in public transport services and provide transportation such as GRAB and taxi, which may help in offering free travel to hospitals or at a discounted rate or introduce a monthly travelling pass (a transportation scheme for PLHIV community and their ICGs).

"Sometimes, my uncle wont around, I must think how to travel to the hospital, take taxi also cost about RM20, then must get another bus… hassle, so tiring, both getting old, I also have many health problems (ICGS also HIV positive), I would get free of mind if they provide transportation …something like van, car to reach hospital" (to attend medical appointment).

(Age 51, female, married, part-time restaurant cleaner, FGD3 Teluk Intan)

"If they could provide transport, I won't depend on my brother to send us to the hospital, he shouldn't take off for work".

(Age 29, male, cohabitate with partner, admin clerk FGD3 Teluk Intan)

"My son…you see right? he couldn't walk now (19 years old son living with HIV, physically disabled), I am asking for wheelchair…no response, I went to welfare department few times ready (to seeking for help)".

(Age 48, female, single mother, restaurant cleaner, FGD 2 Kedah)

Stigma reduction awareness

Based on this study, stigma is one of the major driving factors of the emotional burden among ICGs. They experienced community stigma at multiple levels, including family level, community, and institutional level, from relatives, neighbours, at school, working workplace, health care workers, and public and private social service providers. Notwithstanding, Pulerwitz (2010) noted that the first step in stigma reduction is identifying or recognising the existence of stigma on HIV at the organisational and institutional level before proceeding to the community level, for example, among healthcare workers, in the workplace, in school; thus, the public and private institutions should conduct co- workers assessment, survey among their staff to identify the degree of HIV related stigma. Once this is determined, an education intervention is required with a concrete explanation as to creating an understanding to avoid HIV stigma and discrimination.

For example, a study conducted in West Malaysia among the Indian population shows that the respondents (general public) demonstrated a negative opinion that HIV is a ‘sin’ or ‘punishment’ disease. Therefore, PLHIV deserves some public discrimination. However, after being given a brief HIV knowledge and discussion session by social workers, the respondents expressed regret for having a discriminatory attitude perception towards PLHIV. They stated they were willing to accept them as part of their society (Sarasuphadi et al., 2019).

Therefore, it is essential to sensitise the Malaysian community and broaden social engagement for environmental change. This may start with the intervention in sharing information on HIV knowledge to educate them on how HIV is transmitted, how HIV is not spread, and provide awareness of PLHIV’s rights. The government and NGOs should scale up effective awareness campaigns, booths, and media programmes in many local languages.

In addition, health institutions and NGOs should scale up the one-to-one counselling to ICGs to help reduce self-stigma and encourage the PLHIV community in social activities. Stigma reduction allows the PLHIV community and ICGs to escape from shame and the fear of being stigmatised and discriminated against. Further, it may help them to present themselves to social support and medical treatment support. On the other hand, this helps reduce their various caregiving and emotional burdens.

Caregiver’s support group

HIV-related NGOs such as the Malaysian AIDS Council, PT Foundation, and CASP in Malaysia facilitate hospital peer support group systems for PLHIV in providing emotional support, HIV knowledge, and practical help in urban areas and limited rural areas. However, there are no specific caregiver support groups to support ICGs in Malaysia. Based on the majority of HIV-negative participants, HIV-related knowledge, medical knowledge, and emotional support are provided for PLHIV by healthcare workers for PLHIVs; meanwhile, the ICGs gain little knowledge and emotional support when they accompany their CR to attend medical appointments and NGO meetings or programmes. Thus, it is essential to form a specific long-term support group for ICGs to access and gain knowledge on HIV/AIDS, share caregiving knowledge, and channel them to health facilities and community-level services.

Further, one-to-one telephone call follow-up and training, for instance, Stewart (2001) pointed out the intervention of a telephone support group to follow-up progress of ICGs of PLHIV ripped positive responses and decreased loneliness among Canadian ICGs. The follow-up consists of the investigation of interaction between caregivers and peer supporters or psychology trainers, such as an individual home visit by trainers, which may help in ensuring success for the ICGs with regards to assisting the CR and improving their confidence level, which in return increases the caregiving motivation and makes it easier to obtain cooperation from the CR and the problem-solving process.

Yazdankhahfard et al. (2019) noted that caregivers and social workers should share their feelings and experiences and provide sufficient medical education and practices with their peer support groups, which social experts represent. Therefore, the adaptation of the Balint support group system, which was introduced by Michael Balint in 1950, could be implemented, as it can help to provide efficient intervention to manage ICG issues. The Balint model is a case presentation or emotional expression session given by ICGs to several social experts such as facilitators, social experts, health care workers, social leaders, and experts to get feedback and further intervention to solve ICGs problems. Several studies have noted the importance of expert peer supporters' role in reducing emotions and coping among caregivers using Balint support groups (Frost, 1994; Popa-Velea et al., 2019; Yazdankhahfard, 2019). Among the significant issues considered was the assurance of ICG privacy in handling this model among the HIV community.

DISCUSSION

The study found that ICGs in this study played a critical role in communities' readiness to respond to the HIV epidemic. Although the FGD data set supports the findings of this study, the secondary evidentiary documents such as field notes, salary slips, medical supplements receipts, children's school fees receipts, family photos, NGO financial support forms, welfare application forms, phone messages of peer supporters were referred to justify their statement. The indications that participants in this study were struggling with household finances, insecure employment, food, school fees, community stigma, and instrumental needs, e.g., wheelchair, transportation needs to attend medical appointments and other healthcare activities, consistent with other studies in Kenya (Kimemia, 2006), Thailand (Vithayachockitikhun, 2009), India (Asadullah et al., 2017).

All Malaysians are provided equal rights in getting medical treatment and free first-line treatment in public hospitals and health organisations. The National Strategic Plan Ending AIDS 2016 -2030 highlighted testing and treatment as one of the leading national responses to end AIDS in 2030 in Malaysia. Malaysia expects 90 per cent coverage of ART (90 per cent of diagnosed HIV infection will receive antiretroviral therapy) and is expected to achieve viral suppression as well as reduce HIV-related death (Malaysian AIDS Council, 2018; UNAIDS, 2014). The decline in HIV/AIDS-related death does not imply that it improves the life quality of PLHIVs in Malaysia. Knowing that HIV and HAART medication is intolerant of the body as well as the PLHIV's demographic trend, which reported that a majority of them are in their middle age and are moving into the group of ageing cohort persons, the emotional and biological challenges in the future may increase. Therefore, the role of ICGs is significant in providing emotional support and assisting HIV care recipient to perform their daily activities of ADL and IADL.

Most ICGs from lower income categories indicated financial assistance needs and instrumental support to improve their care recipients' health. In addition, employment management and financial support for their children's education are the most lamented needs among ICGs instead of asking for help for their self-health care or personal development. Knowing the fact that the majority of the ICGs are also HIV positive, this foregone ignorance of self-well-being could have significant health consequences among ICGs. As demonstrated by Folkman and Lazarus (1980), the social economic pressure and workload burden of daily caregiving activities may influence the mood of individuals to perceive a negative outcome (e.g., mental disturbance, anxiety, suicidal ideation, behavioural disengagement, social withdrawal).

Moreover, it could allow HIV transmission to non-HIV groups. For instance, several studies on African, American, Asian, and Latin American populations reported that poverty among the HIV community, including their family members and caregivers, led to HIV risk behaviour. For instance, the impoverishment made them vulnerable to drug culture and other substance use, commercial sex work, trading sex for food, or paying their education fees or transport fees (Kaufman & Stavrou, 2004).

Therefore, further research in measuring health conditions among ICGs is crucial, particularly among hardcore poor or B40 category ICGs. Like those above, the welfare department, with the collaboration of NGOs, should conduct an assessment survey among the PLHIV community and their ICGs to identify their socioeconomic challenges in accessing social services available in Malaysia. The policymaking and community-based health promotion intervention should align with government social development policies integrate with universal policies and local socio-ethnic cultural values, essential for addressing ICG's caregiving challenges.

Malaysia has very limited protective and supportive policies for improving the quality of life of ICGs. Meanwhile, other regional neighbour countries have begun to serve their ICGs. For instance, the Singapore Health Ministry implemented the Caregiver

Support Action Plan, which covers e-platform to ICGs access to informational, workplace support and grant (Work-Life Grant) financial support, caregivers training grants, community outreach teams to support caregivers' socio-emotional needs (Ministry of Health Singapore, 2019).

Studies also show that underdeveloped countries such as India or African regions with limited economic support and social resources successfully developed their intervention for ICGs. Their social interventions are bound to have a significant impact on home-based care for PLHIV (Osafo et al., 2017; Rotheram-Borus et al., 2011). For instance, Vumilia is one of the intervention programmes implemented in Western Kenya for 30 HIV ICG women; the Self-Help Group (SHG) was formed in the neighbourhood together with church support to train these participants. The local business icons and social workers donate their farms to HIV-positive people to help them farm and grow vegetables to provide food for their families. The social worker also offered emotional support training and counselling programmes to the ICGs, primarily women. As the study's outcome reported, their group successfully produced and supplied vegetables for 700 people who lived in neighbouring villages (Osafo et al., 2017).

In addition to a more rigorous outcome, the intervention strategies and its management should consider a high degree of confidential assurance due to the sensitivity of issues dealing with HIV. This is because the caregivers of HIV patients often provide a 'hidden' caregiving role due to the social stigma and moral disengagement blame attached to them. This is different from caregivers managing other diseases or disabilities. The intervention programme would require a considerable budget. Ultimately, it would depend on government and social support systems to form effective collaboration, including multi-level, e.g., local, and international social networks, thereby promoting better engagement.

Further, the seed fundraising may also include financial contributions from international non-profit organisation donors. For example, the national movement of Grassroots Organizations Operating Together in Sisterhood (GROOTS) in Kenya Community Based Association for Community Welfare (UCOBAC) in Uganda launched the Home-based Care Alliance (the Alliance) in Africa. Their collaboration provided a global network to support ICGs. The Alliance provides an outline for home-based caregivers in providing advocacy, mobilization, networking and organising as well as negotiating on ICGS employment; their programme successfully identified many 'hidden' ICGs with registered 30,000 participants as of 2012(Ransom & Asaki, 2014).

CONCLUSION

The study demonstrates fundamental information on intervention and issues encountered by ICGs of HIV people in accessing social services. Therefore, addressing their unmet socioeconomic needs with environmental and behavioural medicine is essential to overcome the adverse effects of caregiving services. Sustaining attention at individual, community, societal, and organisational levels in reducing burden and boosting positive coping strategies must be a high priority. Meanwhile, it should be available for all segments of the community regardless of religious restriction, cultural control, gender identity, or ethnic variations in order to alleviate suffering and maintain PLHIV dignity. Thus, assessment and further studies on social needs screening, as well as opinion-sharing sessions with the HIV community, related NGOs, health care workers, religious and community leaders, social workers, and other relevant authorities, is essential for spelling out the intervention mechanism.

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