Lessons and Challenges of Social Work Practice: Reflections from Managing Complex HIV/AIDS Cases in Uganda

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Abstract

This article explores the complexities of working as a social worker with people who have HIV/AIDS in Uganda. The exploration takes the form of a detailed case study

Introduction

My career as a social worker started during the era of HIV/AIDS which in my country (Uganda) has existed since 1982. It is now twenty-five years since the first cases of HIV/AIDS were identified in Uganda and to date 1.1 million people are living with HIV while numerous others are being infected each day. AIDS deaths are estimated to be over one million which has left a generation orphans and a mark on the country as one with the highest number of HIV/AIDS orphans in the world (1.7 million) (UAC, 2005). This is in addition to many widows and families headed by children. HIV/AIDS has also weakened the traditional social support mechanisms that have long provided safety nets for individuals and communities, especially in terms of moral, psychosocial and material support. The extended family network in particular has been weakened.

Given the above circumstances, social work practice in Uganda is becoming more challenging than ever before, especially given the fact that some of the social work functions were being informally executed by families and community networks many of which have been weakened or wiped away by HIV/AIDS. Added to these difficulties is the challenge of dealing with several cultural dynamics involved in providing help to people infected and affected by HIV/AIDS. Such dynamics are related to 'valued' cultural practices like widow inheritance, female genital mutilation, traditional circumcision, child adoption, early marriage, polygamy and many others which are common among some tribes in Uganda.

Critical to note also is the fact that the impact of HIV/AIDS on individuals has multi-faceted dimensions ranging from social, cultural, psychological and economic which culminate in interlocking and penetrative effects on the livelihoods of people infected and those affected. It is also clear that HIV/AIDS not only affects individuals but also families, groups, and communities that are part of the client base of social workers, and in this way, the profession is presented with many challenges when confronting this scourge.

It is therefore evident that since social work is concerned with people and their total life worlds, it cannot extricate itself from the impact of HIV/AIDS. In this regard therefore, the case management process can be viewed as a direct service in which the critical client-case manager relationship enables case managers to assist and support clients as they manage their disease and their multiple needs.

Recognizing that HIV/AIDS case management work is complex as highlighted above, I often take an ecosystems approach or systems approach. According to Mattani and Meyer (1998), this is a way of seeing complex phenomena (the person and environment) in their interconnected and multilayered reality to order and comprehend their complexity and avoid over simplification and reductionism. The case study below represents what I found to be 'a complex phenomena' and how I dealt with it from a systems perspective.

The case of Sophie

When I was employed as counselor in an NGO dealing with HIV/AIDS, my role was to provide moral and psychosocial support to HIV/AIDS widows and youth as well as referring them to other agencies where they could seek further support depending on their situation and level of need. It was then that I met Sophie; a young widow of twenty –four years with two children, whose case I have chosen to utilize in order to highlight the lessons derived and challenges

encountered in HIV/AIDS related case work as well as recommendations for contemporary social work practice in Uganda.

Sophie was widowed at twenty-four and was sure that her husband had died of HIV/AIDS because he was tested during his long hospitalization and found to be HIV positive. Sophie feared to take the test at that time because she was scared of the added impact it would have given the shock she got after learning of her husband's status and the fact that it was too late for him to start Antiretroviral therapy (ARVs) . Sophie's husband had died a month after testing positive. In addition, Sophie came from a tribe (the Samya tribe) where widow inheritance[1] is a 'valued' cultural norm which is compulsory for all widows.

Sophie's agony began on the night of her Husbands' burial when the clan leaders insisted that she should be inherited and had to undergo cultural practices that very night to formalize the 'new' marriage to her brother in law who was six years younger than her and had been under their care in their home while the husband was still alive. The cultural practice she had to undergo that night was to have unprotected sex with her supposedly new husband as it is always done in that culture. Although Sophie had been socialized in that very culture and had witnessed the practice for years, she rebelled to be inherited on grounds that she suspected that she had AIDS although she had not tested. She also informed the clan leaders that she could not infect the brother in law who had been under her care and expecting that saving his life would provide security for her children since she thought she would not live to see them grow. Her arguments were rejected by the clan leaders who accused her of claiming that their late son had died of AIDS which to them wasn't the cause of his death but witchcraft by her because he was well off. They wanted to force her to undergo the ritual but she disappeared in the night and returned to the city to the annoyance of her in-laws.

Upon her return, she came to our agency seeking help and it is then that I was assigned to handle her case. Her immediate request was help to do an HIV/AIDS test since she had no money. Our agency does not provide testing services but I referred her to a testing center, which tested her and her children for free. Unfortunately she was found positive together with one of her children. Sophie traveled back to the village of her husband deliver the bad news but they were furious and rejected the results saying she had forged them. Upon her return her house had been besieged and was refused entry and her children taken.

[1] *A practice where a widow marries one of her hubands realtives most often a brother*.

Lessons and challenges arising from Sophie's case

A widow- with HIV, an HIV positive child, property grabbed, children taken, no income and at risk of family rejection.— Sophie's case was multifaceted and rather complicated but I had to deal with it . As Roslyn H Chernesky noted HIV/AIDS case management should be seen as a 'client-focused process that supplements and coordinates existing care services' and involves advocacy and service development. Roslyn H Chernesky's view of case work management in HIV/AIDS derives from the ecosystems perspective of social work which considers problems as arising from the poor fit between a persons environment and his or her needs, capacities, rights and aspirations; hence the overarching goal of social work intervention is to enhance the person: environment fit by promoting change at micro, meso and macro levels (Germain & Gitterman 1996, p.50 cited in Healy 2005 p 135).

This same ideology is emphasized in the broad definition for social work developed by the IFSW which states that social work utilizes 'theories of human behavior and social systems, to intervene at the points where people interact with their environments' (IFSW 1994). I viewed Sophie's case as a mismatch between her and the environment around her, which had to be dealt with if my aim of counseling her to live positively was to succeed. I must

however note that the fact that I came from a different tribe from Sophie's meant that I was overwhelmingly shocked at the impact of cultural difference between my own tribe and hers. From my cultural background, I viewed widow inheritance as inhuman, barbaric and an abuse of human rights hence Sophie's case for me was beyond human imagination. In her tribe, it was normal and acceptable although she was rejecting it but coming from a different tribe, I was extremely challenged because it was difficult for me to comprehend her cultural reality. It was indeed a test to my cultural tolerance and a form of cultural 'shock' which will never cease to amaze me. It also confirmed to me what Berger and Luckman note that reality is indeed abstract and more so it is socially constructed (Berger & Luckmann, 1966). With that form of understanding, added to her motivation to challenge the inheritance, I was able to go ahead and deal with the case.

However, Sophie's needs were beyond what I could provide for according to the agency policy hence I had to agree with her on the way forward including utilizing referral networks to enhance our problem solving process. As Healy notes, 'in an ecological assessment, the service provider and the service user work to gather data about and analyze the impact of multiple systems on the user's situation (Healy, 2005 p.146). Compton and Galaway emphasize the importance of working together by stating that social work is a partnership – an agreement, in which the client participates in all the decisions during the problem solving process rather than the social worker doing things for the client. My agreement with Sophie on the way forward was also a way promoting her self determination which was critical in building our professional relationship.

Although published originally in 1951 there is still much truth in Biestek's comment 'A case work relationship is a dynamic interaction of attitudes and emotions between the case worker and the client, with the purpose of helping clients achieve a better adjustment between themselves and the environment' (cited in Compton and Galaway , 1989 p. 272). This is exactly what I wanted to achieve in my relationship with Sophie, hence I considered her a key actor in the process. I was also constantly reminded by the words of my social work lecturer who often said that 'in Social work we do not solve problems for people but we help people to solve their problems or rather we help people to help themselves… we build capacity for self help'. Compton terms this 'engaging people in a problem solving process by which they resolve their problems' (Compton & Galaway, 1989 p11). With these insights, I and Sophie worked out an ecomap which showed the impact of different systems on Sophie's situation. In her case we identified the key systems to include family, cultural systems, health and welfare institutions as well the legal system.

Based on this, we developed a plan of action directed at each of the systems. One key action was development of a referral schedule consisting of other agencies where she could be referred to seek support for her other problems beyond psychosocial counseling. These agencies included, a family protection network that would help her secure her children who had been forcefully taken by their auntie and a temporary shelter for them and basic needs, A legal aid clinic to help her secure her husband's property including her matrimonial home and a drug access center where she could access free antiretroviral treatment (ARVs) for her and her child. Utilizing the referral network, Sophie was offered emergency shelter by the family protection unit which also took on her case to claim her children. The legal aid clinic took on the case of helping her to reclaim her home and property. She was also able to access free ARVs to boost her CD4 count which was very low. This confirms the critical role of social work in HIV/AIDS affected societies as highlighted by Rampal that, under such circumstances, "social workers are particularly positioned to serve as co-coordinator and network of people and resources and to render assistance at different stages of the illness" (Rampal (2000) cited in Shardlow, 2007).

I must note however that there are many challenges facing the process of referral especially in

resource constrained settings like Uganda. In this case, coordinating all the referral agencies was not easy because the facilities at my agency were insufficient like shared telephones, poor internet connection and transport constraints. This meant that I had to physically visit the agencies by hiring a motor cycle – a stressful experience and running from one agency to another on a speeding motorcycle on bad roads and with no helmet. I also learned that, in some instances, a diagnosis of HIV or AIDS brings people who have been independent into the service sector for the first time – and so was Sophie. She had never sought social work help from an agency before and had mixed expectations of the services that she would receive.

On the other hand, many individuals delay seeking services to address their medical and health needs until confronted with unmanageable crises like Sophie's husband who never tested for HIV until his critical time when little could be done to save his life. Sophie's doubts were however erased slowly, as I continued to reassure her about absolute confidentiality throughout the process in addition to my continued empathy about her situation. This not only strengthened our relationship but also empowered her to sustain the struggle for her rights and her life. From my relationship with Sophie, I learned to accept people as they are and make a personal introspection as well as reflection on my own personality (self awareness). I also realized how difficult it is to maintain absolute confidentiality in a case like Sophie's because I recall discussing it with a senior colleague who picked so much interest that he often wanted to know the progress and I was challenged with the task of balancing between telling him the actual progress and maintaining confidentiality of the case.

Having facilitated Sophie's linkages to other organizations, I took on my role of counseling Sophie on positive living which was the main direct service that our agency would render to her. This however necessitated me to deal with the other underlying dynamics which included family mediation given that she had been rejected by her in-laws and this was bound to affect her psychosocial wellbeing and coping progress. I mediated in two family meetings between Sophie's family and that of her in laws on the issue of inheritance where I highlighted the fact that Sophie could not be inherited by the brother in law given that she had openly declared her positive status. Some of her in-laws especially those who were literate accepted her status and agreed with the fact that their cousin (Her husband had died of HIV/AIDS). This confirms what Compton emphasizes that case mangers function as brokers, facilitators, linkers, mediators and advocates and must therefore be skillful in mediation and advocacy. It was however unfortunate that the elders refused to admit that Sophie was HIV positive and maintained their cultural stand that she had to be inherited.

Meditating in this case was a challenging experience for me given my age at that time (twenty -five) which was also exploited by the clan leaders who often insulted me throughout the mediation process. I recall one old man calling me a grandchild who had no moral authority according to him to mediate in a case involving old men like him and also the fact that I was from a different culture was exploited because I was considered ignorant and disrespectful of their culture. This was really very frustrating for me as a young professional who had devoted all my energies to help and at the end of the mediation meeting, I chose to apologize to the elders for being misunderstood but maintained my client's position against inheritance. It was surprising to me that the old men ended up apologizing to me for the insults as well although they still maintained their stand. This taught me that that it is important to be tactful and to package our responses very well while dealing with cultural issues. Although the meeting ended in disagreement, I am glad that we agreed to disagree and parted peacefully. This Scenario is therefore clear indictor of the challenges facing case work management in societies with cultural values and norms that reinforce the spread of the disease and where people are reluctant to accept the reality of HIV/AIDS. Social workers like me are therefore faced with the multiple dilemma of dealing with several dynamics which is often frustrating especially given the many cases we have to handle at a time; and surely, as the number of cases increases, you just don't have the luxury of doing as much for one individual case. At the time of Sophie's

case, I was handling four other equally complicated cases and you can imagine the impact of this caseload to a young social worker who also has personal life to deal with!

What helped me in this case was the strength that Sophie had to fight her inheritance and also the fact that she was not illiterate. It also confirmed to me what I had learnt that clients often have some inherent strength within them which is very vital in problem solving; hence as a case worker I considered Sophie as an active participant rather than a passive recipient in our relationship. This not only helped Sophie to progress towards positive living but also empowered her to take charge of her destiny despite her problems.

The fact that Sophie was educated up to lower secondary school also meant that she was easier to work with especially when it came to understanding issues of drug intake, resistance and adherence, nutrition and other issues. She basically eased my work as compared to other cases involving illiterate clients who are often ignorant of their rights and take longer to understand critical health issues. It reminds me of the struggle I went through while counseling another lady who had acquired HIV from a rape. Despite the medical evidence that she was suffering from HIV/AIDS, she kept on referring to information obtained from her witch doctor that the rapists never infected her with HIV but she was being haunted by the spirit of her step mother. As if that was not enough, her appreciation for having good nutrition was very deficient. She could not be convinced to have fish and fruits on her menu for traditional reasons, being from the Bahima tribe who are cattle keepers, the belief that eating fruits and fish affects milk production were so strong and she could not overcome it. As a social worker, I felt that it is easier to work with clients who have some form of basic education like Sophie.

Counseling Sophie also helped me to keep learning about the issues related HIV/AIDS and I was particularly encouraged to read more on ARVs and their impact as well as other issues which broadened my sphere of knowledge and understanding on HIV/AIDS. This confirms what Compton and Galaway (1989) call upon us to do as social work practitioners:

> ....you will be expected as a professional to understand the knowledge base of your profession and to keep in touch with the new developments [...] you will be doing regular literature searches to learn from what others have done and to make knowledge available to your clients.

Sophie motivated me to learn more and more because as client, she was well informed about many issues some of which I was not aware of both socially and scientifically regarding HIV as a disease. I am realizing now that I was unfair to her many times when she explained to me some issues which I did not actually know but did not acknowledge or thank her for teaching me. Sometimes I would wait for the session to end and then browse the internet to get meanings of some of the issues she had talked about. I actually found it difficult to acknowledge her contribution to my knowledge and it is only now that I realize that if I had done so, it would have empowered her more and probably boosted our relationship further. Indeed Sophie's case compelled me to read more about HIV/AIDS than ever before in addition to what I learnt from her from our meetings, and I must admit that this not only broadened my sphere of understanding about HIV/AIDS but also enriched my acceptance and appreciation of the livelihoods of people living with HIV/AIDS.

After six months, Sophie was strong enough to join a support group of other young people living with HIV/AIDS. I facilitated this linkage through my professional contacts with the national network of people living with AIDS. Joining this network empowered Sophie more than I expected and to my surprise, Sophie was elected chairperson only after three months of membership. I continued to counsel her and also follow up the other cases that I had referred to other agencies. Sophie's CD4 count improved steadily and she was able to inspire more young people through her testimony. Her support group grew in membership with many young

women willing to discuss more with each other about their difficulties.

Endings

Compton and Galaway (1989) note that 'social work intervention is always time centered. At its best, it is directed towards the realization of goals that are specific enough for progress to be measured against them' (p 643). In Sophie's case, there were impressive indicators to show that she had obtained stability and these included the improvement in her CD4 count, the fact that she had joined a support group and was now publicly open with her HIV status, the fact that she had regained her property and children and most important for me as a counselor, she had progressed towards positive living and had plans for the future of her children. I was therefore certain that she was strong enough to gradually deal with the termination process of our relationship and throughout our discussions she actually declared that she had realized her potential.

Recommendations for practice derived from Sophie's case

First I have to note that social case work is not a rational technical application of scientific principles of helping but essentially a practice. By implication I consider practice a personal interaction between two people and the knowledge that is used by the practitioner is contextualized within the experiences of that interaction. In essence, I agree with writers like England (1986) who refer to the art of social work and note that social work can only be analyzed from an artistic perspective and not a rational scientific framework. Others like Scott (1990) cited in Camilleri, 1996) even make it clearer by arguing that social work practitioners build up knowledge and theories of intervention from their experiences of working with the clients.

Secondly, it is important to note that the proliferation of social work theories, frameworks, models and methods in social work appears to confuse rather than illuminate practice. For practitioners, the problem is working out how to help people like Sophie hence theories and frameworks must be in essence pragmatic tools. From my experience, I have come to realize that we as practitioners rely on our experiences of helping others like Sophie, experiences of our colleagues through professional discussions, the services we are delivering and the clients themselves.

It is also important to note that problems of living in the contemporary world tend to be more complicated, multifaceted and immensely overwhelming for both the clients and the practitioners – Sophie's case is an example. Social work is further complicated by the limited resources compared to the demand for services. This therefore means that a practitioner may need to triangulate the theoretical models to ensure that clients' problems are effectively dealt with. We should therefore appreciate the fact that that no theory, concept, model or approach can take everything into account.

Critical to note also is the fact that the personal interaction between the client and practitioner is key to social case work. Practitioners tend to express more ideological commitment to the value of the person hence we just utilize models of practice creatively to enhance the individual levels of control over their circumstances. On the other hand however, the nature of practice even at practitioner level goes beyond the face to face interaction to involve referrals, appearing in courts, networking with other practitioners, report writing etc. fitting all this into one theoretical framework would be rather challenging hence flexibility is very essential

The importance of the client is another critical aspect that needs not to be under estimated in social work. This should not be seen only in terms of the value base for practice but also in terms of the learning from the client. I have realized from practice that some clients are

actually a resource base or 'experts' on their situations whose insights are very beneficial to the enrichment of our practice. This therefore necessitates the need for us to treat clients as active participants rather than passive recipients which is also directly in line with our valued principle of client self determination. Personally I have learnt that this is very useful as it eases the helping process because our role as social workers as mentioned earlier is not to solve problems for clients but to help them solve their problems and one way of doing this is to engage them .

Closely related to the above therefore is the need for us as practitioners to respect the value of self determination which is the recognition of the rights and needs of the client's choices in making decisions on issues that affect their wellbeing. This is what our ethical standards term as 'a right to self determination' (IFSW 1994). For people living with HIV/AIDS , this is not only an empowering tool but also a form of emotional therapy and an indication that they are valued human beings despite their condition.

The above analysis has also highlighted that social work for people with AIDS encompasses multiple roles for the social worker. These include counseling, ensuring appropriate individualized medical plans, encouraging adherence to medical treatment, linking clients with appropriate services to minimize the burden of HIV/ AIDS on individuals and their social networks, expediting access to services, and coordinating the range of services needed to maintain optimal physical and social functioning. This is exactly what I did in expediting Sophie's case and to be honest it was not easy but being a professionally qualified and experienced social work practitioner enabled me to utilize all the necessary techniques and channels to expedite the problem solving process as highlighted above.

Lastly, I have to note that social work for people with HIV illustrates some of the most challenging scenarios for social work practice in contemporary Uganda. This is partly because HIV is a relatively recent phenomenon hence the literature on best practices for social case management for people with HIV is sparse. Added to this is the fact that people with HIV face multiple challenges meaning that a case manager like me must be able to rely on skills and a knowledge base that encompasses sensitivity to critical issues like confidentiality, client self determination, individualization and must also be able to perform multiple roles which may include brokerage, advocacy, referral, networking and other roles depending on the cases. That is probably the reason why in many HIV service agencies like my agency, more weight on the job description is placed on the experience of "case managers" with populations affected by HIV than with academic or theoretical training in social case management. In other words, while certain core tasks remain constant for HIV social case managers as noted above, much of our work and our knowledge base centers on the client population we are serving. Therefore, HIV case managers like me often apply generalist skills within this particular area of specialization that reflects the uniqueness of our client base.

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