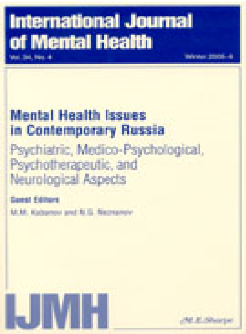

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The influence of caregiver stress and affiliate stigma in community-based mental health care on family caregiver wellbeing

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ABSTRACT

Previous studies have noted the inadequacies within Ghana's mental health system. These studies highlighted challenges associated with caregiving before the passage of Ghana's current Mental Health Act (Act 846) of 2012. Yet, there is paucity of research on the wellbeing of caregivers in community-based mental health care, following the passage of the Mental Health Act. This study investigated the influence of caregiver stress and affiliate stigma on family caregiver wellbeing. Further, it assessed the differences in stress, affiliate stigma, and wellbeing between community and institutional family caregiver groups in the Eastern Region of Ghana. Two hundred and eighty family caregivers of persons living with any type of mental illness were purposively sampled for the study. Results of Hierarchical Multiple Regression analysis showed that, caregiver stress negatively significantly influenced caregiver wellbeing. Moreover, results of a Multivariate Analysis of Covariance showed a significant difference between community and institutional family caregivers in the combined experience of stress, affiliate stigma and wellbeing, with community family caregivers scoring higher on wellbeing than did institutional family caregivers. Implications for caregiver interventions in the Eastern Region of Ghana are discussed.

KEYWORDS
Affiliate stigma; caregiver stress; community-based mental health care; mental illness; wellbeing

Introduction

Mental disorders are debilitating conditions that account for 12–15% of the world's total disability (Thornicroft & Tansella, 2003). According to De Hert et al. (2011), people with severe mental illness, including schizophrenia, have a high death rate, which is 2-3 times more than the general population often due to untreated physical illness. This translates to 13–30 year shortened life expectancy, which has widened in recent decades, even in countries with quality health care systems (see e.g., De Hert et al., 2011). The World Health Organization (WHO, 2001) estimated that about 450 million people experience some kind of mental disorder at any given

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time globally. Mental disorders have great impact on daily life, and account for more than 30% of all years lived with disability (Thornicroft & Tansella, 2003). In Africa, mental disorders constitute 19% of all disability, and 5% of the total disease burden (WHO, 2001). It is said to reduce productivity and increase the risk of physical diseases (Monteiro, 2015). Fortunately, there is evidence of treatment success in reducing symptoms and disabilities caused by mental disorders (Corrigan, Druss, & Perlick, 2014). For instance, Patel et al. (2007) found psychopharmacological agents, psychotherapy, among others effective in treating persons with mental disorders in low and middle income countries.

In 2003, the WHO acknowledged the family as primary caregivers who provided support for mentally ill relations (WHO, 2003a). Although the skills needed by family caregivers to support patients' care have not been properly established as a concept in nursing (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000), the family as a support system has been studied extensively. For instance, Berkman (2014) highlighted the protective role of support systems against psychological distress. As noted, one out of four families globally has a minimum of one member with a mental health problem (WHO, 2003a), a situation that is usually associated with stress, although difficult to assess and to quantify. Consequently, the extent of the burden placed on family members is usually ignored, in spite of its significant effect on the family's quality of life (WHO, 2003b). The Canadian Mental Health Association (2006) explained that, individuals' position in the family determines the magnitude of stress experienced through caring for mentally ill relatives. The Association further asserted that children whose parents had addiction or mental health problems were predominantly distressed, as these children may assume nurturing roles for ailing parent, or become a confidante for a parent tending an ailing spouse or child. Nonetheless, other factors have been linked to the family's burden in caring for relatives with mental disorders.

According to Leggatt (2002), failure of mental health professionals to incorporate families in the management and care plan for their mentally ill relatives affects family caregivers. Family members provide intervention in emergency situations, provide shelter, assist with daily activities, among others, and in some cases, are more conversant with and may even have a better understanding of some aspects of their relative's illness than professionals (Canadian Mental Health Association, 2006). Leggatt (2002) asserts that family caregivers in developing countries play a vital role in the reintegration of patients in society due to lack of rehabilitation professionals. The diverse role of families has been deemed beneficial to patients, their families, and the mental health system at large (Canadian Mental Health Association, 2006). In spite of this, caregivers of persons with mental illness perceive society's attitude toward them as one of stigma and discrimination (Bonsu & Salifu Yendork, 2019; Chang, Yen, Jang, Su, & Lin, 2017; Morris et al., 2018).

Beliefs and attitudes of society often intensify families' burden with extra guilt (Spaniol et al., 1992). Kyei-Mensah (2016) reported that, the stigma attached to mental disorder results in sufferers' exclusion from communities, leading to deprivation of basic human rights, including rights to health, social and economic wellbeing. Stigma is said to be strongly rooted in cultural beliefs. For instance, Sokhela (2016) reported relationships between mental disorders and witchcraft in certain communities in South Africa, which promoted stigma. Moreover, Jimenez, Bartels, Cardenas, Dhaliwal, and Alegría (2012) noted that, beliefs enfolding mental disorders were influenced by race or ethnicity.

Caregiving involves a lot work (Fothergill, Edwards, & Burnard, 2004). Vermeulen et al. (2015) suggested that, one in four family caregivers of persons with mental illness feels unfit to adapt to the consistent tension (emotional challenge) that accompanied the caregiving role, with one out of three feeling lonely and separated (social challenge). According to Skaff and Pearlin (1992), the overwhelming nature of caregiving due to the roles of the caregiver resulted in the lack of social contact and responsibilities, leading to a massive loss of self. To Skaff and Pearlin (1992), this loss did not only correlate with elevated depressive symptoms, but also, it correlated with lower self-esteem and skills. Vitaliano and Katon (2006) found that prolonged experience of stress due to the demands of caring has a possible impact on family's daily living, health, career, finances, and social relations. Consequently, Northouse, Katapodi, Schafenacker, and Weiss (2012) revealed a significant interconnection between family caregiver's wellbeing and that of their patients. Evidence of recent and dated studies indicated that caregiving had impact on caregivers' wellbeing, especially on psychological wellbeing (González-Salvador, Arango, Lyketsos, & Barba, 1999; Northouse, Katapodi, Schafenacker, & Weiss, 2012; Talley & Crews, 2007). The need to recognize the enormous roles of family caregivers, adequately support them to lessen their burden, and to promote their wellbeing cannot be overemphasized.

Although some previous studies have adequately identified increased stress, worry, and poor physical and emotional health as consequences of caregiving in caregivers (Grunfeld et al., 2004; Pressler et al., 2009), most researchers have concentrated on exploring the challenges associated with mental health service delivery, and in some cases, the challenges with the implementation of community-based mental health care (Bonsu, 2018). For example, the effect of inadequate resources on mental health service delivery has been reported in some African countries, including South Africa, Malawi, Uganda and Ghana (Bonsu, 2018; Marais & Petersen, 2015; Ssebunnya, Kigozi, Kizza, & Ndyanabangi, 2010; Udedi, 2016). Moreover, there are inconsistencies in the findings of previous studies on caregiver experiences, which have often been linked to the differences in methods used (Pinquart & Sörensen, 2003).

Mental health in Ghana

Akapule (2015) noted that, Ghana has an estimated three million people living with mental disabilities. The Chief Executive of the Mental Health Authority of Ghana had stated that "about 40 percent of all general hospital attendances have a mental illness component" (Osei, 2018, para. 8). Notwithstanding this, mental illness in Ghana is estimated to have a treatment deficit of 98% (Akapule, 2015). For example, Roberts, Asare, Mogan, Adjase, and Osei (2013) reported that, of Ghana government's total expenditure on health in 2011 (i.e., GH₵ 398,857,000 [USD 82,322, 596]), only 1.4% was allocated for mental health care. The remaining 98.6% of the total healthcare spending in 2011 went to physical health. Correspondingly, the ripple effect of this is a poor mental health service delivery, contrary to what Ghanaians expected after the passage of Mental Health Act 846 of 2012 (Akapule, 2015).

Previously, persons with mental illness were cared for in institutions (i.e., asylums) in Ghana (Osei, Roberts, & Crabb, 2011). Unfortunately, institutional care has been identified with problems including reduced family involvement, inadequate funding, extremely poor standard of treatment and care, isolation of patients and staff, progressive loss of potentials, and the accumulation of deficit symptoms in patients (Kofie & Montana, 2017; Thornicroft & Tansella, 2003). Some researchers have associated the unfavorable conditions within institutional care to a disregard for patients' rights (Kofie & Montana, 2017; Thornicroft & Tansella, 2003). However, in recent years, Ghana has attempted a shift to community-based mental health care, deemed to resolve challenges identified with institutional care (Roberts, Mogan, & Asare, 2014).

The passage of the Mental Health Act 846 of 2012 put a smile on the faces of mental health sympathizers, and was deemed by both mental health professionals and family caregivers, including patients as a means to address the unfavorable experiences in the field (Chibaro, 2013). Approximately six years on, certain unfavorable mental health challenges that pre-dated the Act have reemerged. For example, there is inadequate funding for mental health services in Ghana, including community-based mental health services (Roberts, Asare, Mogan, Adjase, & Osei, 2013), resulting in high service charges, family caregivers living with patients despite low socioeconomic status and or busy work schedules, and frequent shortage of free Psychotropic medications. These are contrary to what Ghanaians expected after the passage of Act 846 of 2012 (Akapule, 2015).

While existing related studies focused on the challenges with mental health care in Ghana, the limited studies on Ghana's mental health system has been emphasized (Read & Doku, 2012). Although caregiver experience in Ghana has been explored (see e.g., Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Bonsu, 2018), studies on community-based mental health care, the influence of caregiver stress and affiliate stigma on family caregiver wellbeing, and the difference between community family caregivers (i.e., a family member who shoulders responsibility of a mentally ill relative receiving care at home) and institutional family caregivers (i.e., a family member who adopts responsibility of a mentally ill relative who has been admitted to a mental health facility or unit) in stress, affiliate stigma and wellbeing are limited. Hence, studies on the influence of caregiver stress and affiliate stigma on wellbeing were deemed necessary. In addition to providing additional evidence on the link among stress, affiliated stigma and caregiver well-being, the present paper makes a unique contribution by highlighting the differences in stress, affiliate stigma, and well-being between community and institutional family caregivers.

The Eastern Region of Ghana was selected for this study because it is close to the national capital of Ghana, Accra. It has a well-structured community-based mental health care system as well as institutional mental health care for the mentally ill. Most community-based mental health care programs are piloted and implemented in this region. Previous research has assessed the effectiveness of the community-based mental health programs in the region (Akapule, 2015; Roberts, Asare, Mogan, Adjase, & Osei, 2013). However, these studies have not examined issues relating to family and institutional caregiver stigma and stress and their influence on caregiver wellbeing. Understanding the experiences of caregivers in the Eastern Region may provide an insight into the caregiver wellbeing situation and provide a foundation for future research. In addition, evidence of the programme's impact on caregiver well-being will strengthen the argument for an improved mental health system in Ghana. Based on the previous studies reviewed, the present study examined the following hypotheses (H). Caregiver stress and affiliate stigma will negatively influence caregiver wellbeing after controlling for potential covariates (H1); perceived stress, affiliate stigma and wellbeing will significantly differ between community and institutional family caregivers after controlling for potential covariates (H2); perceived stress will be significantly higher among community family caregivers than it will be among institutional family caregivers (H3); affiliate stigma will be significantly higher among community family caregivers than it will be among institutional family caregivers (H4); and community family caregivers will report significantly lower wellbeing than institutional family caregivers (H5).

Methods

Participants and procedure

Two hundred and eighty (280) participants were surveyed. There were 140 participants each for the community and institutional family caregiver groups. Family caregivers were family members who shoulder responsibility of a mentally ill relative receiving care at home. Family caregivers were recruited at home in the Koforidua township of the Eastern Region. Institutional family caregivers were family members who took responsibility of a mentally ill relative who has been admitted to a mental health facility or unit. They were recruited at mental health facilities in the Koforidua township. Participants were individuals aged 18 years and older, who played significant role(s) such as providing financial and emotional support, making arrangements for hospital appointments, supervising treatment, feeding, grooming, among other needs of persons with any type of mental illness. The participants were purposefully and conveniently sampled from a population of family caregivers of persons reporting any type of mental illness. Survey questionnaires were piloted to examine their meaningfulness and contextual validity. For the main study, participants provided data on stress, affiliate stigma, and wellbeing, during caregivers' appointments to the hospital and also during professional visits to patients' home. Participants who needed assistance to complete the questionnaires (46) were assisted to do so by the investigators. Questionnaires took approximately 20 min to complete.

Measures

Demographic Questionnaire

Demographic Questionnaire was completed by family caregivers. This helped to gather participants' sociodemographic information. These included: age, sex, religious affiliation, highest level of education, number of years as a carer, marital status, relationship with the patient, family caregiver status (community or institutional), and income status.

Kingston Caregiver Stress Scale (KCSS; Hopkins & Killik, 2018; Sadak et al. 2017)

The Kingston Caregiver Stress Scale (KCSS) was used to assess stress in caregivers. This is a 10-item primary scale, with three subscales; "Caregiving issues," "Family issues" and "Financial issues." The 10 items on

KCSS are neutrally worded questions that represent potential sources of stress to the caregiver. These items measure caregiver stress on a Likert scale from 1 (*no stress, coping fine, no problem*) to 5 (*extreme stress, feeling at "end of rope," health at risk*) (Hopkins & Killik, 2018). It measures caregiving issues with 7 items (1, 2, 3, 4, 5, 6, and 7), family issues with 2 items (8 and 9), and financial issues with 1 item (10). It is used in conjunction with the KCSS Administration and Interpretation Manual, and takes less than 5 min to complete. High scale scores indicated greater perceived caregiver stress. Subscale scores were summed and the total score was computed by averaging the total scores for each of the three subscales. Pitsikali, Galanakis, Varvogli, and Darviri (2015) reported a Cronbach's alpha of .85, whereas the present study recorded a Cronbach's alpha of .92.

Affiliate Stigma Scale (Mak & Cheung, 2008)

The Affiliate Stigma Scale was used to measure affiliate stigma experienced by family caregivers. This measure has 22 items that assess the cognitive, affective and behavioral components of affiliate stigma. The three components constitute three subscales. Each subscale is measured on a four point Likert scale format from 1 (*strongly disagree*) to 4 (*strongly agree*). High scale scores indicated greater perceived affiliate stigma. Subscale scores were summed and the total score was computed by averaging the total scores for each of the three subscales (i.e., cognitive, affective, and behavioral). Cronbach's alpha ranging from .93 and .94 have been reported for this scale (Mak & Cheung, 2008; Werner & Shulman, 2013). The Affiliate Stigma Scale has been used in different languages and populations (Chang, Su, & Lin, 2016; Chang et al., 2015; Saffari et al., 2019). The scale has also been used in the Ghanaian context (Cobbinah, 2015). Cobbinah (2015) recorded α value of .94 using the original 22 items. Similarly, the present study recorded α value of .94 using the original 22 items.

Caregiver Well-Being Scale, 16-item version (CWBS; Tebb, Berg-Weger, & Rubio, 2013)

The 16-item shortened version of the Caregiver Wellbeing Scale was used to assess family caregiver wellbeing. This version was developed from the original 43-item Caregiver Well-Being Scale (CWBS, Tebb, 1995). The 16-item shortened version has two subscales namely "Basic Needs (BN)," and "Activities of Daily Living (AOL)," with 8 items assessing each subscale. CWBS measures family caregiving experience from a strength-based perspective by assessing caregivers' basic human needs and satisfaction with activities of daily living (Rubio, Berg-Weger, & Tebb, 1999). CWBS is a self-report, measured on a five-point Likert scale ranging from 1 (*rarely*) to

5 (*usually*). The maximum score is 80 and the minimum score is 16. The mean score was used to indicate caregiver wellbeing. In this study, subscale scores were summed and the total score was computed by averaging the total scores for each of the two subscales (i.e., basic needs and activities of daily living). Tebb et al. (2013) found a good reliability for the subscales and total scale as follows: BN, α =. 73; ADL, α = .74; total scale, α =.83. Alpha of .84 was recorded in the present study for the overall scale.

Ethics considerations

The researchers obtained ethics approval from the Ethics Committee for Humanities, University of Ghana (ECH 036/17-18). Again, participants' consent was sought, with details of the study effectively communicated before participation. For instance, the right to decline without consequences, and any potential benefit or harm were explained to participants. Participants were also assured of privacy, confidentiality, and issues of confidentiality. To guarantee anonymity, no personal information was obtained from the participants.

Data analysis

The Statistical Package for Social Sciences (SPSS) version 23.0 was used to analyze the data. Hierarchical Multiple Regression was used to examine the influence of caregiver stress and affiliate stigma on caregiver wellbeing. This was done by entering control variables at step 1, whereas caregiver stress and affiliate stigma (i.e., independent variables) were entered at step 2. One-way Multivariate Analysis of Covariance (MANCOVA) was used to assess differences between community family caregivers and institutional family caregivers in stress, affiliate stigma, and wellbeing, while controlling for age, number of years as a carer, relationship with patients, level of education and income status. The p-values for the MANCOVA were thus adjusted for the covariates.

Results

Preliminary analysis

Initial data screening found no missing data. The continuous variables were inspected for normality by assessing skewness, kurtosis and outliers. The variables were well within acceptable ranges of −2 to +2 for skewness and kurtosis (Tabachnick & Fidell, 2007). The means, standard deviations and Cronbach's alphas for each of the scales used are presented in Table 1.

Table 1. Mean, standard deviation, Cronbach's alpha, skewness and kurtosis for the study variables ($n = 280$).

Variable	*M*	*SD*	Cronbach's alpha (α)	Skewness	Kurtosis
Caregiver stress	23.16	9.26	.92	.44	−.52
Affiliate stigma	44.03	10.92	.94	.36	1.21
Caregiver wellbeing	52.36	9.19	.84	−.56	.77

Descriptive statistics

The community caregiver sample was made up of women (66.4%) and men (33.6%). The institutional caregiver sample was made up of 66.3% women and 35.7% men. In terms of relationship with a patient, a greater number of participants (38.6 and 43.6% for community and institutional family caregivers respectively) were parents, followed by siblings (22.9% and 17.9% for community and institutional family caregivers respectively). Individuals caring for their mentally ill parents formed the third largest number of participants (21.4 and 15.7% for community and institutional family caregivers respectively). Distant relatives and carers who were not biologically related constituted "others," with a total of 22.8% (10.7% and 12.1% for community and institutional family caregivers respectively). Spouses formed the least (6.4 and 10.7% for community and institutional family caregivers respectively) of family caregivers in the study. Other relevant demographic information is presented in Table 2.

According to Hopkins and Killik (2018) a score of 16 and below indicates mild stress, 16–24 indicates moderate stress and above 24 indicates severe stress on Kingston Caregiver Stress Scale (KCSS). Therefore, individual participants whose total scores fall within these range of values were categorized as having mild stress, moderate stress, and severe stress. In addition, Mak and Cheung (2008) categorized respondents who score greater or equal to 55 on Affiliate Stigma Scale into high affiliate stigma and those who score less than 55 into low affiliate stigma. Following Mak and Cheung (2008), we also categorized individual participants whose total scores fall within these ranges as experiencing high or low affiliate stigma. Furthermore, we used the mean score on the caregiver wellbeing scale to categorize participants' scores. Thus, caregivers who scored greater or equal to 48 were categorized as having high wellbeing, whereas those who scored less than 48 were categorized as having low wellbeing.

From the foregoing, our descriptive results showed that, 97 of institutional family caregivers experienced moderate to high stress compared to 103 of community family caregivers who experienced moderate to high stress. Also, 43 of institutional family caregivers experienced mild/low stress compared to 37 of community family caregivers who experienced mild/low stress. About 16 of institutional family caregivers experienced high affiliate stigma compared to 16 of community family caregivers who experienced high affiliate stigma. Similarly, 124 of institutional family caregivers experienced mild/low affiliate stigma compared to 124 of community family caregivers who experienced mild/low affiliate stigma. Generally, the majority of family caregivers ($n = 248$) experienced low affiliate stigma while ($n = 32$) experienced high affiliate stigma. Consistent with earlier findings, quite a large number of community family caregivers ($n = 104$) scored higher on wellbeing compared to institutional family caregivers ($n = 99$) who scored high on wellbeing (Table 3).

Table 2. Demographic characteristics of the sample ($N = 280$).

		Community family caregiver		Institutional family caregiver		
Variable	Category	(%)	*M* (*SD*)	(%)	*M* (*SD*)	*p*
Age (years)			49.5 (15.7)		47.3 (13.4)	.207
Caregiving tenure (years)			10.1 (8.3)		7.8 (9.2)	.033*
Gender	Men	47 (33.6%)		50 (35.7%)		.802
	Women	93 (66.4%)		90 (64.3%)		
Relationship with patient	Child	30 (21.4%)		22 (15.7%)		.387
	Sibling	32 (22.9%)		25 (17.9%)		
	Spouse	9 (6.4%)		15 (10.7%)		
	Parent	54 (38.6%)		61 (43.6%)		
	Other	15(10.7%)		17 (12.1%)		
Highest education level	No formal education	17 (12.1%)		29 (20.7%)		.481
	Primary-JHS	52 (37.1%)		51 (36.4%)		
	O/A Level/SSCE	41 (29.3%)		33 (23.6%)		
	Diploma	19 (13.6%)		19 (13.6%)		
	Degree	8 (5.7%)		6 (4.3%)		
	Post-graduate	3 (2.1%)		2 (1.4%)		
Religious affiliation	Muslim	8 (5.7%)		16 (11.4%)		.039*
	Christian	132 (94.3%)		119 (85.0%)		
	Traditional	0 (0.0%)		3 (2.1%)		
	Other	0 (0.0%)		2 (1.4%)		
Marital status	Single	29 (20.7%)		22 (15.7%)		.811
	Married	72 (51.4%)		80 (57.1%)		
	Divorced	14 (10.0%)		13 (9.3%)		
	Widowed	21 (15.0%)		22 (15.7%)		
	Separated	4 (2.9%)		3 (2.1%)		
Income (monthly)	No monthly income	45 (32.1%)		63 (45.0%)		.052*
	GH₵1.00–GH₵300.00	42 (30.0%)		23 (16.4%)		
	GH₵300.00–GH₵500.00	27 (19.3%)		25 (17.9%)		
	GH₵500.00–GH₵1,000.00	17 (12.1%)		16 (11.4%)		
	> GH₵1,000.00	9 (6.4%)		13 (9.3%)		

Note. $^{*}p < .05$.

Table 3. Frequencies, percentages, means, standard deviations and ranges for stress, affiliate stigma and wellbeing.

	Community family caregiver			Institutional family caregiver		
Variables	High range	Moderate range	Mild/Low range	High range	Moderate range	Mild/Low range
Stress	61 (43.6%)	42 (30%)	37(26.4%)	54 (38.6%)	43 (30.7%)	43 (30.7%)
Affiliate Stigma	16 (11.4%)	–	124 (88.6%)	16 (11.4%)	–	124 (88.6%)
Wellbeing	104 (74.3%)	–	36 (25.7%)	99 (70.7%)	–	41 (29.3%)

Hypotheses testing

An initial Pearson Product-Moment Correlation Coefficient analysis was conducted to examine existing relationships between the study's variables and demographic characteristics. This correlation analysis revealed that age, number of years as a carer, relationship with patients, educational level, and income status significantly correlated with some of the study's dependent variable (see Table 4). Therefore, age, number of years as a carer, relationship with patients, highest level of education and income status were treated as control variables in the subsequent statistical analyses.

Impact of caregiver stress and affiliate stigma on caregiver wellbeing

The first hypothesis stated that caregiver stress and affiliate stigma would negatively influence caregiver wellbeing controlling for potential covariates. In Table 5, the second Step ($F_{(7,\ 272)} = 10.47$, $p = .000$, $R^2 = .21$, $\Delta R^2 = .142$) shows that the contribution of the two predictor variables to the model was significant. This result indicates that all the study variables together accounted for a total of 21% variance in caregiver wellbeing, with the two main predictor variables (i.e., affiliate stigma and caregiver stress) alone accounting for 14.2% of the variance in the dependent variable. In Step 1 where age, number of years as a carer, relationship with patient, formal education, and income status were entered as control variables, the model ($F_{(5,\ 274)} = 4.14$, $p = .001$, $R^2 = .07$, $\Delta R^2 = .07$) was significant. This indicates that age, number of years as a carer, relationship with patient, formal education, and income status accounted for a 7% variance in caregiver wellbeing. Further, caregiver stress significantly influenced caregiver wellbeing ($\beta = -.329$, $p < .001$), whereas affiliate stigma did not significantly influence caregiver wellbeing ($\beta = -.089$, $p = .171$). In summary, the hypothesis that "caregiver stress and affiliate stigma would negatively influence caregiver wellbeing controlling for potential covariates" was partially supported.

Difference between community and institutional family caregivers in stress, affiliate stigma and wellbeing

Results from MANCOVA (see Table 6), controlling for age, number of years as a carer, relationship with patients, highest level of education and income status indicated a statistically significant difference between community and institutional family caregivers on the combined dependent variables (i.e., caregiver stress, affiliate stigma, and caregiver wellbeing), Wilks' Lambda $= .95$, $F_{(3,\ 271)} = 4.89$, $p < .05$; partial $\eta^2 = .05$. Thus, the main hypothesis that perceived stress, affiliate stigma, and wellbeing will

Table 4. Person product-moment correlation coefficient analysis for study variables and demographic characteristics of participants.

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Sex	–											
2. Relationship with client	.03	–										
3. Religious affiliation	−.04	.09	–									
4. Marital status	.21***	.06	−.05	–								
5. Income status per month	−.17**	−.03	.12*	−.15**	–							
6. Family caregiver status	−.02	.08	−.01	.02	−.03	–						
7. Non formal education	.14*	−.01	−.09	.15**	−.26***	.12	–					
8. Formal education	−.14*	.01	.09	−.15**	.26***	−.17	1.00**	–				
9. Age	.10	−.04	−.02	.39**	−.10	−.08	.15**	−.15**	–			
10. Caregiver stress	.04	.14*	.05	.10	−.17***	−.07	.08	−.08	−.01	–		
11. Caregiver wellbeing	−.04	−.10	−.03	−.01	.09	−.17***	−.11	.11	.17**	−.39**	–	
12. Affiliate stigma	.05	.04	.05	.07	−.13*	.06	.06	−.06	.01	.56***	−.29***	–

Note: *$p < .05$, **$p < .01$, ***$p < .001$.

Table 5. Hierarchical multiple regression for the impact of caregiver stress and affiliate stigma on caregiver wellbeing.

	B	*SE*	*β*	*t*	*p*
Step 1					
Age	.097	.040	.155	2.435	.016
Number of years as a carer	.105	.066	.100	1.597	.112
Relationship with client	−.547	.349	−.091	−1.568	.118
Formal Education	2.939	1.504	.119	1.955	.052
Income status per month	.550	.428	.078	1.283	.201
Step 2					
Age	.091	.037	.145	2.470	.014
Number of years as a carer	.112	.061	.108	1.850	.065
Relationship with client	−.253	.326	−.042	−.778	.437
Formal education	2.560	1.390	.103	1.841	.067
Income status per month	.113	.401	.016	.282	.778
Caregiver stress	−.327	.066	−.329	−4.984	.000
Affiliate stigma	−.075	.055	−.089	−1.373	.171

Note: Step 1, $R^2 = .07$, $\Delta R^2 = .07^{**}$, $F = 4.14$; Step 2, $R^2 = .21$, $\Delta R^2 = .142^{***}$, $F = 10.47$.

Table 6. Results of MANCOVA on caregiver stress, affiliate stigma and caregiver wellbeing of community and institutional family caregivers.

	Community family caregivers		Institutional family caregivers				
Dependent variable	*M*	*SD*	*M*	*SD*	*F*	*p*	η^2
Caregiver stress	23.83	9.49	22.50	9.01	2.51	.12	.01
Affiliate stigma	43.41	11.08	44.65	10.77	.44	.51	.00
Caregiver wellbeing	53.91	9.30	50.81	8.83	4.80	.03	.02

significantly differ between community family caregivers and institutional family caregivers was supported by the data. However, the univariate results revealed no statistical significant differences between community family caregivers and institutional family caregivers in stress, ($F_{(1,\ 273)} = 2.51$, $p > .05$) and in affiliate stigma, ($F_{(1,\ 273)} = .44$, $p > .05$). Yet, there was a significant difference in the mean scores of community ($M = 53.91$, $SD = 9.30$) and institutional family caregivers ($M = 50.81$, $SD = 8.83$) in wellbeing, $F_{(1,\ 273)} = 4.80$, $p < .05$, partial $\eta^2 = .02$ (see Table 6). This suggests that community family caregivers reported higher wellbeing than did institutional family caregivers, which was not in the direction hypothesized by the researchers.

Discussion of findings

The results of the present study revealed a negative influence of caregiver stress and affiliate stigma on caregiver wellbeing, although only caregiver stress significantly negatively influenced caregiver wellbeing. Also, there was a difference between community and institutional family caregivers in the combined experience of stress, affiliate stigma, and wellbeing, with community family caregivers reporting a higher wellbeing. In addition, the stress and affiliate stigma experienced by these two groups of family caregivers did not differ significantly. This finding is consistent with a previous study that found psychiatric caregiving to be stressful (Fothergill et al., 2004) and another that confirmed affiliate stigma among caregivers of persons with mental illness (Yin et al., 2014). Regarding the differences, even though there was no much difference in frequencies in the ranges of stress and affiliate stigma experienced by community and institutional family caregivers, the magnitude of difference in the range of their wellbeing was prominent.

The finding on the negative influence of caregiver stress and affiliate stigma on well-being was validated by previous studies that noted the impact of caregiving on caregivers' wellbeing (Pinquart & Sörensen, 2003; Son et al., 2007). Inadequate funding for mental health services and the absence of needed structures to augment community-based mental health care seemed to be contributing to caregiver stress in the current sample. As explained by Son et al. (2007), inappropriate behaviors and the indifferent attitude of some persons with mental illness amount to care receivers' stressors, which have potential to trigger undesirable subjective feelings in caregivers.

Kyei-Mensah (2016) noted some of the consequences of stigma and discrimination associated with mental illness to include: sufferers' exclusion from communities, deprivation of basic human rights, such as the rights to health, social and economic wellbeing. The findings of a previous study had confirmed the retarding nature of stigma on patients' recovery (Link et al., 2001). However, by virtue of association, the stigma and discrimination directed toward persons with mental illness transcend to caregivers (Yin et al., 2014). Following these thoughts, Mak and Cheung (2008) defined affiliate stigma as the degree of self-stigmatisation among relations of an affected interest group.

In line with the researchers' hypothesis, caregiver stress significantly influenced caregiver wellbeing but affiliate stigma did not. However, other researchers reported contrary results on the relation between affiliate stigma and caregiver wellbeing. For example, Werner, Mittelman, Goldstein and Heinik (2012) observed that, caregivers' view on stigma was linked with an added burden. Iseselo et al. (2016) also confirmed stigma as one of the factors that influence caregiver psychosocial wellbeing. Moreover, a previous study conducted by Liu (2011), which examined the connection between perceived stigma and depressive symptoms found that, perceived stigma among caregivers correlated with the experience of depressive symptoms, a situation that was intensified with a heightened perception of stigma. However, Cobbinah (2015) postulated that most caregivers with high affiliate stigma also had low psychological wellbeing. Cobbinah (2015) obtained such finding due to the fact that most of the caregivers were parents of developmentally disabled children and having such bond with the child heightens the impact of stigma on psychological wellbeing. The challenges with mental health care in Ghana, even after 6 years of the passage of Ghana's current mental health act continue to persist and do not only affect persons living with mental illness, but their family caregivers, and for that matter their wellbeing. Given this, we think that a possible reason why affiliate stigma did not significantly affect caregiver wellbeing may be that, although these relatives of the mentally ill experience some form of stigma as a result of their relationship with the mentally ill, this stigma does not seem to be potent enough to affect their wellbeing. In addition, it is also possible that these family relations have other social support systems or resources that help to mitigate the effect of stigma on their wellbeing.

The hypotheses on difference between community and institutional family caregivers in the combined experience of stress, affiliate stigma and wellbeing, was confirmed by our data. The difference in caregiving setting, and the relative amount of resources available to support caregiving could explain this difference. Yet, the outcome that community family caregivers had a higher wellbeing than institutional family did not confirm the researchers' hypothesis. Higher wellbeing among community family caregivers than their institutional counterparts may be due to differences in the severity of the mental illness they manage. Thus, clients with severe forms of mental illness are more likely to be managed in institutional settings than in communities. Again, the present study found that, perceived stress and affiliate stigma did not differ between the two groups of family caregivers, which contradicted the researchers' initial predictions. Although there is no known study to support this finding, to the researchers' knowledge, the outcome implies that, regardless of the setting (community or institution), family caregivers go through similar experiences in stress and affiliate stigma.

Conclusion and implications for intervention

There is a negative influence of caregiver stress and affiliate stigma in community-based mental health (CBMH) on family caregiver wellbeing. Caregiver stress and affiliate stigma result from inadequate funding for mental health services; resources and structural constraints; risk associated with caregiving; burden or stress associated with caregiving; stigma and discrimination. Both community and institutional family caregivers seem to experience the same amount of stress and affiliate stigma, even though community family caregivers reported a higher wellbeing than institutional family caregivers in this study.

The present study found that stress influenced wellbeing. In view of that, there is the need for the provision of adequate resources to assist caregivers in the management of the persons with mental illness. Caregivers should be equipped with needed resources and structures suitable for the nature of care rendered to clients to reduce the risk and burden associated with caregiving. Thus, support for the provision of rehabilitation centers, vocational training centers for persons recovering from mental illness, halfway homes, family caregiver assistance programs, tele-psychiatry, emergency teams, adequate and right mix of mental health professionals, must be a priority for government and the ministry of health. Mental health units or departments can be made available in all health facilities across Ghana to ensure easy access to mental health care. This may reduce stress experienced by family caregivers.

Also, there is the need for psycho-education to increase knowledge and awareness of mental illness. This will reduce stigma. The combined effects of the reduction in stress and affiliate stigma will be an improvement in wellbeing. Nonetheless, there should be periodic health checks (averagely every 6 months) for caregivers of persons with mental illness to detect and manage any physical or psychological effect of caregiving.

Again, the present study identified that community family caregivers experienced a higher wellbeing than institutional family caregivers. In this regard, there is the need for improvement in institutional mental health care. Government must deem it necessary to step up budgetary allocations for mental health services to cater for service requirements. Better still, government should consider policy amendments to ensure mental health care is fully covered by the national health insurance scheme. This may reduce the burden of institutional family caregivers, which has been noted to have a negative influence on wellbeing. Most importantly, there is the need for governmental backing to facilitate the effective implementation of Ghana's Mental Health Act (Act 846) of 2012 to guarantee the provision of good standards of mental health care that preserves the wellbeing of caregivers and the rights of persons with mental health problems.

Limitations and implications for future research

For the purpose of interpretation of the findings of the present investigation, there are few limitations that are worth noting. First, although the study aimed to explore the experiences of caregivers in the Eastern Region of Ghana, only caregivers in one municipality within the region were recruited, which constitutes a relatively small portion of caregivers in the region. Also, differences in culture and belief systems among caregivers in different parts of the region may influence their experiences. These variables were not controlled for in the current study. It is possible that the influence of stress and affiliate stigma will have different influence on caregivers in other parts of the region. Hence, the study findings cannot be generalized to caregivers in other settings in the Eastern Region of Ghana. It is recommended that future studies should use a larger sample that includes caregivers across the entire region.

Second, the study was conducted using a cross-sectional design. This may have not been enough to gain adequate insight into caregivers' experiences in CBMH in terms of possible fluctuations in experiences over time, as a result of potential changes in patients' condition and circumstances surrounding caregiving. Future researchers should consider a longitudinal study to gain sufficient information about potential trends in caregiver experiences with community-based mental health care.

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