



Sentiments, Demands and Knowledge of Informal Caregivers on Willingness to Care for Patients with Chronic Disease in the Ashanti Region, Ghana

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Abstract

Background: Willingness is not a stable attitude because it decreases and caregivers experience fluctuate from time to time.

Objective: This study investigates the informal caregivers' sentiments, demands, knowledge and willingness to care for patients with chronic disease in the Ashanti Region, Ghana.

Methods: A cross-sectional descriptive survey plan was used with 396 participants. Data were analysed using frequency distribution, Pearson's chi-squared test of independence and binary logistic regression.

Results: Statistically, significant relationship was found in all the hypotheses postulated in the study.

Namely: informal caregivers' sentiment, informal caregivers' demands as well as informal caregivers' knowledge and willingness to care for chronic disease patient. It was emerged that caregivers share sentiments when they realise family members fail to do more to support the patient. It was revealed that pain management as well as basic needs, turning and repositioning the patient were some of the informal care demands. The study unearthed that caregivers feel knowledgeable about providing care for the patient's specific health needs.

Conclusion: The study recommends that informal caregivers should endeavour to have time for their health while caring for the patient.

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Introduction

Willingness is not a stable attitude because it decreases and caregivers experience fluctuate from

time to time [1]. Informal caregivers are expected to be willing to care for relatives with care needs [1]. While caregiving can be a very rewarding and

bonding experience, it can also be very demanding. When you are a caregiver it is easier to forget about your own needs while caring for others [2]. This creates a stressful and potentially unhealthy situation for both parties. The emotional stress involved with providing care, particularly for those who are workers can be devastating and even drain the most capable person [3]. The resulting feelings of anger, anxiety, sadness, isolation, exhaustion – and then guilt for having these feelings – can exert a heavy toll including physical problems [4]. It has been established that caregivers suffer more psychological distress and fatigue than non-caregivers. The length of service makes a pronounced difference. Long-term caregivers have much higher rates of physical symptoms like headaches, body aches and abdominal discomfort [5].

Therefore, healthcare's shift toward patient-centricity and shared decision-making combined with breakthrough advances in treating chronic disease requires that caregivers understand complex therapeutic options in order to offer effective support for patients as they decide on a treatment plan [6]. A lot has been done about the enormous emotional and physical stress that chronic disease caregivers often encounter [7,8]. While there are countless programmes dedicated to assist caregivers liberate this distress, the everchanging healthcare landscape adds new challenges which makes caregivers face with information needs as soon as their loved ones are diagnosed, when they immediately become immersed in helping to make medical choices for which they are illprepared [9,10].

For many, caregiving is a common aspect of life [11]. However, individuals who take on the responsibility of caring for another person due to illness, disability, or declining abilities, it can often be challenging, lonely, costly and exhausting [6]. For instance, as common as caregiving may be, when a loved one receives a serious diagnosis, the path forward may still feel like navigating uncharted territory [11]. Whether you have been designated as your loved one's primary caregiver or are simply trying to be a supportive friend, knowing the right words to say and actions to take can be difficult [11]. Hence, managing a chronic or advanced illness can consume a lot of time and energy that would otherwise be spent on routine

activities. Building a strong support network around yourself and your loved one can help prevent undue stress for caregivers. A lot of caregivers are burning the candle at both ends, which can lead to burnout. People can get stuck in a mindset of toxic positivity where there is no room for uncomfortable emotions [11,12].

Unfortunately, many caregivers who encounter advanced chronic disease are neither supported nor prepared [13,14]. Informal caregivers not only have responsibilities for managing patients' needs but also require support throughout the treatment trajectory or when confronted with their own concerns and emotion [13]. Regrettably, most healthcare systems do not provide adequate support to caregivers [15]. In fact, caregiving concerns increase fatigue among caregivers of patients with chronic disease [13]. Hence, many caregivers perceive that they are not well prepared to navigate through the challenges brought by chronic disease caregiving [16].

Surprisingly, it appears our search did not yield studies centered on the knowledge, demands and sentiments of informal caregivers of patients with chronic disease using quantitative approach within the Ghanaian context. Therefore, it is crucial to investigate informal caregivers' sentiments, demands, knowledge and willingness to care for chronic disease patients in the Ashanti Region, Ghana by specifically: (1) analysing if informal caregivers' sentiments influence willingness to care for chronic disease patients in the Ashanti Region, Ghana; (2) ascertaining if caregiving demands of informal caregivers predict willingness to care for chronic disease patients in the Ashanti Region, Ghana and (3) examining whether informal caregivers' knowledge predicts willingness to care for chronic disease patients in the Ashanti Region, Ghana. The study further hypothesized that informal caregivers' sentiments, demands and knowledge do not predict willingness to care for chronic disease patients.

Methods

Study Setting and Participants

Ashanti Region was chosen as the study site. It was necessary because the region has one of the referral facilities for managing chronic diseases. In the region, the Komfo Anokye Teaching Hospital [KATH] particularly the Oncology Unit was deemed appropriate

for the study. Hence, it offers specialize treatment options for chronic disease patients [17,18,19]. This facility serves almost half of the Ghanaian population with its regional coverage including Ashanti Region, Bono, Ahafo and Northern Regions of Ghana [17-19]. In all, the study enrolled 400 informal chronic disease caregivers who brought their patients to the hospital for healthcare services.

Inclusion Criteria

For a caregiver to qualify to participate in the study, he or she must be caring for chronic disease patients; must be primary caregiver; be eighteen years and above; must live in Ashanti Region and must have at least one year experience in caregiving. Therefore, caregivers that do not satisfy the above conditions were excluded from the study.

Study Design and Data source

A descriptive cross-sectional design was utilized for the study. The descriptive design starts by identifying the population of interest, collects the data, and classifies the participant, either as having the outcome or phenomena of interest or not [20]. Moreover, it enables researchers to collect data across a wide range of subjects at a single moment, aiming to capture a comprehensive picture of a particular research question [21]. The design was adopted because the aim of the study fit into it thus, classifying the informal caregivers either as having the willingness to care for chronic disease patients or not considering their sentiments, demands and knowledge regarding the care. Data were obtained in the field from informal caregivers of chronic disease patients using questionnaire. The questionnaire was designed based on literature and already developed survey instruments were reviewed and items that found to help measure some constructs of this current study were adopted.

Sample and Sampling Technique

A sample of 400 were enrolled in the study with the help of Table for determining sample size for a finite population. The authors expressed that a finite population of 50000, 381 is ideal for a sample. Therefore, considering the number of cases (52,863) Ashanti Region recorded in 2016, then, 381 could be used as an ideal sample for the study [22,23]. However, due to refusal and incomplete responses, a non-response rate of 5% was added which made the actual

sample to be $(381 \times 0.05) + 381 = 400.05$. Therefore, the sample size for the study was 400.

With the help of systematic sampling approach, these 400 participants were selected. The approach was deemed appropriate because it allows participants to be selected at regular intervals from a sampling frame or without a frame [24]. The intervals are carefully chosen to ensure an adequate sample size [25,26]. The study needed a sample of 400 from a chronic disease patient population of 52,863. So, we calculated our sample interval as follows: $52863/400 = 132.16$. Random number 3 was generated between 1 and 132 which served as the 1st participant so starting from the entrance of the oncology unit of KATH the 1st participant was selected follow by the 2nd participant $3 + 132 = 135$ th. The process continued until the last participant was reached.

Measures

Caregivers' sentiment indicators include [guilt, grief, burnout, resentment, anxiety sadness/depression and anger/frustration]; informal care demands indicators include [physical and psychological burden, opportunity costs, and training] and knowledge indicators include [perceived knowledge, resources and training, and caregiver confidence [27,28]. Willingness to care indicators include [relationship, attitude, time spent with care recipient, commitment, and empathy [29,30].

Data Collection Procedure

Data collection commenced on 26th of September 2022 and ended on 25th of August, 2022 after The Research Ethics Committee of the University of Health and Allied Sciences has approved the research protocol with the help of two trained research assistants of which their services were compensated for. In all, one month was used to collect the data. Questionnaire was used to solicit data from the participants at the KATH. All the participant that took part in the study consented orally. The average time spent on each questionnaire in the field was 25 minutes.

Reliability and Validity

In order to ensure reliability in the study, careful measures were put in place to ensure that data were solicited from the right source with a comprehensive coverage. Aside that, data collection methods, data cleaning and

preprocessing as well as standardized metrics were keenly observed to help minimize errors. In terms of validity, appropriate time scale and methodology was chosen taking into consideration the characteristics of the study subjects. Further, the study adopted the most suitable sample method and lastly, the participants that took part in the study were not pressured in any ways to select specific responses among the answer sets. All these measures were put in place to help achieve validity.

Data Processing and Analysis

First of all, data collected from the field were cross checked for errors. Items that requested multiple responses and the open-ended questions were recoded to ease entry. The data were then transferred to SPSS version 27 for cleaning and processing. After cleaning the data, 396 responses were analysed. Frequency distribution, Pearson's chi-squared test of independence and binary logistic regression analyses were run. The frequency distribution was used to summarise participants socio-demographic characteristics, sentiments, demands, knowledge and willingness to care for chronic disease patients. The Pearson's chi-squared test of independence was used to test the hypothesis that there is no statistically significant relationship between informal caregivers' sentiments, demands, knowledge and willingness to care for chronic disease patients. The binary logistic regression analysis was run to make predictions from the explanatory variables studied in the study.

Ethical Consideration

To ensure that ethical issues were managed well in the study, participation was made voluntary and participants were told they can decline at any time. In the field, oral informed consent was obtained from participants and was witnessed by the participant's any elderly person who directly related to the participant. Further, in the field, all data that could identify participants such as names, addresses and telephone numbers were avoided. In addition, ethical clearance (with ID number UHAS-REC A./111/21-22) to conduct this study was sought from The Research Ethics Committee of the University of Health and Allied Sciences, Ho, Ghana.

Results

Table 1 presents information on the socio-demo

graphic characteristics of the research participants. The study participants composed of 72.7% females and 27.3% males. About sixty-four per cent (63.6%) of the participants were between the ages of 45 and 54 years while a little above nine per cent (9.1%) were in the 15-24; and 25-34 age groups. Regarding education, only 9.1% of the caregivers had tertiary education compared to 45.5% who completed secondary school. Whereas not employed was a dominant category of employment status constituting over sixty per cent (63.6%) of the total participants, the employed category was the least (9.1%). Concerning religious affiliation, Christianity dominated (63.6%) and those belonging to traditional religion were 9.1%. In terms of caregiver relationship to the patient, about 45.5% of the participants were spouses while 9.1% were friends. Regarding duration of care, more than forty per cent (45.5%) have been in care for 3 years while the least duration was 4 years and above constituting 9.1%. Concerning type of care provided, health monitoring dominated constituting over forty per cent (45.5%) while emotional support was the least (9.1%).

Table 1: Socio-demographic Characteristics of the Research Participants

Variable	F	%
Sex		
Male	108	27.3
Female	288	72.7
Age		
15-24	36	9.1
25-34	36	9.1
35-44	72	18.2
45-54	252	63.6
Religion		
Christianity	252	63.6
Islam	108	27.3
Traditionalist	36	9.1
Education		
None	72	18.2
Primary	108	27.3
Secondary	180	45.5
Tertiary	36	9.1
Employment Status		
Employed	36	9.1
Not employed	252	63.6
Self-employed	108	27.3
Relationship to Patient		
Relative	72	18.2
Spouse	180	45.5
Child	108	27.3
Friend	36	9.1
Duration of Care		
1year	72	18.2
2years	108	27.3
3years	180	45.5
4years and above	36	9.1
Type of Care		
Physical Assistance (Help with Mobility and Bathing)	108	27.3
Medication Management and Emotional Support	72	18.2
Health Monitoring	180	45.5
Emotional Support	36	9.1
Total	396	100.0

Source: Fieldwork (2022)

To find answers to informal caregivers' sentiments about caring for chronic disease patients, a number of questions were asked which span from guilt, grief, burnout, resentment, anxiety, sadness/depression and anger/frustration. The results are presented in Table 2.

Table 2: Informal Caregivers' Sentiments about Caring for a Chronic Disease Patient

Variable	F	%
Guilt expression		
Feel regrets	108	27.3
Not doing enough for the Patients	216	54.5
Yell at the Patient and Unfair Treatment	72	18.2
Grief Expression		
Loss of Time and Future Plans	108	27.3
Loss of Future Plans	180	45.5
Loss of time	72	18.2
Other Losses that come with Caring for Loved Ones	36	9.1
Cause of Burnout		
Physical Exhaustion	36	9.1
Stress	360	90.9
Describe your Resentment		
Become Angry when Family Members Fail to do more to Support the Caregiver	72	18.2
Become Angry when Family Members Fail to do more to Support the Patient	216	54.5
Become Angry when Friends Fail to do more to Support the Caregiver	108	27.3
Anxiety Expression		
Worry	180	45.5
Fear	72	18.2
Tension	144	36.4
Sadness/Depression		
Crying	72	18.2
Sad thoughts	216	54.5
changes in Eating Habits	108	27.3
Total	396	100.0

When participants were asked to indicate how they express their guilt revealed that 54.5% said it is not doing enough for the patient while 18.2% reported yelling at the patient and unfair treatment (see Table 2). Regarding grief expression, more than forty per cent (45.5%) indicated loss of future plans while 9.1% reported other losses that come with caring for loved one. Whereas 90.9% indicated that their burnout is from stress 9.1% said is from physical exhaustion (see Table 2).

Nearly fifty-five per cent (54.5%) of the participants said they become angry when family members fail to do more to support the patient while 18.2% reported they become angry when family members fail to do more to support the caregiver (see Table 2). Regarding anxiety expression, about forty-six per cent (45.5%) of the participants reported worry while 18.2% indicated fear. When participants were asked to indicate what makes them sad or depressed revealed that about fifty-five per cent (54.5%) indicated sad thoughts while 18.2% said crying (see Table 2).

To unravel the influences informal caregivers’ sentiments, have on willingness to care for a chronic disease patient, a number of questions regarding willingness to care for a patient including relationship, attitude, time spent with care recipient, commitment, and empathy were raised. The results are shown in Table 3.

Table 3: Willingness to Care for a Chronic Disease Patient

Variable	F	%
Willingly Care for a Chronic Disease Patient		
Yes	324	81.8
No	72	18.2
Total	396	100.0

Source: Fieldwork (2022)

When participants were asked to indicate whether they willingly care for a chronic disease patient or not, the result revealed that 81.8% of the participants answered in affirmative while 18.2% said they do not (see Tale 3). Among the 324 participants who confirmed they willingly care for a chronic disease patient, 44.4% said in a day, they spend less than 2hours with the patient, 33.3% intimated they spend more than 5hours with the patient while 22.2% reported 2-5hours. Concerning how caregivers perceive their relationship with the patient, 44.4% said it is cordial, 22.2% said it is securely attached while 33.3% said insecure avoidant. Among the participants that said they willingly care for a chronic disease patient, majority (88.9%) said they have good attitude towards the patient while 11.1% said they do not. Regarding whether caregivers are committed to their role or not, the results revealed that 77.8% are committed to the role while 22.2% said they are not committed to the role.

Table 4 shows Pearson’s chi-square test of independence results on the relationship between informal caregivers’ sentiments and willingness to care for a chronic disease patient. This analysis was conducted to test the hypothesis there is no statistically significant relationship between informal caregivers’ sentiments and willingness to care for a chronic disease patient. Statistically significant relationships were found among all the variables studied under informal caregivers’ sentiments namely: guilt expression [p=0.001], grief expression [p=0.001], burnout [p=0.001], resentment [0.001], sadness/depression [0.001] as well as anxiety [0.001] and willingness to care for a chronic disease patient.

Table 4: Relationship between Informal Caregivers’ Sentiments and Willingness to Care for a Chronic Disease Patient

Variable	Willing (%)	Not willing (%)	Total n(%)	Chi-square	P-value
Guilt Expression				73.333***	0.001
Feel Regrets	100.0	0.0	108(100.0)		
Not doing Enough for the Patient	83.3	16.7	216(100.0)		
Yelling at and Unfair Treatment of the Patient	50.0	50.0	72(100.0)		
Grief expression				234.667***	0.001
Loss of Time and Future Plans	33.3	66.7	108(100.0)		
Loss of Future Plans	100.0	0.0	180(100.0)		
Loss of Time	100.0	0.0	72(100.0)		
Other Losses that come with caring for Loved one	100.0	0.0	36(100.0)		

Burnout				178.200***	0.001
Physical Exhaustion	0.0	100.0	36(100.0)		
Stress	90.0	10.0	360(100.0)		
Resentment				33.000***	0.001
Angry with Family Members for not doing more to Support the Caregiver	100.0	0.0	72(100.0)		
Angry with Family Members for not doing more to support the Patient	83.3	16.7	216(100.0)		
Angry with Friends for not doing more to Support the Caregiver	66.7	33.3	108(100.0)		
Sadness/Depression				113.667***	0.001
Crying	50.0	50.0	72(100.0)		
Sad thoughts	100.0	0.0	216(100.0)		
Changes in Eating Habits	66.7	33.3	108(100.0)		
Anxiety				93.500***	0.001
Worry	100.0	0.0	180(100.0)		
Fear	50.0	50.0	72(100.0)		
Tension	75.0	25.0	144(100.0)		

Note: Row percentages in Parenthesis, Chi-Square Significant at (0.001) ***, (0.05) **, (0.10) *
 Source: Fieldwork (2022).

To analyse informal care demands, participants were asked a lot of questions including physical and psychological burden, opportunity costs, and lack of training. The results are shown in Table 5.

Table 5: Informal Caregivers’ Demands for Caring for a Chronic Disease Patient

Variable	F	%
Physical and Psychological Burden you Face		
Basic Needs, Turning and Repositioning the Patient	72	18.2
Sleep, Emotional Needs, and Practical Needs	144	36.4
Pain Management	180	45.5
What Constitute Your Opportunity Costs for Caring For A Chronic Z		
Lose Earnings	180	45.5
Lose Career	72	18.2
Lose Entitlements	144	36.4
Trained to Perform the Caregiving Task		
Yes	324	81.8
No	72	18.2
Psychological Pain Experienced		
Feeling Overwhelmed with Responsibilities	36	9.1
Sad and Lonely	180	45.5
Tired and Deserted	108	27.3
Isolation	72	18.2
What Causes Stress and Worry to you		

Spending a lot of Time Thinking about the Loved one’s Health and what will happen in the Future	72	18.2
Spending a Lot of Time Thinking about the Loved one’s Health	108	27.3
Spending a Lot of Time Thinking about what will happen in the Future	216	54.5
Experience Financial Strain		
No	72	18.2
Yes	324	81.8
Have Impaired Relationships		
Yes	324	81.8
No	72	18.8
Experience Sense of Hopelessness		
No	36	9.1
Yes	360	90.9
Total	396	100.0

Source: Fieldwork (2022)

Participants were asked to indicate the physical and psychological burden they face and the results revealed that 45.5% indicated pain management while 18.2% reported basic needs, turning and repositioning the patient (see Table 5). On what constitute caregivers’ opportunity costs for caring for a chronic disease patient, about forty-six per cent (45.5%) indicated lose earnings while 18.2% intimated lose career. Whereas 81.8% of the participants said they were trained to perform the caregiving task 18.2% reported that they were not trained (see Table 5).

Close to forty-six per cent (45.5%) of the participants reported that the psychological pain they experience is sad and lonely while 9.1% said it is feeling overwhelmed with responsibilities (see Table 5). Regarding what causes stress and worry to caregivers, about fifty-five per cent (54.5%) of the participants reported spending a lot of time thinking about what will happen in the future while 18.2% said it is spending a lot of time thinking about the loved one’s health and what will happen in the future. Whereas 81.8% of the participants said they experience financial strain 18.2% said they do not (see Table 5).

Concerning whether participants have impaired relationships or not, the results revealed that about eighty-two per cent (81.8%) of the participants have impaired relationships while 18.2% said they do not have (see Table 5). Whereas overwhelming majority (90.9%) of the participants indicated they experience sense of hopelessness 9.1% said they do not (see Table 5).

Table 6 presents Pearson’s chi-square test of independence results on the relationship between informal caregivers’ demands and willingness to care for a chronic disease patient. This analysis was run to test the hypothesis there is no statistically significant relationship between informal caregivers’ demands and willingness to care for a chronic disease patient. Statistically significant relationship was found in all the variables studied under informal caregivers’ demands namely: physical and psychological burden encounter [0.001], what constitute opportunity cost [0.001], trained to perform the task [0.001], psychological pain encounter [0.001], causes of stress and worry [0.001], experience financial strain [0.001], have impaired relationship [0.001] as well as experience sense of hopelessness [0.001] and willingness to care for a chronic disease patient.

Table 6: Relationship Between Informal Caregivers’ Demands and Willingness to Care for a Chronic Disease Patient

Variable	Willing (%)	Not willing (%)	Total n(%)	Chi-Square	P-value
Physical and Psychological Burden Face				93.500	0.001
Basic Needs, Turning and Repositioning the Patient	50.0	50.0	72(100.0)		
Sleep, Emotional Needs and Practical Needs	75.0	25.0	144(100.0)		
Pain Management	100.0	0.0	180(100.0)		
Opportunity Costs				154.000	0.001
Lose Earnings	100.0	0.0	180(100.0)		
Lose Career	100.0	0.0	72(100.0)		
Lose Pension Entitlement	50.0	50.0	144(100.0)		
Trained to Perform the Caregiving Task					
Yes	22.2	77.8	324(100.0)		
No	100.0	0.0	72(100.0)		
Psychological Pain Encounter				105.600	0.001
Feeling Overwhelmed	100.0	0.0	36(100.0)		
Sad and Lonely	60.0	40.0	180(100.0)		
Tired and Deserted	100.0	0.0	108(100.0)		
Isolated	100.0	0.0	72(100.0)		
What Causes Stress and Worry to you				73.333	0.001
Spending a lot of Time Thinking about the Loved one’s health and what will happen in the Future	100.0	0.0	72(100.0)		
Spending a lot of Time thinking about the Loved one’s Health	100.0	0.0	108(108)		
Spending a Lot of Time Thinking about what will happen in the Future	66.7	33.3	216(100.0)		
Experience Financial Strain				19.556	0.001
Yes	77.8	22.2	324(100.0)		
No	100.0	0.0	72(100.0)		
Have Impaired Relationship				19.556	0.001
No	100.0	0.0	72(100.0)		
Yes	77.8	22.2	324(100.0)		
Experience Sense of Hopelessness				8.800	0.001
No	100.0	0.0	36(100.0)		
Yes	80.0	20.0	360(100.0)		

Note: Row Percentages in Parenthesis, Chi-Square Significant at (0.001) ***, (0.05) **, (0.10) *

Source: Fieldwork (2022).

In an attempt to unravel informal caregivers' knowledge about willingness to care for chronic disease patients made me asked a number of questions revolving perceived knowledge, resources and training, and caregiver confidence. The results are presented in Table 7.

Table 7: Informal Caregivers' Knowledge about Willingness to Care for Chronic Disease Patients

Variable	F	%
Feel Knowledgeable About Providing Care for the Patient's Specific Health Needs		
Yes	360	90.9
No	36	9.1
Have Understanding of the Recipient's Condition or Diagnosis		
Yes	324	81.8
No	18.2	72
Have Adequate Knowledge of Emergency Procedures		
I have no Knowledge	252	63.6
Have Extensive Knowledge	108	27.6
Fully Trained in Emergency Procedures	36	9.1
Have the Skills to Handle the Physical Tasks Required in Caregiving		
Yes	324	81.8
No	72	18.2
Received any Formal Training or Education Related to Caregiving		
Yes	396	100.0
Kind of Formal Training or Education Related to Caregiving Received		
Caregiver Training Program	216	54.5
First aid/CPR Certification	108	27.3
Condition-Specific Training (e.g., Dementia Care, Diabetes Management)	72	18.2
Need More Training or Information to Provide Better Care		
I Feel Well-Prepared	36	9.1
Yes, I Would Attend a Training Program if Offered	180	45.5
Yes, but I don't know where to find it	72	18.2
Yes, I am Actively Seeking it	108	27.3
Specific Areas of Caregiving you need more Knowledge or Support		
Medication Management, Pain Management & Nutritional Needs	36	9.1
Personal Care (e.g., Bathing, Dressing) & Legal and Financial Aspects of Caregiving	108	27.3
Mental Health Support, & Communication Strategies (e.g., Dealing with Confusion or Frustration)	252	63.6
Being Confident in Making Decisions about the Patient's Care (e.g., Medical, Daily Living)		
Yes	324	81.8
No	72	18.2
Have Enough Support from Healthcare Professionals (e.g., Doctors, Nurses, Therapists) in Managing Care		
Yes	288	72.7

No	108	27.3
How Often do you Feel Overwhelmed or Uncertain about Providing Care		
Never	20	5.1
Often	376	94.9
Being Likely to Seek Help or Advice if Unsure about a Caregiving Task or Situation		
Likely	360	90.9
Unlikely	36	9.1
Total	396	100.0

Source: Fieldwork (2022)

When participants were asked to indicate whether they feel knowledgeable about providing care for the patient's specific health needs or not, the results revealed that overwhelming majority (90.9%) answered in affirmative (see Table 7). Regarding whether participants have understanding of the patient's condition/diagnosis or not, the results revealed that 81.8% believe that they have better have understanding of the patient's condition while 18.2% said they do not (see Table 7).

Concerning whether participants have adequate knowledge of emergency procedures or not, the results revealed that about sixty-four per cent (63.6%) have no knowledge while 9.1% intimated that they are fully trained in emergency procedures (see Table 7). Whereas 81.8% of the participants said they have the skills to handle the physical tasks required in caregiving 18.2% reported that they do not (see Table 7). On whether participants have received any formal training or education related to caregiving or not, the results revealed that all the participants answered in affirmative (see Table 7).

Regarding the kind of formal training or education related to caregiving received, about fifty-five per cent (54.5%) of the participants reported caregiver training program while 18.2% said it is condition-specific training (e.g., dementia care, diabetes management). On the aspect of if caregivers need more training or information to provide better care or not, the results indicated that 45.5% of the participants said yes, we would attend a training program if offered while 9.1% reported no, we feel well prepared (see Table 7).

Concerning whether participants have specific areas of caregiving they need more knowledge or support or not, the results revealed that about 63.6% said it is mental health support, and communication strategies (e.g., dealing with confusion or frustration) while 9.1% intimated medication management, pain management, and nutritional needs (see Table 7). Whereas majority (81.8%) of the participants indicated that they are confident in making decisions about the patient's care (e.g., medical, daily living) 18.2% said they do not have that confident (see Table 7).

When participants were asked to indicate if they have enough support from healthcare professionals (e.g., doctors, nurses, therapists) in managing care or not, the results revealed that about seventy-three per cent (72.7%) answered in affirmative. Whereas overwhelming majority (94.9%) said they often feel overwhelmed or uncertain about providing care 5.1% indicated they do not feel overwhelmed or uncertain about providing care (see Table 7). Regarding if participants are likely to seek help or advice if unsure about a caregiving task or situation or not, the results revealed that 90.9% of the participants said it is likely while 9.1% said it is not likely (see Table 7).

Table 8 presents Pearson's chi-square test of independence results on the relationship between informal caregivers' knowledge and willingness to care for a chronic disease patient. This analysis was run to test the hypothesis there is no statistically significant relationship between informal caregivers' knowledge and willingness to care for a chronic disease patient. Statistically significant relationship was found in all the variables studied under informal caregivers' knowledge namely: Feel knowledgeable about providing care for the patient's specific health needs [0.003], have understanding of the recipient's condition or diagnosis [0.001], have adequate

knowledge of emergency procedures [0.001], have the skills to handle the physical tasks required in caregiving [0.001], kind of formal training or education related to caregiving received [0.001], need more training or information to provide better care [0.001], specific areas of caregiving needs more knowledge [0.001], confident in making decisions about the patient’s care [0.001], have enough support from healthcare professionals [0.001] as well as feel overwhelmed about providing care [0.003] and willingness to care for a chronic disease patient.

Table 8: Relationship Between Informal Caregivers’ knowledge and Willingness to Care for a Chronic Disease Patient

Variable	Willing	Not willing	Total n(%)	Chi-square	P-value
Feel Knowledgeable about Providing Care for the Patient’s Specific Health Needs				8.800***	0.003
No	100.0	0.0	36 (100.0)		
Yes	80.0	20.0	360(100.0)		
Have Understanding of the Recipient’s Condition or Diagnosis				59.889	0.001
Yes	89.9	11.1	324(100.0)		
No	50.0	50.0	72(100.0)		
Have Adequate Knowledge of Emergency Procedures				50.286	0.001
I have no Knowledge	71.4	28.6	252(100.0)		
Have Extensive Knowledge	100.0	0.0	108(100.0)		
fully Trained in Emergency Procedures	100.0	0.0	36(100.0)		
Have the Skills to Handle the Physical Tasks Required in Caregiving				19.556	0.001
Yes	77.8	22.2	324(100.0)		
No	100.0	0.0	72(100.0)		
Kind of Formal Training or Education Related to Caregiving Received				33.000	0.001
Caregiver Training Program	83.3	16.7	216(100.0)		
First Aid/CPR Certification	66.7	33.3	108(100.0)		
Condition-Specific Training (e.g., Dementia Care, Diabetes Management)	100.0	0.0	72(100.0)		
Need More Training or Information to Provide Better Care				81.400	0.001
I Feel Well-Prepared	100.0	0.0	36(100.0)		
Yes, I would Attend a Training Program if Offered	80.0	20.0	180(100.0)		
Yes, but I don’t know where to find it	50.0	50.0	72(100.0)		
Yes, I am Actively Seeking it	100.0	0.0	108(100.0)		
Specific Areas of Caregiving need More Knowledge				50.286	0.001

Medication Management, Pain Management and Nutritional Needs	100.0	0.0	36(100.0)		
Personal Care (e.g., Bathing, Dressing), and Legal and Financial Aspects of Caregiving	100.0	0.0	108(100.0)		
Mental Health Support, & Communication Strategies (e.g., Dealing with Confusion or Frustration)	71.4	28.6	252(100.0)		
Confident in Making Decisions About the Patient’s Care				19.556	0.001
Yes	77.8	22.2	324(100.0)		
No	100.0	0.0	72(100.0)		
Have Enough Support from Healthcare Professionals				22.917	0.001
Yes	87.5	12.5	288(100.0)		
No	66.7	33.3	108(100.0)		
Feel Overwhelmed About Providing Care					
Often	80.0	20.0			
Never	100.0	0.0			

Source: Fieldwork (2022).

Discussion

Informal caregivers’ sentiments and willingness to care for a chronic disease patient

The study attempted to unravel sentiments, demands and knowledge of informal caregivers towards their willingness to care for patients with chronic disease. Participants demonstrated utmost knowledge on their sentiments. It appeared that participants express their sentiment in guilt in various ways thus felt not doing enough for the patient, yelling at the patient and unfair treatment. The reason for participants accommodating that they feel they do not do enough for the patient could probably be that they do not avail themselves all the time due to numerous responsibility they attend to during the day. This finding confirms study that the caregiver endeavours to provide care that ensures optimal quality of life for the patient. However, it might result in a compromised quality of life for the patient. Further, participants that intimated that they yell at the patient and treat them unfairly reason could probably be that they are fed up with the patient due to persistence frustration and loss of hope in the patient’s condition [31]. The study revealed that caregivers express their grief in loss of future plans. The reason for this finding could be that those caregivers do not get the time to build upon their future plans and that they presume

if such continues, their future might be threatened. Again, it could be that such caregivers spend a lot on the patient which makes them to think that they might be able to realise their future plans.

The study brought to the fore that majority of the caregivers’ experience burnout largely from stress. The reason for this finding could be that caregivers are mostly occupied with responsibility and that they do not get time to rest. This finding affirms study that isolation and diminished social interactions due to the additional demands on caregivers time and energy can contribute to stress [31]. Hence, impacting the quality of life for both caregivers and care-recipients. It emerged in the study that caregivers become angry when family members fail to do more to support the patient. The reason for this finding could be that it is only the caregivers that bear the expenses of the patient as a result of that they find disappointment among the patient’s family members. This finding is in line with a study by that family members may offer support when the caregiving journey begins but may dissipate as the condition worsens or does not improve and the care needs intensify [32].

It was unearthed that caregivers’ express anxiety whenever they are worried. The reason for this finding could probably be that when caregivers realise that they are not getting support from family members of

the patient, they become worried which eventually perpetuate anxiety among them. Further, it could be that these caregivers think about their future and they come into terms that there is no way they can realise their future plans which makes them to be anxious. This finding is in line with study that informal caregivers can experience a variety of emotions such as anger at being forced to provide care and having to give up work [33].

Participants demonstrated fair knowledge about what makes them to be sad/depressed. The most cited was sad thoughts, changes in eating habits and crying. The reason for this finding could probably be that they are always left alone with the patient which eventually makes them to always confined in the house and become lonely hence, they cannot meet with friends to enjoy the beauty of the day. It could also mean that these caregivers do not get any social support, encouragement and warmth from others which could wipe off their tears and motivate them in their pursuance of their duty. This finding corroborates to study that social interactions with family and friends can also be compromised, with intense and prolonged caregiving hence excludes informal caregivers from participating in social interactions/events, including religious and cultural ceremonies, which they may previously have been enjoying [34].

Statistically significant relationship was found between informal caregivers' sentiments and willingness to care for a chronic disease patient therefore, the null hypothesis was not confirmed. This finding motivated me to have a confidence that an effect or pattern exists, and it made sense to me to do further analysis of the data to discover what the effect or pattern seems to be. However, it was unfortunate that in the binary logistic regression, none of the variables studied under sentiments was significant.

Informal Caregivers' Demands and Willingness to Care for Chronic Disease Patient

As the study tries to analyse caregivers demands towards willingness to care for a chronic disease patient revealed pain management; basic needs, turning and repositioning the patient. The reason for this finding could probably be that pain management; basic needs, turning and repositioning the patient drain caregivers a lot and that do not permit them have

time to attend to other duties let alone to have time for themselves. Participants cited lose earnings and lose career as opportunity costs for caring for a chronic disease patient. The reason for this finding could be that caregivers do not get time to perform other activities which could earn them something likewise they do not get the time to indulge in any career venture which they can hold onto for their daily bread in the future. The overwhelming majority that intimated they were trained to perform the patient caregiving task reason could probably be that such training was carried out at out-patient department. It could also mean that such caregivers are professional nurses and that knew the practices involving caring for a chronic disease patient.

It was revealed that the psychological pain caregivers experience is sadness and loneliness and feeling overwhelmed with responsibilities. This signifies that caregivers are always in a dilemma due to the workload on them. Further, it could be that the workload does not permit them make friends which affect their social life. Spending a lot of time thinking about what will happen in the future and spending a lot of time thinking about the loved one's health and what will happen in the future are the causes of stress and worry to caregivers. The reason for this finding could be that caregivers are in suspense about what will be the outcome of their patient's health hence each day what they observe about their patient health status does not motivate them. This finding is in line with a study by study that family caregivers are often so overwhelmed with caregiving that they do not have the time to engage socially with people in the community or the energy to participate [35].

It was revealed that majority of the caregivers experience financial strain. The reason for this finding could probably mean that these caregivers are overburdened financially and do not have any occupation that provides them with income on daily or monthly bases. This finding is in line with study that the financial strain of caregiving to a chronically sick person can be significant, due to the cost of treatments and medications, and home care products associated with personal hygiene or specialized food. Impaired relationships and experiencing hopelessness were found to be some of the caregivers demands. The reason for this finding could be that caregivers do not get the time to make

friends which has affected their social life and makes them feel hopeless in life. This finding corroborates to study that experiencing loneliness is a common outcome of caregiving due to the substantial time and effort it required to provide care, often around the clock [36].

Statistically significant relationship was found between informal caregivers' demands and willingness to care for a chronic disease patient. Therefore, the null hypothesis was rejected. The rejection of the null hypothesis confirmed that pattern or effect exist among the explanatory variables studied under caregivers' demands and willingness to care for a chronic disease patient which calls for further analysis. Unfortunately, no statistically significant relationship was found between the explanatory variables and the outcome variable.

Informal Caregivers' Knowledge and Willingness to Care for a Chronic Disease Patient

Assessment of caregivers' knowledge towards willingness to care for chronic disease patient revealed that caregivers feel knowledgeable about providing care for the patient's specific health needs. The reason for this finding could be that caregivers have practiced caregiving for long and that are experienced when it comes to caring for the chronic disease patient. This finding is in line with study that caregivers are more confident in caring for the elderly with hypertension when they have more knowledge. Majority of the caregivers claimed they have understanding of the patient's condition/diagnosis and have adequate knowledge of its emergency procedures. It could be that these caregivers have lived long with the patient and that have understood the signs and symptoms surrounding the condition/diagnose which they are also abreast of the emergency procedures. Therefore, if the condition escalates, they are equal to the task [37].

Caregivers ascribed that they have the skills to handle the physical tasks required in caregiving. The reason for this finding could be that they have been trained on how to discharge their duties as caregivers. All the caregivers cited that they have received a formal training related to caregiving. The reason for this finding could be that healthcare providers do well to train who so ever accompany a chronic

disease patient to hospital. Though, some caregivers opted that they would attend a training program if offered. The reason for this finding could be that the caregivers are not satisfied with the training they have had and that lacks some basic skills concerning patient's caregiving.

Caregivers intimated that they have enough support from healthcare professionals (e.g., doctors, nurses, therapists) in managing care. The reason for this finding could be that healthcare professionals willingly provide support to informal caregivers whenever the need arises. Overwhelming majority express that they often feel overwhelmed or uncertain about providing care. The reason for this finding could be that these caregivers lack the skill and the enthusiast to care for a sick person. Caregivers remarked that they are likely to seek help or advice if they are not sure about a caregiving task or situation. The reason for this finding could probably be that these caregivers do not want to make mistakes in discharging of their duties.

Statistically significant relationship was found between informal caregivers' knowledge and willingness to care for a chronic disease patient. Therefore, the null hypothesis was nullified. The implication for this finding was that the variables studied under informal caregivers' knowledge were not independent of each other [38,39].

Conclusions

The study was conducted cross-sectionally and lends itself to descriptive survey plan. The study recruited 396 participants with the help of systematic sampling technique. Statistically significant relationship was found in all the hypotheses postulated in the study. Namely: informal caregivers' sentiment, informal caregivers' demands as well as informal caregivers' knowledge and willingness to care for chronic disease patient. The study recommends that informal caregivers should endeavour to have time for their health while caring for the patient.

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Declaration

Ethical Approval

Ethical approval (with ID number UHAS-RCE A./10/111/21-22) to conduct the study was taken from the Research Ethics Committee of the University of Health and Allied Sciences, Ho, Ghana.

Consent to participate in the Study

In the field, verbal consent was taken before a participant could take part in the study.

Consent to Publish

Participants were told that the study was strictly academic and that the results would be published for the purposes of contributing to building academic literature.

Competing Interests

No competing interest existed.

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Availability of Data and Materials

The data is only available to the author hence it was a primary data.

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