



ISSN: 0975-833X

RESEARCH ARTICLE

REDUCING STIGMATIZATION AND DISCRIMINATION THROUGH PROVISION OF CARE AND SUPPORT TO FELLOW PERSONS LIVING WITH THE HUMAN IMMUNODEFICIENCY VIRUS (PLHIV) IN GHANA: THE CASE OF THE 'MODELS OF HOPE'

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ARTICLE INFO

Article History:

Received 11th February, 2014
Received in revised form
08th March, 2014
Accepted 06th April, 2014
Published online 31st May, 2014

Key words:

Human Immunodeficiency Virus (HIV),
Acquired Immune Deficiency Syndrome (AIDS),
Models of Hope,
Training,

ABSTRACT

In view of the stigma attached to HIV and AIDS, many family members and friends of Persons Living with HIV and AIDS (PLHIV) neglect them. In Ghana, some PLHIV voluntarily provide care and support for other PLHIV newly diagnosed of HIV. This study sought to ascertain what motivates them to undertake this task in Ghanaian hospitals, clinics and homes and what impact they make. Data for the study were obtained from 120 purposively selected PLHIV serving as 'models of hope'. Data collection methods employed for this study were questionnaire administration and in-depth interviewing. Quantitative data of the study were analyzed using the Statistical Product and Service Solutions (SPSS), version 17.0., formerly called Statistical Package for the Social Sciences. Additionally, qualitative data were manually analyzed. The theoretical framework for the study is the hope theory. A major result of the study was that the respondents were motivated to care for and support their fellow PLHIV newly diagnosed of HIV with a view to helping them have some hope and live positively with HIV. Although they were faced with financial problems, stigmatization and discrimination, the refusal of some clients to religiously take their drugs after adherence counselling, etc., they still provided the needed care and support. Through their services most of their clients gain a lot of hope, particularly when they regain their health, live positively with HIV and overcome self-stigma. The study recommends that stakeholders encourage these 'models of hope' by giving them adequate training and consistently motivating them through the recognition they give them.

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INTRODUCTION

Informal caregivers are a critical source of support for PLHIV worldwide (Akintola, 2010). As at June 10, 2013, Ghana's HIV prevalence rate stood at 1.3 percent (Kloku, 2013). Compared to many other countries in sub-Saharan Africa, this figure is relatively low. However, there are many PLHIV in the country, who need care and support, since an estimated 235,982 persons, including children, are living with HIV and AIDS (Ghana Health Service, 2013). The onus lies on families and friends as well as health care providers to provide the needed care and support. However, families and friends are either ill-equipped to provide care and support (Akintola, 2010) or they blatantly refuse to take up the challenge because they themselves stigmatise and discriminate against the PLHIV or, as Mwinituo (2006) puts it, they experience stigmatization and discrimination from other people. With regard to the healthcare providers, the problems regarding the care and support they have to provide are at two levels. Firstly, most of the facilities are not adequately staffed because many

healthcare providers have left the country to seek greener pastures (Quartey and Kwakye, 2008/2009). Secondly, as studies have shown, many healthcare providers are not able to manage the PLHIV for fear of contracting HIV through their intervention (Awusabo-Asare and Marfo, 1997). Under the circumstances, there are many PLHIV, who are not given the needed care and support (Amoa, 2005). As a result, many of them lose hope and die from isolation. In order to help surmount this problem and give themselves and others hope, PLHIV described as 'models of hope', who have had various degrees of experiences because of the infection, have taken it upon themselves to provide care and support to their fellow PLHIV. Studies have shown that caregivers of PLHIV face undue burden (Ndaba-Mbata and Seloiwe, 2000; Flakerud & Lee, 2001; Nnko *et al.*, 2000, Lindsey *et al.*, 2003 cited in Akintola, 2010; Kangethe, 2009). A study conducted by the Joint United Nations Programme on AIDS (UNAIDS) revealed that stress that stems from the nature and context of care work is pervasive among volunteers caring for PLHIV (UNAIDS, 2000). Similarly, a study conducted by Akintola (indicated that volunteers caring for PLHIV are confronted with a myriad of challenges, including the sheer difficulty of caring, and maintaining confidentiality, among

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others. However, according to Crook *et al.* (cited in Akintola, 2010), research among volunteers working in AIDS service organizations in Ontario, Canada, reveals that volunteers experience intrinsic rewards, such as improved self-esteem and health, and self-actualization, as well as extrinsic rewards, such as recognition, constructive feedback and participation in decision-making. However, most volunteer caregivers are HIV negative persons. Most PLHIV prefer 'to go into hiding' once they are diagnosed of HIV because of the stigma associated with HIV. The 'models of hope' choose not to hide but rather to take up the challenge of providing care and support to fellow PLHIV, when they themselves are faced with the burden of HIV. The study sought to ascertain what motivates the 'models of hope' to provide care and support to their fellow PLHIV, what knowledge they have about HIV and AIDS, what services they render to their fellow PLHIV, how beneficial their service is to them and their clients and what could be done to energize them into more action. Given the negative experiences that PLHIV go through, when they 'go into hiding' because of the fear of being stigmatized and discriminated against, research on what motivates PLHIV to provide care and support to fellow PLHIV and the experiences they gather, as they do that, could play a critical role in encouraging other PLHIV to also provide care and support, thereby reducing the effects of HIV and AIDS stigmatization and discrimination.

Theoretical underpinning of the study

Research conducted has confirmed the phenomenon of hope as a reality. What came out of the studies embarked upon was a cognitive-based theory of hope (Synder, 1994a, 1994b; Synder *et al.*, 1991; Synder *et al.*, 1991; Synder *et al.*, 1996 cited in Helland & Winston, 2005). Hope theory has been studied in relation to physical and psychological health (Synder, 1996; 1998a; Synder, Irving & Anderson, 1991; Synder *et al.*, 2000), psychotherapy (Synder *et al.*, 1999 cited in Helland & Winston, 2005), academic achievement and sports (Curry, Synder *et al.*, 1997). The basic premise of the hope theory (Synder *et al.*, 1991; Synder, 2002) is that hope is comprised not only of emotion, but thinking as well. In actual fact people, who nurture hope, do a lot of thinking, and therefore thinking is at the core of hope (Synder, 2002). The thinking done, which is the catalyst for future action, is goal-directed (Synder, 2002). However, depending upon the hope orientation that people have, they may pursue their goals using different approaches. People nurturing high hopes pursue goals with "affective zest", whereas people, who nurture low hope, demonstrate "affective lethargy" in their pursuit to attain their goals (Synder, 2002, p. 252). Another remarkable difference is that people nurturing high hope may not only reach their goals by applying a lot of energy, they may also "generate more goals" (Synder, 2002, p. 253). When obstacles or "surprise" events that may be positive or negative hit high hope persons and low hope persons in the face, what happens is that the former may comparatively experience less stress and adopt and execute more effective coping strategies than the latter. Whereas the high hope person is resilient and therefore is able to redirect goal pursuits, the low hope person doubts his/her ability to achieve his/her goals. He/she, therefore, may not take future actions (Michael, 2000; Synder, 1999; Synder, 2002). In

addition to the above, high hope persons build positive relationships and, when they and others make the efforts to attain goals, "high hoppers serve to make the group not only more productive but also perhaps equally important, an interpersonally enjoyable arena" (Synder *et al.*, 1997, p. 115 cited in Helland & Winston, 2005). High hoppers do aim at achieving their individual goals, just as they want the group in which they find themselves to attain collective goals. As high hoppers nurture hope, they do that in relation to others, and together with these other persons they pursue "common goals" (p. 114 cited in Helland & Winston, 2005, p. 45). As people pursue goals, they may not be cock sure that they would achieve them. However, it appears that this uncertainty does not have a negative impact on high hoppers. They appear to be better able to cope with uncertainties, since they are hopeful that there would be answers that for the moment have not been made manifest. As Ludema *et al.*, (1997 cited in Helland & Winston, 2005, p. 45) point out: "When people hope, their stance is not only that reality is open, but also that it is continually becoming. Rather than trying to concretise and force the realisation of a preconceived future, hoping people prepare the way for possible futures to emerge. In this sense, hoping can be seen as a deeply creative process, one that requires steadfast patience and the willingness to accept uncertainty as the open future is explored and molded into a compelling image of possibility" (p. 12 cited in Helland & Winston, 2005, p. 45).

Study area

Ghana is situated in West Africa and shares borders with Togo to the East, Burkina Faso to the North, La Côte d'Ivoire to the West and the Atlantic Ocean to the South. According to Population and Housing Census Report of the Ghana Statistical Service, Ghana's population in the year 2010 stood at 24,658,823 million. With an intercensal annual growth rate of 2.5%, (Ghana Statistical Service, 2010), the population is further projected at 32.8 million in 2025 and 47.3 million in 2050. Ghana has an average density of 103 persons per sq. km (Ghana Statistical Service, 2012). It has a total land surface area of 230, 000 sq. km and experiences mostly tropical conditions. It has ten administrative regions that have been zoned into districts, municipalities and metropolises. Altogether there are 216 districts. The capital town of Ghana is Accra. The Ghanaian population is made up of many ethnic groups. According to the results of the 2010 population census, the largest ethnic group, the Akan, accounts for 47.5% of the population. Other major ethnic groups are the Mole-Dagbani (16.6%), Ewe (13.9%), Ga-Adangbe (7.4%), Gruma (5.7%), Guan (3.7%), Grussi (2.5%) and Mande-Busanga (1.1%). A number of smaller ethnic groups make up the remaining 1.6%. The prevailing religious beliefs and practices may be divided into three (3) major groups namely, Christianity, Islam and African Traditional Religion which account for 71.2%, 17.6% and 5.2% of the population respectively (IndexMundi, 2013).

The economy of Ghana is mixed, consisting mainly of small capital intensive modern sector involving mining and a few manufacturing establishments, a growing informal sector of small businessmen, artisans and technicians and a large traditional agricultural sector made up mostly of and small-scale peasant farmers. The agricultural sector alone absorbs

three-fifths of the country's labour force and accounts for more than half (51%) of the Gross Domestic Product. The duration of basic education has been reduced from 10-15 years to nine (9) years. This includes six (6) years of primary education and three (3) years of Junior High School (J.H.S.) Education. J.H.S. is followed by an optional additional three (3) years of Senior High School (S.H.S.) Education. These reforms seek to improve access to education for all children, increase the proportion of females in school, and increase the proportion that completes a given level of education.

DATA AND METHODS

Data for the study were collected through a questionnaire from 120 respondents serving as 'models of hope' in hospitals and clinics as well as homes throughout the length and breadth of the country. The targeted sample represented approximately 69 percent of the total number of 'models of hope' serving in the country as at the time of data collection in January/February, 2012. The respondents were sampled from a list obtained at the Head Office of the Association of PLHIV in Ghana, NAP+ Ghana. The questionnaire was made up of two main sections. The first part, which covered the demographic characteristics of respondents, includes: age, educational level, religious affiliation, ethnicity and occupation, while the second section consisted of specific issues such as the respondents' motivation for caring for and supporting fellow PLHIV, their knowledge about HIV and AIDS, the benefit of their service to them and their clients and what problems they were confronted with. To ensure content validity, the researcher presented the questionnaire to colleagues in the Department of Sociology and Anthropology of the University of Cape Coast to determine whether the items in the questionnaire would adequately assist in obtaining information for answering the research questions and also detecting ambiguities in the items.

Their comments indicated that there were no serious ambiguities. Having done minor revisions of problems that the colleague pointed out, the researcher pre-tested the questionnaire among 'models of hope', who had not been selected to answer the questionnaire. In order to analyze the data gathered from the questionnaire, quantitative content analysis was done with the use of the Statistical Product and Service Solutions (SPSS). Content analysis was used for the analysis of the open-ended questions from the questionnaire. Responses were categorised and coded based on themes that were generated. Once the codes were generated a systematic quantitative analysis of the occurrence of particular categories based on the themes were generated. In-depth interviews were also conducted in addition to the administration of questionnaires to the respondents, in order to have more viewpoints and standpoints that cast light on the topic (Olsen, 2004) and help the researcher to achieve a deeper understanding of the respondents' world (Sarantakos, 1993). The interviews were conducted through face-to-face and telephone interactions, after the interviewees comprising 12 females and 9 males had been conveniently sampled. With their approval, all that they said was tape-recorded and later transcribed to enrich the quantitative analysis. The data collected were manually analyzed.

RESULTS

Socio-demographic background of respondents

This section, as indicated in Table 1 below,

Table 1. Socio-demographic characteristics of respondents

Variable	Frequency	Percentage
Sex		
Male	43	35.8
Female	77	64.2
Total	120	100.0
Age		
20-24	3	2.5
25-29	2	1.7
30-34	20	16.7
35 and above	92	76.7
Not stated	3	3.0
Total	120	100.0
Marital Status		
Single	33	28.3
Married	57	48.3
Divorced	6	5.1
Widowed	18	15.3
Separated	5	4.2
Total	120	100.0
Ethnic Background		
Ga/Adangbe	17	14.2
Ewe	29	24.2
Mole-Dagbani	6	5.0
Guan	6	5.0
Akan	46	38.3
Others	16	13.3
Total	120	100
Number of Children		
None	26	21.7
Less than 3	43	35.8
3-5	42	35
More than 5	9	7.5
Total	120	100.0
Highest Educational Level Attained		
No formal education		
Basic level	3	2.5
Second cycle	80	66.7
Tertiary	29	24.1
Total	8	6.7
	120	100.0
Profession/Occupation		
Teacher	11	9.2
Secretary	8	6.7
Trader	40	33.3
Driver	3	2.5
Others	37	30.8
Unemployed	21	17.5
Total	120	100.0

Source: Data from Fieldwork, 2012

provides information on the socio-demographic characteristics of the 'models of hope' and covers age, sex, marital status, ethnicity, highest educational level attained, number of children and occupation/profession. The rationale behind the gathering of this information was to identify socio-demographic facts about the and 'models of hope'. The data indicate that 77 out of the 120 respondents, representing 64.2 percent, were females and 43 (35.8 percent) were males. This finding supports the general recognition "that women and girls are the principal caregivers...and bear the greatest degree of responsibility for the psychosocial and physical care of family and community members" (Ogden *et al.*, 2006, unpagged). The majority of them, 92 representing 76.7 percent were 35 years

and above; 20 (16.7 percent) were between the ages of 30 and 34 years; 3 (2.5 percent) were between the ages of 20 and 24 years; 2 (1.7 percent) were between 25 and 29 years of age; 3 (3 percent) did not state their ages. Fifty-seven (57) of them representing 48 percent were married; 33 (28.3 percent) were single; 18 representing 15.3 percent were widowed; 6 (5.1 percent) were divorced; and 5 (4.2 percent) were separated from their partners. Forty-three (35.8 percent) had less than three children; 42 (38 percent) had between three and five children; 26 (21.7 percent) had no children; and 9 (7.5) had more than five children. A substantial proportion of them, 80 (66.7 percent) had been educated up to the basic level; 29 (24.1 percent) had been educated up to the senior high school level; eight (6.7 percent) had had tertiary education; and three (3) representing 2.5 percent indicated that they had had no formal education. The majority of the respondents (82.5 percent), had learnt various professions. Forty (40) of them (33.3 percent) were traders; 3 (2.5 percent) were drivers, 8 (6.7 percent) were secretaries, 11 (9.2 percent) were teachers and 21 (17.5 percent) were unemployed. With regard to the ethnic groups, to which the respondents belonged, 46 (38.3 percent) stated that they were Akans; 29 (24.2 percent) Ewe; 17 (14.2 percent) Ga/Adangbe; 6 (5.0 percent) Guan; and another group of 6 (5.0 percent) Mole/Dagbani. The fact that the greatest proportion of the respondents belonged to the Akan ethnic group is in support of the data from the 2010 Population and Housing Census that indicates that the majority of Ghanaians belonged to the Akan ethnic group.

Respondents' motivation for providing care and support to their fellow PLHIV

The majority of the respondents, 80 (66.6 percent), indicated that they were motivated by the fact that they wanted the newly diagnosed PLHIV to have some hope and live positively with HIV; 20 (16.6 percent) stated that they wanted to support humanity; 15 (12.5 percent) indicated that they did not want their fellow PLHIV to go through suffering out of ignorance.

Table 2. Respondents' motivation for providing care and support to their fellow PLHIV

Response	Frequency	Percentage
Provide hope for positive living with HIV	80	66.6
Support humanity	20	16.6
Help fellow PLHIV not to go through suffering	15	12.5
Others	5	4.16
Total	120	100.0

Source: Data from Fieldwork, 2012

Respondents' knowledge about HIV and AIDS

The researcher wanted to ascertain respondents' knowledge about HIV and AIDS. When asked to give the full meanings of HIV and AIDS, 103 (85.8 percent) out of 120 respondents gave the full meaning of HIV and 106 (88.3 percent) gave the full meaning of AIDS. In order to find out their knowledge about the modes of transmission of HIV, the researcher gave them a number of correct and incorrect answers to tick. Ninety-six (80 percent) stated that HIV can be spread by sharing contaminated skin-piercing instruments; 99 (82.5 percent) stated that when people receive contaminated blood

they can contract HIV; 112 (93.3 percent) said HIV can be spread through casual sex and 114 (95 percent) indicated that HIV can be spread from mother-to-child; and 116 (96.6 percent) indicated that mosquitoes do not spread HIV. When asked to indicate whether one can tell from physical appearance whether someone is HIV positive or not, 77 (64.2 percent) said 'yes', while 43 (35.8 percent) said 'no'. The researcher also wanted to ascertain the respondents' knowledge about the major and minor signs and symptoms of HIV and AIDS. Forty-two (35 percent) and 22 (18.3 percent) respectively indicated that they did not know the minor and major signs and symptoms. Of those, who claimed they knew the major and minor signs and symptoms, the majority could not provide correct answers. A male respondent, for example, indicated loss of weight, continuous diarrhoea and continuous malaria as major signs and symptoms and loss of weight, continuous diarrhoea and continuous boils or shingles as minor signs and symptoms. When asked whether they had undergone any training to enable them to do their work, 106 (88.3 percent) said 'yes', while 14 (11.66 percent) answered the question in the negative. Of those who indicated that they had had some training, they cited the National AIDS Control Programme (NACP), Catholic Relief Services (CRS), Strengthening HIV and AIDS Partnerships (SHARP), OIC International, Family Health International (FHI), Adventist Development and Relief Agency (ADRA) and Hope for Future Generations (HFFG) as the organisations that had trained them.

Table 3. Services respondents render to their fellow PLHIV

Activity	Frequency	Percentage
Open up folder for clients		
Yes	75	62.5
No	42	35
Missing system	3	2.5
Total	120	100.0
Prepare clients to see the physician		
Yes	74	61.7
No	43	35.8
Missing system	3	2.5
Total	120	100.0
Weigh clients		
Yes	49	40.8
No	66	55.0
Missing system	5	4.2
Total	120	100.0
Counsel clients		
Yes	94	79.1
No	21	17.5
Missing system	4	3.3
Total	120	100.0
Identify close relatives/friends to help them adhere to the taking of drugs		
Yes	71	59.2
No	45	37.5
Missing system	4	3.3
Total	120	100.0
Others		
Yes	32	26.7
No	84	70.0
Missing system	4	3.3
Total	120	100.0

Source: Data from fieldwork, 2012

Services respondents render to their fellow PLHIV

When the researcher asked the respondents about the services they provided to their fellow PLHIV, who came for treatment,

care and support, they stated that they helped them to pick their folders, prepared them to see the physicians, counselled them and identified their close relatives/friends to help them adhere to the counselling they received on antiretroviral therapy by taking their drugs religiously.

How beneficial respondents' service has been to them and their clients

The researcher wanted to ascertain how beneficial their service has been to them and their clients. From the responses given, it was evident that the respondents derived both intrinsic and extrinsic rewards from their service.

Gaining knowledge about HIV and AIDS and living positively

The majority of the respondents stated that through their service they and their clients had gained a lot of knowledge about HIV and AIDS and they as well as their clients were living positively with HIV. A male respondent, who was over 30 years stated: *I have acquired knowledge about HIV and AIDS.* Another male respondent said: *"It [service] has helped me to know the Dos and Don'ts in life"*. A female respondent, who was over 30 years old, mentioned: *"I know how to care for myself and my children as well as my clients"*. Another female respondent between the ages of 30 and 34 years stated: *"It [service] has helped built my life. It has also helped me to plan my life"*. Another female respondent, who was over 30 years old, indicated: *Through the service we are able to teach and know how to relate. I was not able to relate to people, but now I can educate and relate to people"*.

Making clients happy and feeling good about it

The care and support provided by the 'models of hope' for clients make the latter happy. A female respondent in reference to their clients stated: *"It [service] makes them happy and hopeful and so they take their medications with the objective of living long"*. Another female respondent, who was over 30 years old, indicated the appreciation of their clients with regard to their service: *"It [service] makes them happy and if I am not able to go to the clinic to provide service, they [clients] call me on phone to know my whereabouts"*. A male respondent between the ages of 30 and 34 years said: *I love helping others and because of stigma if someone is diagnosed for the first time and you are able to disclose to her/him that you are with them they become happy.*

Fighting stigmatization and discrimination

Some respondents stated that through their service they had been able to respond effectively to HIV stigmatization and discrimination. A male respondent, who was over 30 years old, stated: *"I am free from stigmatization and discrimination and some clients have also overcome stigmatization and discrimination"*. Similarly, a female respondent, who was also over 30 years old, indicated: *"It [service] gives them [clients] hope and reduces discrimination"*.

Problems respondents encounter in the execution of their service

When the researcher asked about problems the respondents encountered in the execution of their service, the majority, 88 representing 73.3 percent indicated that they were faced with a myriad of problems; 23 (19.2 percent) said 'no'; and 9 (7.5 percent) gave no response. This result confirms the findings of earlier studies (Akintola, 2008; Kangethe, 2009. Ama & Seloilwe 2010). The following are some problems, which the respondents, who indicated that they had problems, stated: A female respondent said: *The nurses don't give us chance to work; they say we are taking their jobs from them.* Another female respondent said: *Some nurses stigmatise the infected persons. We have problems with the nurses during our duties. Some nurses don't value us.* Yet another female respondent stated: *Some of the clients rely on us for financial assistance, and stigma forces some of them to plead to put up with us.* A male respondent said: *I find it difficult using the blood pressure machine [sphygmomanometre] to measure the blood pressure of clients.* A female respondent indicated: *I do not know much because I am not a trained 'model of hope'.* Another female respondent indicated: *We face financial difficulties – how to cater for our utilities, children's school fees and money for transport to visit our clients. We are not remunerated for the work we do. Some of us are given incentives by some non-governmental organisations, while others get nothing. Even those who get the incentives do not get them regularly.*

DISCUSSION AND CONCLUSION

The study ascertained what motivates PLHIV known as 'models of hope' to provide care and support to fellow PLHIV in Ghanaian hospitals and clinics and also to undertake home visits to their clients. Most of the literature on caregiving points out the fact that caregivers are confronted with a burden of care, such as adverse physical, mental and socio-economic consequences. The study revealed that majority of the 'models of hope' came face-to-face with burdens including financial difficulties, difficulty feeding themselves, stigmatization, lack of incentives, etc. However, these experiences did not stop them from providing care and support to their fellow PLHIV, who needed their service. Using Charles Synder's hope theory as its theoretical underpinning, the study indicates that 'models of hope' are high hoppers, who in relating with the PLHIV they care for and support, aim at achieving a common goal with them, that is living positively with HIV. The study revealed that they did achieve their goals because most of their clients became happy and accepted to live positively with HIV. By providing the service, they derived some satisfaction because they gained a lot of knowledge about HIV and AIDS, which they needed, to educate and counsel their clients, adopted positive behaviours and perceived that they were effective in their work in view of the fact that their clients were happy with them. Just as Akintola (2010) indicated in his research on caregivers in South Africa, through the positive feedback that they get from their clients the 'models of hope' experience a high sense of well-being. Although some hospital and clinic staff, particularly some nurses, did not value their service, as some of the respondents claimed, interviews with some

management staff in these institutions indicated that they cherished their services. This positive feedback made the 'models of hope' develop a sense of pride and satisfaction. Majority of them, therefore, expressed their willingness to continue offering the service. They, however, indicated that they needed to be given regular incentives and offered more skills training by the Ghana AIDS Commission (GAC), NACP and civil society organization. The views of these 'models of hope' are in line with similar sentiments expressed by Biriwasha (2010), as he writes: "It is critical for governments... to develop policy and legal frameworks as well as budgetary mechanisms that empower caregivers to properly cater for clients. International donors also need to seriously consider increasing the financial support targeted directly at making caregivers do their work better and not at the expense of their own lives"

Competing interests

The researcher hereby declares that he has no competing interests

Acknowledgement

The researcher would like to express his profound gratitude to the 'models of hope' for willingly consenting to participate in the study by answering the questionnaire and granting the interviews. Without their participation this study could not have been possible. He would also like to thank Mr. John Windie Ansah, a colleague in the Department of Sociology and Anthropology of the University of Cape Coast for taking time off his heavy schedule to read through and make comments on an earlier draft of the manuscript.

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