

## Article

# 'I need help': caregivers' experiences of caring for their relatives with mental illness in Jamaica

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### ABSTRACT

The findings reported here form part of a larger research project that examined non-compliance with medication among the mentally ill patients attending public clinics in a specific parish in Jamaica. The aim of the research was to explore the perceptions of caregivers about caring for the mentally ill at two outpatient psychiatric clinics. Caregivers involved in looking after their relatives with mental illness played a vital role in mental health promotion. This study sought to examine the caregivers' perception of mental illness, including how they thought the illness was best controlled, the reasons why their relatives found it difficult to take their medication as instructed, and the coping skills that they employed when caring for their relatives. There were two focus groups, consisting of four individuals each, at two psychiatric clinics.

The results revealed the following about the majority of the caregivers. First, it was recognised that caregivers have a good knowledge (and awareness) of medication usage inferred by either the absence or the presence of their relatives' symptoms. Secondly, they sometimes felt sad and hopeless as a result of being the victims of violent attacks by those for whom they provided care. Thirdly, they highlighted issues of cost, accessibility and availability of medications as being problematic. Fourthly, in some cases they received little or no assistance from other family members.

**Keywords:** caregivers, family, Jamaica, medication, mental illness, relationship

## Introduction and background

The past few decades have witnessed tremendous growth in the study of family interventions for serious mental illness. These developments have been motivated by several important factors. First, deinstitutionalisation has resulted in family members having greater responsibility for caring for their relatives without having the necessary knowledge, skills and support to do this.<sup>1</sup> Secondly, most mental health providers believe that educating families about mental illness is very important.<sup>2</sup> Consequently,

many mental health professionals have modified their view of families, moving away from a pathological paradigm (viewing the family as in need of a cure) to a competence paradigm (focusing on family strengths and empowerment).<sup>3</sup> Research on the impact of stress on caregivers, directly linked to their care and support for mentally ill family members, is a relatively recent phenomenon.<sup>4</sup> Studies conducted between the 1940s and the 1960s viewed the family as causing mental illness, and this resulted in

family members who were caregivers being blamed and criticised by treatment professionals for their caregiving role.<sup>4</sup> The expressed emotion (EE) studies by Leff and Vaughn<sup>5</sup> absolved families of blame for causing mental illness, but implied that families which have high levels of expressed emotion perpetuate mental illness in a family member who already has mental illness.<sup>5,6</sup> Lefley argued that family members who are caregivers are 'a potentially at-risk population whose needs may equal or even outweigh those of the persons around whom they revolve' (p. 303). The health and social risks associated with caregiving have been confirmed by an Australian study in which 30% of the 1500 caregivers who were surveyed mentioned being mentally exhausted, stressed, bored, frustrated and easily upset. Most of them attributed these problems to the stress of caring, social isolation, loneliness, changing relationships, loss and grief.<sup>7</sup>

Caregivers are an important national healthcare resource. Families are often a primary source of home care and support for relatives with or without (serious) mental illness.<sup>8</sup> Marks and colleagues<sup>9</sup> have pointed out that parents with mental illness consider their relationships with their children to be extremely important in terms of delegating the duties normally assigned to the parental role. They may prioritise their children's needs and neglect their own. They may struggle to fulfil the multiple roles demanded of them, and experience stress as they try to maintain the household, cope with the demands of work, and manage the behaviour and activities of their children. Their primary relationship and family life may suffer under these circumstances, although this may also be true for parents without mental illness. Non-adherence to treatment regimens is pervasive among patients with schizophrenia, and is therefore a major source of frustration and tension for families.<sup>10</sup> In a cross-sectional survey conducted by Pusey-Murray<sup>11</sup> among 344 mentally ill patients in Jamaica, it was found that of those who adhered to the treatment regimen, 46.7% had family support, whereas of those who did not adhere to it only 27.8% had family support, which suggests that there is a significant relationship between compliance and family support.

Fenton and colleagues<sup>12</sup> found that factors that supported treatment adherence included patient sociodemographic factors, illness characteristics, medication factors (including side effects and the route and frequency of administration), the level of family/social support and the quality of the physician-patient relationship. Veltman and colleagues<sup>13</sup> conducted a qualitative study in which they examined caregivers' perspectives on the negative and positive aspects of caregiving. They conducted 20 in-depth, audiotaped, semi-structured interviews

focusing on caregivers' positive and negative personal experiences when caring for a relative with mental illness. Caregivers reported both negative and positive effects of caregiving, which included stigma, systems issues, feelings of gratification, love and pride.

Caregivers who attempt to balance caregiving with their other activities, such as work, family activities and leisure pursuits, may find it difficult to focus on the positive aspects of caregiving and may experience more negative reactions, such as an increased sense of burden,<sup>14</sup> although other studies have described caregivers who did not feel burdened by caregiving.<sup>15</sup> However, more than 50% of patients were in settings with families and caregivers who lacked information about mental illness or about the medications used to treat these patients' conditions, and also lacked management and coping skills.<sup>16</sup> Ricard and colleagues<sup>17</sup> examined factors associated with the burden faced by primary caregivers of mentally ill patients. They found that the most difficult behaviours to cope with related to disturbances. Miller and colleagues<sup>18</sup> outlined the concern that caregivers can place their relatives at risk by engaging in harmful behaviours toward their care recipients, particularly when caring for people with cognitive impairments, due to the demanding nature of such caregiving. However, Beach and colleagues<sup>19</sup> pointed out that depressed caregivers are more likely to harm their partner. Caregivers who are at risk of depression while caring for a partner with significant cognitive or physical impairments are more likely to engage in neglect or abusive behaviours, such as screaming, yelling, threatening to abandon the patient or use physical force, withholding food from them, hitting them and handling them roughly. Patients who are actively psychotic and not taking their antipsychotic medication, or who see no response in terms of symptom alleviation, can be the most threatening to caregivers. Similarly, Lauber and colleagues<sup>20</sup> looked at determinants of burden for caregivers of patients with exacerbating schizophrenia. They found that family members and caregivers were most concerned about threats from their severely mentally ill relative, and they recommended that families should be included in decision making to determine whether an affected person should be hospitalised. Szmukler and colleagues<sup>21</sup> examined the experience of caregivers for relatives with serious mental illness, and found their experience to be multidimensional. They ascertained that negative behaviours affected satisfaction with the caregiver's role and their sense of burden, and they identified threatening behaviour as a serious precursor to feelings of 'being a burden.' In addition, caregivers who do not administer medi-

cation in the manner prescribed by psychiatrists were identified as a cause for concern.

Much of the research in the field of caregiving distinguishes between the care that family members give as assistance with activities of daily living (ADLs) and the care that they provide in assisting with instrumental activities of daily living (IADLs). However, these concepts do not adequately capture the complexity and stressfulness of caregiving.<sup>22</sup> For example, assistance with bathing does not capture the experience of bathing a person who is resisting a bath.<sup>23</sup> Helping with medications does not adequately capture the hassles of medication administration,<sup>24</sup> especially when the care recipient is receiving multiple medications several times a day, including injections, inhalers, eye drops and crushed tablets. The need to make decisions on behalf of family members who are unable to do so is stressful, as this is contrary to the caregiver's normal role, and they will be concerned about whether the decisions are the correct ones. Supervising people with dementia and observing for early signs of problems, such as medication side effects, are serious responsibilities, as family members are often unable to interpret either their meaning or their urgency.<sup>25</sup>

There is a paucity of research data about the caregiver's knowledge of mental illness and their coping skills in Jamaica. The aim of this study was to explore possible solutions to reducing non-adherence to medication among mentally ill patients.

## Theoretical framework

Article 1 of the Universal Declaration of Human Rights (1948)<sup>26</sup> states that 'All human beings are born free and equal in dignity and rights.' This suggests that mentally ill individuals have the same rights and dignity as everyone else. Article 7 also states that 'All are equal before the law and are entitled without any discrimination to equal protection of the law', which implies that the government, through both the legislature and judiciary, has a responsibility to secure and safeguard the rights of all citizens. Importantly, Article 17 of the Convention on the Rights of Persons with Disabilities and Optional Protocol states that 'Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.'<sup>27</sup> Indeed the guiding principle of the Convention and Optional Protocol is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for

their inherent dignity underpinned by the principles set out in Article 3:<sup>26</sup>

- respect for inherent dignity, individual autonomy (including the freedom to make one's own choices), and independence of persons
- non-discrimination
- full and effective participation and inclusion in society
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities.

Support mechanisms for disabled individuals, including mentally ill patients and their families, the role of families and the role of the state are set out in Article 8.<sup>26</sup> The disabled person's right to enjoy a family life is foregrounded in Article 23 of the Convention.<sup>26</sup>

## Ecological systems theory

The ecological systems theory posits that development is the result of a range of environmental influences that are divided into five discrete but interrelated layers.<sup>28</sup> By examining the layers of influence concerning mentally ill patients in Jamaica, the ecological systems theory focuses on the quality and context of a person's environment by analysing five layers of influence, namely the microsystem, mesosystem, exosystem, macrosystem and chronosystem.

The *microsystem* is the layer closest to the mentally ill patient, and is made up of structures such as family, school, neighbourhood and childcare environments, with which the child has direct contact. In other words, the microsystem represents the relationships and interactions that an individual has with their immediate surroundings.<sup>29</sup> At this level, relationships have two likely impacts, away from the child and towards the child. For example, a child's parents may affect his beliefs and behaviour. However, the mentally ill patient also affects the behaviour and beliefs of the caregiver. Bronfenbrenner<sup>30</sup> calls these *bi-directional influences* and suggest that they have the greatest impact on an individual.

The *mesosystem* is the layer that provides the connection between the structures of the child or young person's microsystem, such as the connection between an individual's caregiver, religious institutions and the neighbourhood.<sup>29</sup> That said,

the mesosystem represents a filter which aims to protect the individual from harm.

The *exosystem* is the layer that defines the larger social system within which the mentally ill patient does not function directly, although they may be affected and/or influenced by it. The structures in this layer affect the patient's development by interacting with other structures in their microsystem, and in the present context they represent education, social security and legal bodies that interpret and apply relevant laws and policies on the patient's behalf. It should be noted that although the mentally ill patient may not be directly involved at this level, they do feel the impact of the positive or negative outcomes of these interactions.

The *macrosystem* is the outermost layer in an individual's environment, consisting of cultural values, customs and laws.<sup>29</sup> Whatever is defined by the macrosystem can have a dominant impact on the interactions of all the other layers. In the present context, this represents a discrete arena of influence, as the Jamaican government is party to several laws and policies aimed at protecting its citizens, regardless of race, creed and colour, from abuse. According to Bronfenbrenner,<sup>28</sup> these issues can have an adverse effect on interactions within the microsystem and on the ability of the microsystem itself to work effectively on behalf of an individual.

The *chronosystem* is the layer that encompasses the dimension of time as it relates to an individual's environments. Elements within this dimension can be either internal or external, and as mentally ill patients have more and more negative experiences, they may show apathy towards environmental influences. In the present context, this represents those mentally ill patients who do not have confidence in the systems and individuals who are charged with supporting them.

## Methodology

This study was part of a larger research project that examined non-compliance to medication among mentally ill patients attending two public clinics in a select parish in Jamaica. The study population consisted of 344 participants. Two focus groups of four caregivers each were convened. All of the participants were female. The participants were drawn from caregivers who attended two clinics in a select parish in Jamaica, using the convenience sampling technique. They were selected on the basis of convenience, as in the majority of cases the patients kept their appointments at the clinic while unaccompanied. The main aim of the study was to gain a

deeper understanding of the perceptions of the caregivers caring for their relatives with mental illness. The questions were semi-structured, allowing flexibility for the participants to raise or share their personal experiences. The caregivers' ages ranged from 50 to 84 years. Family caregivers' questions were focused on their perception of mental illness, how they thought mental illness was best controlled, the reasons why patients found it difficult to take their medications as instructed by the doctor, and the coping skills employed by them when dealing with their relatives with mental illness. There were eight caregivers in total in the study. Recorded interviews were played and the scripts scrutinised in order to identify key themes and ideas. The data were stratified into different subheadings, and a list of codes for the different themes was used. Relevant parts of the data that represented different views, feelings and experiences were summarised under themes. The themes were then explained, linked and compared. Open, axial and selective coding was used. Open coding was used initially for classifying and labelling the data, followed by axial coding for identifying the important concepts for the study. The data were broken down, examined and compared for similarities and differences. All of the participants consented to the interview being tape recorded. The project proposal and survey instrument were submitted and approved by the Ethics Committee of the Faculty at the University. The research question that was being addressed was 'To what extent are the caregivers knowledgeable about mental illness?'

## Results

The results presented here are set out under four broad categories, namely caregivers' perceptions of mental illness, caregivers' perceptions of how mental illness can be controlled, the reasons why patients found it difficult to take their medication according to medical advice, and caregiver coping skills.

### Caregivers' perceptions of mental illness

Caregivers expressed their views about what mental illness is and how it could be controlled. However, they appeared to be somewhat confused about what mental illness is. They put forward a number of suggestions, such as *brain not functioning well*, *confused about everything*, *disorientated*, *something wrong with them*, *hearing voices*, *excess talking* and *depression*.

### Caregivers' perceptions of how mental illness can be controlled

Caregivers were under no illusions about what they felt was the most appropriate mechanism for controlling mental illness. They were unanimous in stating that 'the medication is the only means of controlling mental illness.' This realisation underpinned their experiences as caregivers:

One day my son attended a fun day and there was an argument between him and another guy. He became very aggressive. However I didn't pay it much mind. Some weeks after, I received a call from his teacher saying that he carried a pair of scissors to school and attempted to stab a girl. When he got home from school he was quarrelling to himself. I was sitting around the sewing machine and when I looked up, he was holding a knife over my head. The only thing I could do was to pray. I was afraid but eventually he put it down. I then called a friend who told me to take him to the clinic. I am happy I did because from that day he received prescribed medication and from then he is doing much better. He assists with chores at home and takes part in sports. He even reminds me when the electricity bills are due.

(Caregiver A, aged 70 years)

If he wasn't taking the medication he would be on the street running up down.

(Caregiver B, aged 65 years)

I think that the medication should not run out. It is hard supporting your child alone without any family support. I cannot afford the medication at times. The government should do more for us.

(Caregiver C, aged 84 years)

Despite the unanimous belief that the use of medication was the most effective treatment for bringing about the recovery of the mentally ill patients, two participants highlighted the side effects of the medication:

The medication is not helping my son because it makes him walk extremely slow and crunched over. Also, I think the medication increases burps, because when he is not taking it he has fewer burps.

(Caregiver D, aged 56 years)

My son's mouth is usually dry. He complains of not seeing clearly sometimes. When he is not on the medication he has no complaint.

(Caregiver E, aged 77 years)

The medication helped sometimes but we have to take him to the bush doctor [obeah man] who can

give him some other things to boost up the medication since it has to do with other spiritual matters. [She further pointed out that although she gave him what the bush doctor ordered, as soon as it was finished she continued with the doctor's medication, as the seer man's (obeah man's) order was not good enough.]

(Caregiver F, aged 80 years)

### The reasons why patients found it difficult to take their medication according to medical advice

The reasons why patients did not want to take their medication were multiple, and ranged from their perception of themselves to the caregiver's belief that the patient was being over-medicated. In the words of one caregiver:

Majority of the times when I tell my son to take his medication, or when I try to give it to him, he tells me I am trying to kill him. He says he is not sick and he is not taking any mad people pill. So, to get around that, I have to crush the tablets and dissolve them in his tea and that's how he receives his medication.

(Caregiver E, aged 77 years)

My child is receiving too much medication and I have not observed any improvements, so I only give him half of the amount of medication prescribed.

(Caregiver G, aged 50 years)

It should be noted that at this point during this focus group interview, the other caregivers joined in and condemned the actions of the caregiver who withheld her son's medication, stating 'You are not helping your child ... withholding his medication is not good for him.'

My son is 35 years old and he has been attending this clinic since he was 23 years old because he smoked ganja. But he complains that the medication is making him sleep too much on the job. That's a problem because he doesn't want people knowing he is sick or else he could lose his job.

(Caregiver H, aged 74 years)

As a pensioner it is hard to purchase the medications monthly, hence I give my son 'bush tea' and take him to bush doctors who can try [to] 'cure' him because I don't have money to buy repeat medications.

(Caregiver E, aged 84 years)

## Caregiver coping skills

A plethora of views emerged concerning how caregivers coped with looking after a mentally ill family member. One caregiver was visibly upset when she recounted her experience of her son inflicting wounds on her face and hands because he had relapsed as a result of his refusal to take his medication. However, she pointed out that if he attempted to harm her again, she would 'defend herself' and 'not take it lightly.'

One caregiver had strong views about the value of family support:

My grandmother, who is the patient, stays with my uncle, but when he needs a break she stays with me. When she doesn't want to take the medication she leaves home for up to two days at a time. She hides her pills under the bed. It is very difficult to care for her. If, as a family, everyone didn't help in terms of taking care of her, then perhaps she would have been placed in a home or unit.

(Caregiver B, aged 65 years)

However, caregivers also described not being able to cope due to a number of factors, including the patient denying that they were mentally ill, inadequate support at home, and threats made to the caregiver by the patient. One caregiver stated that she could not cope with looking after her son at all:

It gives me high blood pressure. Sometimes he doesn't want to wash his clothes. He often refuses to attend clinic because he says he isn't sick.

(Caregiver H, aged 74 years)

He does not want to do anything. He has been ill for 12 years. He is not my husband's child and I don't want him to wreck my marriage, so I support him with everything. Even when I am sick I do it because no one cares about him. I am really stressed out.

(Caregiver G, aged 50 years)

Sometimes I question God. I had two sons and one died as a result of a motor vehicle accident. He was a good child. This one does not help with the chores at home. The worst thing is: he told me 'you are not my mother.' That was hard. I wish it was he who had died. But I try my best to look after him because there is no one else to do it.

(Caregiver E, aged 84 years)

On the day of the appointment my son stated that he did not want the medication and if I forced him he would hurt me. So I obeyed. On reaching the clinic there was another mother who had taken her daughter to the clinic but she [the daughter]

was swearing rather badly. Her hair had not been combed and she was doing a lot of unusual things. So one day I asked my son if he remembered her and he said yes. I said that's how he is going to end up if he does not take his medication. He told me 'No way.' From that day, he takes his medication without a problem.

(Caregiver F, aged 80 years)

## Discussion

Families play an integral part in the care and rehabilitation of their mentally ill relatives. Medication alone is not sufficient to meet the needs of these patients. The demands of caregiving for mentally ill patients are problematic, as caregivers often have to grapple with the societal stigma associated with mental illness, emotional stress caused by caring for a sick relative or the symptoms associated with a family member's illness, and the combined emotional and physical stress caused by the actions and/or attitudes of patients. In some cases, there is also a cost factor incurred by treatment. These demands have been described as burdens by Gibbons and colleagues.<sup>30</sup>

The family members in this study reported feelings of hopelessness and being the victims of violent attacks by those for whom they provided care. One participant stated that her son had held a knife to her head. This is consistent with the findings of Lauber and colleagues<sup>20</sup> that family members/caregivers are most concerned about threats from their severely mentally ill relative. Family members expressed fear of being hurt (or being hurt again) by their children, with one participant even suggesting that if her son should try hitting her again she would 'defend herself' and 'not take it lightly, by taking him to the police station.' Situations such as these raise a myriad of questions. How are caregivers of mentally ill patients supported at the community level? What systems of support (e.g. counselling) does the state provide for caregivers of mentally ill patients? What opportunities exist for caregivers to get some 'time out' for rest and recuperation? The answers to these questions are not immediately clear. However, what is clear is the failure of actors and agencies in the mesosystem and macrosystem to adequately support mentally ill patients, which is the antithesis of the findings of Veltman and colleagues.<sup>13</sup> By deduction, one could argue that if caregivers are well supported, mentally ill patients will be better supported, too, as has been identified by Lively and colleagues.<sup>31</sup>

Interestingly, all of the caregivers in the study were aged 50 years or older, and they were all female. This significant finding speaks to a larger socio-cultural issue, an unwritten code in Jamaica that says 'Women are nurturers and carers' and that 'If there is a disabled child in the family, he or she is the responsibility of female family members, and in the case of a child, a grandparent.' This unwritten code requires further exploration, but the latter half of this code in particular underpins the stigma that is often directed at the disabled and their caregivers by community members.

This study has clearly shown that caregivers recognise the importance of and value social interaction with family members and the community, both for themselves and for their sick relative. Caregivers also highlighted problems of cost, accessibility and availability of medications. Some caregivers are hindered financially, due to their age and/or lack of employment, from purchasing the medications that have been prescribed. This raises another important question: 'How are caregivers supported financially when they are the sole caregiver and breadwinner?' This situation points to a failure of both the macro-system and the chronosystem to adequately and appropriately support mentally ill patients through appropriate social relief mechanisms that are grounded in national and international legal obligations.

Caregivers reported that mentally ill patients sometimes refused to take their medication as prescribed. Unpleasant side effects and lack of insight were the primary reasons for this. Pusey-Murray and colleagues<sup>32</sup> found a significant association between compliance and family support. The findings of this study indicate the need for a serious look at the meso-, macro-, chrono- and exosystems. In other words, the community, community organisations (religious and civil), government and related agencies need to do more to support those who care for mentally ill relatives. Some caregivers showed great awareness of the issues involved in caring for mentally ill relatives. However, it was also clear that some caregivers' actions were not in the best interests of their relative (e.g. withholding their medication on the basis of perceived side effects, which included drowsiness and dry mouth, or due to fear of being hit while administering medication). The need to educate caregivers about how to care for their relatives with mental illness, while simultaneously protecting their human rights, is of paramount importance.

The absence of a Disabilities Act in Jamaica makes caring for mentally disabled patients more problematic. The data suggest that the state has failed to adequately assist caregivers in securing and preserving the dignity and worth of each mentally ill person through administrative and financial means. This is a clear breach of Article 1 of the Universal Declar-

ation of Human Rights and Articles 8 and 17 of the Convention on the Rights of Persons with Disabilities and Optional Protocol. In a modern democratic Jamaica, there is clearly more work to be done on this issue.

## Conclusions

Families who care for their mentally ill relatives make great sacrifices, which are often personal ones. In doing so, they take on the important roles of getting their relatives to and from clinics, administering their medication, and providing them with general care and protection. The impact of these efforts on rehabilitation cannot be over-emphasised.<sup>33</sup> However, where the systems are not in place to support caregivers, then what they on their own are able to offer may not be sufficient and may not achieve the most effective outcomes for the mentally ill patient.

This is perhaps most clearly demonstrated by the belief that taking a mentally ill patient to the bush doctor or the obeah man will result in a 'cure', a position that is consistent with some caregivers' views about how mental illness can be controlled. But why should this be the case in twenty-first century Jamaica? Sadly, even in cases where caregivers felt that the bush doctor's treatment might be less effective than the prescribed medication, they still chose the bush doctor on the basis that they were cheaper than a visit to the pharmacy. This is clearly an issue that needs to be addressed urgently by the government and those involved in the social protection of the vulnerable.

This paper has demonstrated that caregivers in Jamaica make an invaluable contribution to society and to those for whom they provide care. In addition, administrative and other means need to be fully deployed by the state to educate caregivers about safe treatment practices. Furthermore, appropriate support mechanisms which are aimed at making those involved in the care of mentally ill patients feel more valued need to be put in place.

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#### CONFLICTS OF INTEREST

None.

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