International Journal of Psychosocial Rehabilitation, Vol.24, Issue 09, 2020
ISSN: 1475-7192

The Role of HIV/AIDS Cadre on Improving Quality of Life among Women with HIV/AIDS in a Community Setting: A Qualitative Study

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Abstract--- *In responding to the AIDS epidemic in Indonesia, HIV/AIDS cadres have been formed derived from various elements of society, but their role is still below the optimal target to support for care, physical and psychosocial mildness of vulnerable women with HIV/AIDS. The aim was to explore the experience of of the role of HIV/AIDS cadres on improving quality of life among women living with HIV/AIDS in a community setting. A qualitative research method through a case study approach was conducted in some areas where HIV/AIDS cadres have formed such as: Cirebon West Java, Kudus, and Jepara district of Central Java, Indonesia. A purposive sampling method was applied to recruit the participants. In-depth interview was undertaken with 15 participants using a set of semi-structured questions about: "what HIV/AIDS cadres have been done to date, what skills they must conquer on and how the surrounding supported response". Thematic content analysis using manual combine an inductive approach. Fives themes were identified which described respondents' experiences such as: roles as cadre, cadre skills, harmonization with healthcare providers, community response and motivation become a cadre. This study also identified that HIV/AIDS cadres were significantly supporting people with HIV/AIDS in term of acceptance, against the stigma and discrimination in the community. Participants assessed the quality of life among women with HIV/HIV to have improved gradually post accompaniment. However, participants also faced complexity problems and resistance from the community. Cadres' self-capacity needs to be improved through standardized training to improve their competencies and skills before they implement accompaniment to women with HIV/AIDS in the community.*

Keywords--- *Role, HIV/AIDS Cadre; Quality of Life; Women with HIV/AID; Community*

I. INTRODUCTION

Community participation is needed to improve the health status of vulnerable groups, especially women living with HIV/AIDS (WLHA). The quality of life of WLHA was low in physical and mental aspects [1]. In another study, almost all the components of quality of life were low with an average score of 0.38 (scale range 0-3, SD = 0.3) [2]. They have felt even worst at a younger age, live in rural environment, have new case been diagnosed HIV positive,

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have not yet started treatment and have low social support [2] Stigmatized families and communities have caused physical, social, emotional and spiritual difficulties [3]. Specific interventions in homogeneous populations are needed to facilitate collective action to reduce stigma and improve quality of life in the community setting [4].

All parties providing care must be sensitive to the various need of WLHA [5]. However, in reality, people fear to be involved because of lack of knowledge related to HIV/AIDS, limited accessibility, affordability and harmonious relations between services [6]. Community awareness of people with HIV/AIDS is still limited among sufferers or peer support groups [7]. During this time, Indonesia's people have participated independently in a good role in overcoming health problems, for example, through integrated health services by civil society (Posyandu), cadres for children under five years, the elderly and others. HIV/AIDS cadres are not yet widely known, even though AIDS care communities have been formed anywhere at the village.

The term cadre was previously used for a community social worker. Their task is to intervene at the point where people interact with the environment. The basic principle of a social worker is to fight for human rights and social justice [8]. The role and task of social workers or cadres in HIV/AIDS programs in several countries is to support patients and act as mediators to health services [9], motivators for access to HIV testing and care, promotion to access health services, conduct care referrals and strengthen PLHIV compliance strategies [10], offer intervention as a counselor and supporter, educator or navigator [11]. However, their role is still below the optimal target to support for care, physical and psychosocial mildness of vulnerable women with HIV/AIDS. The purpose of this study was to explore the experience of the role of HIV/AIDS cadres on improving quality of life among women living with HIV/AIDS in a community setting.

AI. METHODS

A qualitative research design was used in this study because of its ability to produce in-depth information about the experience of the role of HIV/AIDS cadres [12]. A case study approach was conducted in an area where HIV/AIDS cadres have formed.

- Sample

A purposive sampling method was applied to recruit the participants. In-depth interview was conducted with 15 participants by using a set of semi-structured questions about: "what HIV/AIDS cadres have been done to date, what skills they must conquer on and how the surrounding supported response". The inclusion criteria were set in this study as: 1) health cadres who were recruited and received capacity building about HIV/AIDS; 2) cadres active in the community in the past 3 months; 3) cadres in the area's local community.

- Setting

This study was conducted among HIV/AIDS cadres as social participants in Cirebon West Java, in the Jepara and Kudus districts of Central Java, Indonesia. Cadres help in health care services as well as socially. Not all HIV/AIDS cadres have provided assistance and home services for women living with HIV/AIDS. These three regions were selected to see variations in experiences of the role of HIV/AIDS cadres in a community setting. In-depth interviews were done at the home of the cadre coordinator in Jepara and Kudus districts, facilitated by the local area cadre coordinator. Meanwhile the cadre of Cirebon city gathered at the office of Cirebon big mosque, facilitated by the head of the cadre forum.

- Data collection

Formal written informed consent was provided to the participants along with demographic data needed in this study before each interview was undertaken. Interviewers also clearly explained that participants had the right to withdraw from the interview process whenever they felt uncomfortable.

Interviews were held on the HIV/AIDS cadres' experiences with open semi-structured questions about "What have the HIV / AIDS cadres done to date?, what skills they must conquer on?, and how the surrounding supported response?". Field notes and MP4 recorder were used to perform complete documentation of the interview. Interviews were conducted from September 2019 to November 2019, and lasted 45 to 60 minutes. All participants received a transportation fee as of IDR 75,000 to 200,000 after fulfilling the interview session.

Thematic content analysis using manual combine an inductive approach. Determination of the theme was used seven steps inductive thematic analysis from Colaizzi: 1) transcribing all the description of subjects, 2) extracting significant statements, 3) creating formulated meanings, 4) aggregating formulated meanings into theme clusters, 5) developing exhaustive description, 6) identifying the fundamental structure of the phenomenon, and 7) returning to participants for validation [13].

This research follows ethical principles such as confidentiality, beneficence and non-maleficence, respect for persons, and justice. Data collection permit granted by the head of a non-governmental organization "Mitra Alam", and head of cadre forum Cirebon City. Information about the aims and objectives of the study is explained in advance and subjects have the right to accept or refuse to be involved in this research by giving informed consent.

BI. RESULTS

- Participants' Characteristics

A number of 15 HIV/AIDS cadres who identified about their experiences implementing their role as cadre in the community with range of age between 27-65 years old (Table.1).

Table1. Participants' demographic data (n=15)

Demographic information	**n**	**%**
Gender		
Male	6	40
Female	9	60
Marital status		
Married	12	80
Unmarried/divorce	3	20
Education level		
Low education	2	13.3
Middle education	9	60
High education	4	26.7
Occupation		
Civil servant	3	20
Private sector worker	8	53.3
Pensionary	3	20
Lawyer	1	6.7
Time of experience as HIV/AIDS* cadre		
1 year	6	40
3 years	3	20
5 years	5	33.3

Demographic information	n	%
10 years	1	6.7
Origin place		
Kudus district	5	33.3
Jepara district	4	26.7
Cirebon city	6	40

**HIV:Human Immunodeficiency Virus; AIDS: Acquired Immune Deficiency Syndrome*

- Research Themes

Thematic analysis generated five themes, such as:

1) Roles of HIV/AIDS cadre in the community

The New cadre within a year experience implemented socialization to the outspread of community but did not dare to accompany women living with HIV/AIDS (WLHA):

> *"We just socialized about HIV/AIDS and how to prevent it to the family, surrounding community in the social gathering, family welfare movement (PKK) meeting and others. But, we have never met and accompany WLHA. Even though there was who feel it is impossible to get this disease for them*" (Mrs. S, 50 years old, AIDS care community cadre, Jepara district).

The liaison role between healthcare provider and community was revealed in mobilizing early detection of HIV and sexually transmitted infections:

> *"We coordinated with local community leader in mobilizing the community to perform health assessment and early detection of HIV and sexually transmitted infections implemented by healthcare providers using mobile VCT in areas where people living with HIV were located.*" (Mrs. SG, 58 years old, AIDS care community cadre, Cirebon district).

In addition, the role of administering a referral to the public health center/hospital:

> *"If we encountered a patient who has symptoms of AIDS or B20 code, then we immediately refer the patient to public health center/hospital. Cadres were known the B20 disease code, so the implementation of the treatment could be more specific*"(Mrs. WL, 50 years old, AIDS care community cadre, Cirebon district).

As community leader, cadre was considerable as person public figures:

> *"We talked carefully, even though we were stand as what we were, but everything we do become the center of attention and also behavior role model in the community*" (Mrs. ER, 65 years old, AIDS care community cadre, Cirebon district).

The cadre also build cooperation with the stake holders:

> *"Since 2018, we have collaborated with the ministry of religious affairs, local health office board, public health center and commission of AIDS protection (KPA). For prospective brides registered at the religious affairs office (KUA) we provided health reproduction counseling and VCT (HIV voluntary counselling and testing) screening recommendation*" (Mr. UK, 65 years old, Chief of cadre forum, Cirebon district).

Family stigmatization to people living with HIV/AIDS generated mental health problems such as: depression and suicide attempts. Those related problem required cadre's accompaniment:

> *"there was an HIV woman encountered depression, she felt sad and wanted to commit suicide because the family refused her. I went to her family and educated them, made a deeply conversation, explained the family that HIV is not transmitted through social relations. I gave them visual example by practicing hand shaking and sitting close to the her. After it all, the family accepted the condition and did not practicing further stigmatization to her. I assigned reinforcement to the woman, her physical and mental health conditions were improving*" (Mrs. SG, 58 years old, AIDS care community cadre, Cirebon district).

In addition, cadre facilitated various counseling such as: health and mental problems, legal aspects, and administration about population people living with HIV/AIDS (PLWHA):

"PLWHA has complexity problems such as: physical health, divorce law issues and spouses lawsuit, and mental health problems (depression, committed to suicide). Moreover, they also faced the problem about population administration matters such the problem of the expiration or disappearance of identity card (KTP) and family card (KK). Those administration documents were very important, if the PLWHA got unwell condition, they needed those administration documents to access health insurance to get free treatments at hospital" (Mr. FJ, 25 years old, peer support group cadre, Kudus district).

Tabel 2. Summary of the findings

Themes	Sub-themes
Roles of HIV/AIDS cadre	Socialization about HIV/AIDS to outspread of community
	Mobilize early detection of HIV and sexually transmitted infections
	Become a public figure
	Referred PLWHA to the hospital/public health center
	PLWHA accompaniment
	Build cooperation with the stake holders
	Facilitate various counseling such as: health and mental problems, legal aspects, and administration about population people living with HIV/AIDS (PLWHA)
HIV/AIDS cadre competencies	Ability to read and write, education degree is not required become a cadre
	Critical thinking capability
	Good at socializing and embracing the community
	Sincere intentions
	Ability to accept the people's difference and diversity
Harmonization between HIV/AIDS's cadre and healthcare provider	Coordinate to form HIV/AIDS cadre
	Cadre elements
	Evaluation of the cadres' working performance
	Cadre legalization and legitimation
	Reward/Reinforcement
Community responses towards HIV/AIDS cadre	Supporting
	Rejection or resistance
Motivation become an HIV/AIDS cadre	Intrinsic motivators:
	- Self-actualization in the community
	- Be happy to have inner satisfaction can help others
	- Delightful and gained an inner contentment by assisting others
	- Grace of being someone's prayers.
	- Meaningful
	- Self-Promised to God
	- Spiritual value

2) HIV/AIDS cadre competencies

Officially, there was no formal requirements to be the community cadres. It usually reflects to their own individual ability such a critical thinking, as stated:

"When we want to step in to a community, we should recognize the social maps (demographic data, description of the person who could be invited to work cooperatively such as community leaders and religious figures) and physical maps (description of land condition at the specific region, the presence of healthcare services and so on). Afterwards, we could build the bridge communication and relationship with the community to start discussing issues related to HIV/AIDS" (Mr. F, 65 years old, AIDS care community cadre, Cirebon district).

At least, HIV/AID cadre should possess three cadre competencies, namely: (1) behave appropriately in the community (2) sincere intentions (3) recognize environmental situations, as stated:

"There were several basic capabilities that should be mastered by cadres such as: behave appropriately in the community (good at socializing and embracing the community), have the whole-hearted sincere intentions (will be shown in the real action), and cadres must be able to recognize the environmental situation (e.g. understand how to fill up the F1 information system form (SIP) of integrated healthcare center (POSYANDU), because there were rolling cadres' task for every 3 months)" (Mrs. SG, 58 years old, AIDS care community cadre, Cirebon district).

In addition, another requirement as a cadre was the sufficient level of reading and writing skills regardless of education level, as stated:

"The capability of cadres raised along with their self-taught and a lot of practices, their knowledge gained from training. As long as they can read and write, anyone can be a cadre. There were some of us only graduated from elementary school" (Mrs. WL, 50 years old, AIDS care community cadre, Cirebon district).

3) Harmonization between HIV/AIDS cadres and healthcare providers

Relationships between cadres and healthcare providers in the community may slightly different. It depend on the situation of each community region. Cadre in Cirebon district felt the harmonization relationship with healthcare providers since the cadre has formed, as stated:

"HIV/AIDS cadres were formed from the health cadres in the community (cadres of toddlers, elderly, mental health, and youth cadres). The cadres formation started from the concern of local community to the higher maternal mortality rate in this district" (Mr. UK, 65 years old, Chief of cadre forum, Cirebon district).

Furthermore, the harmonization efforts were also carried out in Jepara district, as stated:

"The formation of AIDS-awareness cadres was initiated by a non-governmental organization, but the local healthcare providers also been involved (Mrs. R, 30 years old, peer support group cadre, Jepara district).

However, disharmony relationship was perceived by cadres from Kudus district, as stated:

"HIV/AIDS cadres that have existed were generated from peer group support (KDS). While, AIDS care community (WPA) cadres have been formed by NGOs, but there was no further PLWHA accompaniment implementation (Mrs EM, 50 years old, peer support group cadre coordinator, Kudus district).

Encouragement and evaluation of the cadres' working performance regularly been carried out by related local affiliations, as stated:

"The encouragement of cadres were routinely given by public health center, local health office board, and commission of AIDS protection (KPA). We received training about HIV/AIDS, specific skills to prevent the HIV/AIDS transmission and gain recent issues about HIV/AIDS" (Mrs. WL, 50 years old, AIDS care community cadre, Cirebon district).

While the activities of peer support cadres (KDS) with Kudus district healthcare providers have not been aligned, as stated:

"although the HIV issue was the second priority program of SDGs achievement in health office board, however supervision and monitoring activities for the HIV/AIDS program still do not exist. Insufficient budget was the main reason. In my opinion, the health operational support fund (BOK) should be utilized since this fund is flexible" (Mrs. EM, 50 years old, peer support group cadre coordinator, Kudus district).

Legalization letter of cadres formally been given by the head of village as cadres' legalization and binding:

"we received a formal letter of a specific duty from head of village, and we also need to report for all activity we have done back to the head of village" (Mrs.WL, 50 years old, AIDS care community cadre, Cirebon district).

In addition, cadre legitimation was not easy to be obtained, an efforts needed to build a work system. So, it generated community trust to the cadres, as stated:

"We must keep our fighting spirit and do not easy to get despair. The people's trust must be created. Furthermore, the cadres' work system should also be generated for the community legitimation" (Mr. F, 65 years old, AIDS care community cadre, Cirebon district).

Reinforcement of cadres' working performance different in various district. AIDS community care cadres in Jepara perceived by given the uniform and recreation periodically were considerable as sufficient rewards, as stated:

"We received encouragement fee amount of IDR 25.000 each person form the community, we managed and saved the fee carefully to buy uniform and for group recreation one time every two years" (Mrs. S, 50 years old, AIDS care community cadre, Jepara district).

Moreover, incentive rewards caused the devotion 'altruism' move to fade, as stated:

"The annual amount fees of cadres incentive from regional city budget counted IDR 1.250.000 each POSYANDU. While, averagely each POSYANDU has 5 cadres, mostly this fees issue often leaded chaos among cadres. So, for recent time the incentive was given 4 times each year by public health center" (Mr. F, 65 years old, AIDS care community cadre, Cirebon district).

In addition, self-existence recognition was considerable as an important reinforcement for cadres, as stated:

"Fee rewards was not important, but the important role of peer support group (KDS) and the recognition of their working performance is enough" (Mrs. EM, 50 years old, peer support group cadre coordinator, Kudus district).

4) Community responses towards HIV/AIDS cadre

The community supported varying activities carried out by cadres, as stated:

"Community felt delighted with the health education given by the cadres, their knowledge improved significantly and they also have capability to do efforts of sick prevention" (Mr. H, 50 years old, AIDS care community cadre, Jepara district).

Although in recent time, many people in the community supported PLWHA, but some of them performed their rejection or resistance, as stated:

"Initially, the community refused PLWHA without any clear explanations. One of the reason is because it entirely PLWHA's faults. They did deviate and sinful manners. They even behave rudely with community cadres asked: who are you? how could you organize my life like a health broker" (Mr. UK, 65 years old, Chief of cadre forum, Cirebon district).

Furthermore, communication skills in high risk groups were needed to reduce resistance, as stated:

The hardest part being a cadre in community was changing people's behavior. Moreover, I frequently delivered health counseling to the groups of female prostitute at hotspots area. Intervention to change their behavior could not be performed directly, we should begin to know and listen their story of why they did that job, explored their needs, potential customers, asked about their understanding about the risks, then gave them an input afterwards how to minimize the risk by explaining to offer the customers to use a condom, and so on. Most of them were saying wanted to do all of my suggestions such as offering the costumers a condom, when we were doing face to face consultation, but when they faced the customers they did not use condom because they unable to negotiate the customers" (Mr.F, 65 years old, AIDS care community cadre, Cirebon district).

5) Theme five: Motivation become an HIV/AIDS cadre

Motivation become an HIV/AIDS cadre was form of self-actualization in the community, as stated:

"it was wrong if the intention to be a cadre is for money purpose, because there was no fixed salary for cadre. I felt my life always sufficient. I delighted being a person who could be beneficial for the community" (Mrs. S, 50 years old, AIDS care community cadre, Jepara district).

Cadre perceived delightful, meaningful and gained an inner contentment if they can solve others' problems, as stated:

"one day there was a PLHWA cried over because faced a problem related to hospital treatments payment, and eventually I tried to arrange her to get fund support. I felt meaningful and delighted could help people's problems" (Mrs. SG, 58 years old, AIDS care community cadre, Cirebon district).

Furthermore, cadre felt grace of being someone's prayers, as stated:

"I delighted if we could help somebody, and they put me in their prayers, and all praises to God, many of their prayers were granted" (Mrs. WL, 50 years old, AIDS care community cadre, Cirebon district).

In addition, Self-Promised to God and community dedication required whole-hearted intention and sincerity, as stated:

> *"I used to work as a health care provider who responsible to maternal health program, I frequently worked with cadres, I saw they have quick responses with the community programs. I promised, if I have retired I will dedicate the rest of my life as a community cadre"* (Mrs. ER, 65 years old, AIDS care community cadre, Cirebon district).

Lastly, obtained the spiritual value, as stated:

> "*we have a motivation expression SAJUTA 115, it is abbreviation of SAbar (patient), JUjur (honest), TAwakal (trusted to God whole-hearted*)" (Mrs. WL, 50 years old AIDS care community cadre, Cirebon district).

IV. DISCUSSION

The role of social worker practitioners in society as an important matter is central to the mission of social work. Characteristics of the community to be realized are social justice, promoting and enhancing social and economic development [14]. This study found a number the role of HIV/AIDS cadre are 1) Socialization about HIV/AIDS to the outspread of community; 2) Mobilization society to early detection of HIV and sexually transmitted infections; 3) Become a public figure; 4) Refer WLHA to the hospital/public health center; 5) WLHA accompaniment; 6) Build cooperation with the stake holders; 7) Facilitate various counseling such as: health and mental problems, legal aspects, and civil administration of women living with HIV/AIDS (WLHA).

These are in accordance with Minister of Health Regulation No.21/2013 concerning HIV and AIDS prevention approved in article 51 paragraph 1 of the public participating in efforts to combat HIV and AIDS by:1) Promoting healthy living behavior; 2) Increase family resilience; 3) Prevent stigma and discrimination against people infected with HIV and their families; 4) Forming and developing AIDS care citizens; 5) Encouraging citizens who have the potential to carry out risky HIV infections to check themselves into voluntary counseling and testing (VCT) service facilities.

In an effort to reduce the stigma of HIV / AIDS, the role of cadres as a support group specifically for WLHA to provide opportunities to practice disclosure, empower women to respect themselves, facilitate coping / coping strategies, improve friendship networks so as to reduce isolation and shame, bring women to places and situations in togetherness, special psychological interventions for women ODHA, provide anticipatory guidance that has the potential to reduce fear [3]. Cadre can follow training to be able to provide counseling, psychosocial support and peer support to their colleagues [10]. Another study found that the role of cadre provide patient counseling, refer them to social services and advocate for their broader rights [15].

Cadres work effectively because of their unique relationships with the community and often involved with social capital. Sharing roles with health workers in right relations, cadres will discuss the tasks required by the program, and volunteers can focus on the needs of the wider community[16]. Cadres work on HIV/ encounter obstacles of community resistance. A stronger support system for mobilizers, and multiple strategy approach to community [17]. Health worker collaborate with cadre to work in harmony.

The area harmonization is coordination, integration and Sustainability [18]. In kudus district, there seems to be an integration problem. Cadres felt performance is not recognized. This condition is similar with Swaziland. It have barriers to harmonization reported by respondents was the lack of formal recognition of non- Rural Health Motivators (RHM) programs. Non-government organizations (NGOs) each hired their own CHWs who are not recognized by the government [18].

The competencies to care, power and hope are very important for individual cadres to build a community trust. Cadre must Ability 1) to read and write; 2) Critical thinking capability; 3) Good at socializing and embracing the community; 4) Sincere intentions; and 5) Ability to accept the people's difference and diversity.

This study shows that during carrying out their role, cadres of HIV / AIDS have a number of intrinsic factors that influence motivation (motivators) [19] in their work such as: 1) Self-actualization in the community; 2) Be happy to have inner satisfaction can help others; 3) Delightful and gained an inner contentment by assisting others; 4) Grace of being someone's prayers; 5) Meaningful; 6) Self-Promised to God; and 7) Spiritual value. It did not find the extrinsic factors that influence dis-satisfaction among HIV/AIDS cadres. In Uganda, workers have the motivation needed to get better compensation, including setting the time that is not on time and transportation costs, providing for their families, and providing it for their needs [20]. Cadres' motivation and commitment were initially volunteers / unpaid volunteers or altruism motivation [8]. Working to improve quality of life of WLHA in the community setting is not easy, the spirit of mutual cooperation or called "gotong royong" as the original Indonesian culture very good to be developed.

Low monetary rewards did not make cadre motivation decrease, because the spiritual urge to interpret activities carrying out the role of cadres as gifts from God. Community empowerment proceeds along with the awakening of the passion to awaken people, this is called "*conscientizacao*"[21]. Spiritual value is a belief in what happens after life, giving a special spirit to be a motivator or source of strength in carrying out roles. In the spiritual concept of Islamic psychology, the notion of spiritual value lies in the quality of one's confirmation of the Most Great [22]. Spiritual awakening is able to create awareness of WLHA to express HIV and stigma, change positive attitudes to WLHA, increase knowledge and understanding of HIV stigma [23]. Another study found that Islamic values show compassion, non-judgmental, and willingness to act to improve life [24].

V. Conclusion

This study found the role of HIV/AIDS cadre was significantly supporting women living with HIV/AIDS in term of acceptance, against the stigma and discrimination in the community. Participants assessed the quality of life among women with HIV/HIV have improved gradually post accompaniment. However, participants also faced complexity problems and resistance from the community. Cadres' self-capacity needs to be prepared through a standardized training to improve their competencies and skills before they implement accompaniment to women with HIV/AIDS in the community.

Conflict Of Interest

None

Acknowledgements

Authors are very grateful to HIV/AIDS cadre and the community-based organization for giving of their time to participate in the study. We gratefully acknowledge funding support from The Ministry of Education and Culture (KemenDikBud) Indonesia in this year.

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