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Caregivers' Experiences With Major Depression Concealed by Physical Illness in Patients Recruited From Central Ugandan Primary Health Care Centers

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In this article, we present caregivers' grapples with major depression seen among their physically ill patients. A thematic analysis of 29 in-depth caregiver interviews identified four themes: (a) caregivers' perceptions of depression, (b) barriers to caregivers' focus on depression, (c) resources and opportunities for managing depression, and (d) caregivers' perspectives on consequences of depression. Patients' physical illnesses concealed depressive episodes. Caregivers could not apply the label of "depression" but enumerated its indicative features. Stigmatization of depression, common with other mental illnesses and poverty, undermined caregiving. Vital caregiving resources included caregivers' willingness to meet patients' basic needs, facilitating patients' access to health care, informal counseling of patients, and ensuring patients' spiritual nourishment. Caregivers' management of depression in physically ill patients was expensive, but they coped; however, caregiving was burdensome. Ongoing support should be given not only to patients but caregivers, as well. To provide appropriate care, caregivers deserve sensitization about depression in the context of physical illness.

Keywords: *Africa; caregiving, informal; coping and adaptation; depression; developing countries; life stories; primary health care; stress; thematic analysis; Uganda*

It is common for physically ill patients seen in primary health care (PHC) centers to be diagnosed with major depressive episodes (MDEs) as well (Zung, Broadhead, & Roth, 1993). For instance, whereas depression prevalence among patients seen by family physicians from rural and suburban communities of southeastern Michigan in the United States was found to be 13.5% (Coyne, Fechner-Bates, & Schwenk, 1994), it was estimated to range from 20% to 35% in sub-Saharan Africa (Heggenhougen, 1995). Each year, about 3% to 5% of the general population in the developed Western countries is diagnosed annually by general practitioners to have depressive illness; about the same number are not detected as sufferers from the same illness (Jacobs, 1999; Sheppard, 1997), implying that the illness is widespread.

Much of the care for patients with depression in particular, and ill-health in general, is provided by informal caregivers, primarily composed of relatives and friends in a family setting. Of necessity, caregivers are known to be available at all times—including during their leisure time—when the need arises, to take care of the mentally ill (Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006). Whereas they provide the greatest amount of social care and support to the sick, informal caregivers tend to be relatively invisible in comparison to patients they look

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after (Arksey & Glendinning, 2007). In their day-to-day caregiving activities, informal caregivers are reported to contribute savings of about US$23.4 billion to the government budget in Australia (Team, Markovic, & Manderson, 2007).

Though depression can be effectively treated, depressed people who would potentially consume mental health services conceal their symptoms and are reluctant to seek treatment because of stigma associated with mental illnesses (Halter, 2004; Satcher, 1999). In addition, mental health services in resource-constrained and developing societies like Uganda are under great pressure to focus more on patients with severe and enduring mental illnesses (Monkley-Poole, 1995). This has implications for persons who do not fit the severe and enduring mental illness categories, including the physically ill who are also depressed. Consequently, the MDEs commonly found among physically ill patients presenting at PHC centers are more likely to be managed by their family members and friends.

Families often have the intuitive mandate to care for any family member diagnosed with any illness, no matter whether it is physical or mental in nature (Karp & Tanarugsachock, 2000). Because PHC centers provide largely outpatient services, many family members find themselves as de facto care providers to patients attending such centers. A common presumption is that they take on the responsibility of monitoring patient compliance, adherence, and even response to treatment. However, family caregivers might not fulfill all expectations, given the stresses associated with caregiving, limited information on how to cope, and the inability to grasp the depressive aspects of the physical illnesses they confront (Rose, Mallinson, & Walton-Moss, 2002). Unfortunately, there is a paucity of research in published literature from developing societies like Uganda that highlights informal caregiving by relatives of such patients.

The fact that depression is a comorbid condition with many physical illnesses—often leading to poor prognosis and causing significant functional impairment—has been established. The ability to detect and later manage depression by PHC workers is limited (Staab & Evans, 2001). Health workers' knowledge of the physically ill patient's depression is often hampered by the disorder itself. Depression is characterized by negativity and deflates one's self-esteem. Because of stigma, admitting that the problem could be depression might further damage the patient's feelings of self-worth. Even when people accept that they have depression, looking after them is complicated by the available mental health care system, which is oriented toward psychotic illnesses. Potential consumers are unaware of the kind of help they need, and are uncertain that there would be any benefit through seeking care. In the context of limited resources, the PHC strategy is supposed to transform health care to become more consumer- and family-centered and easily accessible by those who deserve it. The goal of family-centered care can be achieved if is premised on an understanding of the dynamics of caregiving in a family context (Rose, Mallinson, & Gerson, 2006).

In traditional African extended families, care has often been given to everyone afflicted by sickness, including the depressed (Ankrah, 1993; Kalibala & Kaleeba, 1989; McGrath, Ankrah, Schumann, Nkumbi, & Lubega, 1993). The family bears and shares the consequent stigma associated with illness, especially if it is mental illness. However, patients seen at general PHC centers are in most cases unaware of their depressive illness, or mistake it for physical illness. Given the lack of awareness, documenting how informal caregivers understand, cope, and respond to a patient's current MDE presenting concurrently with physical ill-health is hoped to go a long way in identifying social dynamics for targeting interventions. It is vital to note that little attention has hitherto been given to how depression is expressed and dealt with by informal caregivers. Much of the existing work has tended to give health practitioners' and patients' perspectives, yet caregiving in the family is crucial to recovery and regeneration. The main research task, therefore, was to investigate the ways in which family caregivers grappled with an affliction they could describe, but could not identify in their patients, which the professional health workers labeled as current MDEs.

In this article we report findings of a study designed to elicit caregivers' insight into current MDEs among physically ill patients identified at PHC centers. The main objective was to investigate caregivers' perceptions about current MDEs seen in patients at PHC centers, as diagnosed using the Mini International Neuropsychiatric Interview (MINI), a derivative of the DSM IV (American Psychiatric Association, 2000; Sheehan & Lecrubier, 1998; Sheehan et al., 1998). In this study we sought to meet the following aims:

1. To explore caregivers' perceptions of presentation and consequences of depression in their physically ill patients, as well as life stressors associated with depression
2. To explore opportunities and barriers to caregiving that targets depression in physically ill patients
3. To explore how caregivers coped with depressive illness in physically ill patients

Methods

Study Site and Context

The study was conducted among people with no or low income in communities served by one urban and two semiurban, government-funded PHC centers providing free health care services. Each of the central Ugandan districts of Kampala, Mpigi, and Mukono contributed respondents whose patients accessed health care from one participating PHC center. Inhabitants of Kampala district, being in the capital city of Uganda, are urbanites who belong to various ethnic and linguistic groups. However, *Luganda* and English are the most common. Luganda is an indigenous Bantu dialect spoken by the *Baganda,* a tribe in Uganda (Okello & Musisi, 2006). Mpigi and Mukono district communities have a lot in common. Although both are rural districts, respondents from each were from communities whose patients accessed health care from a township-based participating PHC center. The most commonly spoken language in the two districts is Luganda. Other languages are spoken by people who have either migrated or intermarried within the two district communities. Mukono is to the east of Kampala, whereas Mpigi is to the southwest. The equator crosses through Mpigi, and the source of the River Nile is in Mukono. Though having tarmac roads, the three districts have mostly seasonal, dusty and pot-holed roads and footpaths traversed mostly by motorcycles and bicycles.

Design of the Study

We used a qualitative research approach to explore caregivers' perceptions and understand their ways of coping with physically ill patients who had a concomitant, describable, but hitherto unidentified depressive illness. We collected data, through in-depth interviews, from caregivers of physically ill patients with concurrent, diagnosable DSM-IV-TR MDEs (American Psychiatric Association, 2000). We did not use other data collection methods such as participant observation to understand phenomena like coping and day-to-day caregiving, because these would have required us to be with caregivers for extended periods of time. We defined a caregiver as a family member or a friend who was informally providing ongoing care and assistance, without pay, to meet the patient's physical, cognitive, or mental health needs.

Participants and Context

Data were collected from a nonprobabilistic purposive sample of 29 caregivers for 29 physically ill patients who also had concurrent MDEs. Selection of caregivers to interview was done in such a way that they represented variation in the phenomenon of interest. Twelve of the caregivers were patients' spouses (8 husbands and 4 wives), 7 were siblings (4 brothers and 3 sisters), 1 was a grandmother, 6 were patients' children (2 males and 4 females), and 3 were patients' close friends (1 male and 2 females). In terms of where they lived, 72.4% (n = 21) were from rural areas whereas 27.6% (n = 8) were from Kampala city. Occupationally, 41.4% (n = 12) were peasants who survived by tilling the land, 31% (n = 9) were regular salary earners, and 27.6% (n = 8) were unemployed at the time of the interview. It is important to note that 51.7% (n = 15) of caregivers were males and 48.3% (n = 14) were females, even though the majority of patients [72.4% (n = 21)] were females. This was perhaps because of a tendency by most married women to consider their husbands would automatically be their caregivers, even when the reality would have been contrary, given the subservient status of women in most of Uganda's patriarchal societies. From a description of their family structure, we found that 69% (n = 20) belonged to an extended family whereas 31% (n = 9) belonged to a nuclear family. All informant caregivers met the following inclusion criteria for this study: (a) they were trusted confidants of physically ill but also depressed patients, (b) they were aged 18 years and above, and (c) they had been providing care and living in the same community with the patient for at least 1 year.

We screened depressed patients from consecutive, adult health care seekers at outpatient departments of three health centers. The first author (WM), assisted by research assistants (a psychiatric clinical officer, a psychiatric nurse, and a clinical social worker), interviewed all those who consented to separate depressed from nondepressed patients. Details of the screening and detection of current MDEs among patients have been reported elsewhere (Muhwezi, Agren, & Musisi, 2007; Muhwezi, Agren, Neema, Musisi, & Maganda, 2007). Permission was sought from patients who screened positive for current MDEs to allow the research team to contact their trusted and closet caregivers. Patients who consented guided the identification of their caregivers, who were the ultimate sources of data for this article. On days when a patient identified at the PHC center could not accompany the research assistant to locate the caregiver, the patient provided a sketched map or written directions to be followed later by the researchers. For most of the patients, the fieldwork team made appointments to visit their communities to locate caregivers. In pursuit of attaining theoretical sensitivity by seeking heterogeneity of participants (Glaser, 1978), caregivers were diverse in terms of relationship to the patient as well as by occupation and gender.

Before any interview took place, the purpose of the study was explained to participating caregivers, and their voluntary consent was obtained. The research team collected and analyzed data until theoretical saturation was reached, when no more new information to enrich theme identification was forthcoming from additional respondents (Guest, Bunce, & Johnson, 2006). The process of identifying themes started when it was realized that patterns which captured interesting issues in data in relation to the research task were emerging (Braun & Clarke, 2006; Guest et al., 2006; Ryan & Bernard, 2003). We started to notice and look for patterns of meaning and issues of potential interest such as perceptions about common illnesses, caregivers' reactions to illnesses and caregiving, perceived causes of the illnesses, and many others in each interview as data collection progressed. By the 29th interview, we began to hear repetition of information—almost verbatim—which prompted us to end data collection.

The interviews. In-depth interviews using open-ended questions were conducted with each of the caregivers. Interviews were conducted at venues convenient to respondents, in Luganda, the local dialect of the Baganda, which numerically predominates in this region. Most of the interviews were conducted in the patients' homes to ensure a nonthreatening environment. The length of interviews ranged from 45 to 80 minutes. Interviewing was based on an interview guide with questions in English, which were formulated prior to data collection in English (Guest et al., 2006), translated to Luganda, and blind back-translated into English to ensure conceptual consistency and accuracy. Two of the research assistants who spoke both languages translated the checklist from English to Luganda, and the third assistant did the back-translation. The first author cross-checked the back-translated version to ensure that it reflected the original English version. Based on a review of an earlier version of the McGill Illness Narrative Interview (MINI) (Groleau, Young, & Kirmayer, 2006), field experience, and research objectives, the first author developed the interview guide, which had a section consisting of demographic-oriented, structured questions, and six other domains of inquiry, with a total of 27 questions, as shown in Table 1.

The researchers discussed and reached a consensus on suitability of the questions, which they pretested on caregivers who accompanied physically ill and

Table 1
Questions Used to Interview Caregivers of Physically Ill Patients With Depression

Demographic features of the caregiver

1. District
2. Gender
3. Age
4. Relationship to patient
5. Occupation
6. Parenthood status
7. Usual area of residence
8. Patient's/caregiver's family structure

Nature of the patient's health problem
  When did the health problem of your patient begin?
  In the past, have any of your family members or any person in your social environment had a health problem that you consider similar to that of your patient?
  In your own words, what do you call your patient's health problem? In other words, how do you label that health problem?
  What would other people in your community call the health problem that your patient has? Do you know of any other person who is suffering from such a health problem? How similar or different is it from your patient's health problem?
  In your own words, describe how your patient's health problem might have a mental illness perspective. If your patient's health problem has a mental dimension, what type of mental illness is it?
  Suppose someone told you that your patient's illness has both a physical side and a mental side to it. How would you react, and why?
Type of care given to the patient
  I would like to know about your experience. Can you tell me how you felt when you realized that your patient had this health problem, and why you felt so?
  What has been your experience in caring for the patient?
  Specifically, as a caregiver for the patient, what do you do for him or her?
  In the event of your patient going to the hospital for this health problem, what has happened to him or her afterward (so far)? (For caregivers whose patients had been going to hospital for a long time)
Linking patient's illness to life events
  Over the last 6-month period, what has been happening in your family, at work, or in your social life that could explain your patient's problem?
  What is the relationship between your patient's health problem and life events that have occurred in his or her life, your family, or your surroundings?
  List/describe those life events for me.
  Which life events make your patient feel better or feel worse?
Ways of coping with the patient's illness
  As a family member/friend (a special person in a patient's life), how do you cope with the patient's illness?
  As a family member/friend (a special person in a patient's life), how do you manage the patient's illness?
  What type of special assistance is obtained for the patient?

(continued)

Table 1 (continued)

- Challenges faced in looking after the patient
  - What problems/challenges (family finances, work, health, relationships) do you face in caring for the patient?
  - What have you done to overcome these problems?
  - Who in the family bears most of the caring responsibility for the patient? (probe)
  - What have been the effects of the patient's illness on your family?
  - If you met someone who has a relative with problems similar to yours, what would you recommend for him or her to do?
- Other issues
  - Kindly let me know if there any questions or issues which you would want answered but we have not discussed it so far.

depressed patients to a national hospital to ensure relevance.

Before commencing the study, interviewers were trained about aspects of qualitative research, notably: dynamics of fieldwork, how to carry out in-depth interviews, how to probe and paraphrase, analysis and interpretation of the data, and their ethical obligations as interviewers. The purpose of training each interviewer was to ensure that they gained the ability to thoroughly probe or paraphrase questions to get exhaustive and in-depth qualitative data. This was deemed vital in eliciting the caregiver's full story regarding the depressive aspect of the patient's illness. After getting brief demographic data from each respondent, interviewers asked questions about the nature of the patient's health problem and sought to learn whether the caregivers could identify the depressive part of the illness. Caregivers were asked to describe their caregiving to the patient, especially what they did to target emotional problems. They were also asked to describe any relationships that might have existed between the patient's health status and the life events experienced. With regard to coping, caregivers were asked to describe how they managed the depressive aspects of the patient's health problems and the challenges faced in looking after the patients. Each interview was tape-recorded after seeking permission of the respondent. Tape-recorded data was later transcribed verbatim by a bilingual speaker (Braun & Clarke, 2006). All interviewers took detailed field notes as they conducted each interview.

Ethical considerations. We obtained ethical clearances from the Research and Ethics Committees of Makerere University (Uganda), the Uganda National Council for Science and Technology Committee on the Study of Human Subjects, the Human Research and Ethics Committee of Karolinska Institutet (Sweden), the District Directors of the Health Services in concerned districts, and, finally, the authorities in charge of PHC centers. Respondents gave us verbal informed consent to be interviewed and we assured and accorded them privacy, anonymity, and confidentiality. We told them of their liberty to freely terminate the interview process at any time. We referred those who asked questions which required therapeutic answers to appropriate professionals for help.

Theoretical framework. Analysis and interpretation of data for this article were inspired by the bio-psycho-social model (Engel, 1977), which postulates that health and illness involve an interplay of biological, psychological, and social factors in people's lives (Schwartz, 1982). The fact of some illnesses being a result of genetic and physiological vulnerabilities; peoples' behavior and mental processes like emotion, cognition, and motivation; and relationships that people form in their social world is easy to comprehend. However, the etiology of many illnesses being the result of an interdependence of biological, psychological, and social variables is widely accepted but still confusing (Sarafino, 2002).

Adolph Meyer's views about the prominence of psychosocial stressors in the etiology of mental disorders influenced conceptualization and interpretations in this study, which we designed to map out stressful life experiences that caregivers could identify in their physically ill patients (Anthonisen & Fairbank, 1953; Pressman, 1997). Meyer asserted that in mental illness, psychosocial stressors are etiologically more prominent compared to biological variables. Consequently, the ensuing interpretation of respondents' views is partly informed by such a view and based on a number of assumptions. First, as people interact with others, they affect and they are affected by the interaction (Sarafino, 2002). The social world in which a patient happens to be is larger than just the people known to him or her, and contains levels of social spheres like the society, the community, and the family; each level affects other levels. Second, society influences the experience, labeling, attribution, and management of a health problem in an individual through pursuit of a unique culture (Okello & Neema, 2007). Illnesses that are not culturally recognized might at best be trivialized or at worst ignored when it comes to seeking help. Third, there are powerful motivations in the form of acceptance, support, rejection, stigma, ridicule, and many others embedded in societies, communities, and families that influence individual patients' choice of health care, how to behave, whom to trust, and help-seeking patterns (Kalibala & Kaleeba, 1989). Fourth, the family has an especially strong influence on people as they transit through life crises as well as when developing character and a behavior repertoire (Sarafino & Armstrong, 1986).

The theoretical frameworks were important in providing conceptual logic and specifying underlying assumptions that underpinned the flow of ideas in the study. They were the mental sketch-maps around which arguments were organized and synthesized to provide direction to the study, make analysis, and reach conclusions. They also underlay description and interpretation of findings and formulation of implications of the study.

Data analysis. Analysis was based on the 29 in-depth interviews with parents, spouses, siblings, children, and friends of physically ill individuals diagnosed with a current MDE. All the collected data were analyzed and interpreted manually. During data collection, notes about key issues and context were constantly recorded (Glaser, 1978). The Luganda audiotapes of all interviews were transcribed following standard guidelines (Lapadat & Lindsay, 1999; McLellan, MacQueen, & Neidig, 2003), translated into English, scrutinized, and categorized by a bilingual speaker. Transcripts were reviewed and checked against original audio recordings by the first author to ensure translation accuracy (Braun & Clarke, 2006). The transcribed data were compiled in a 300-page document. The first author closely read each transcript several times to get a thorough familiarization with the depth and breadth of data content, inscribe notes on margins of the data book, identify key words, search for more meanings and patterns, and write detailed notes on emerging themes (Braun & Clarke, 2006; Ryan & Bernard, 2003).

Coding was approached, in part, with questions that inspired the study in mind and also with an expectation of coming across novel information. Through systematically working through the whole data set, coding progressed from what was started in data collection, to writing notes to indicate potential patterns (Braun & Clarke, 2006; Ryan & Bernard, 2003). In other words, data were sorted based on the identified patterns and coded where they best fit. After identifying 72 codes in the data set, we matched them with comparable "chunks" of data extracts. Examples of codes identified included "fever treated at home but could not heal," "fell down in his house," "complains of joint/bone pains," "I thought she had been bewitched," and "having many disturbing thoughts." After generating a list of codes and collating them with data extracts, the different codes were sorted into potential subthemes and themes. Observed differences and similarities within the data aided in assigning different data segments to different tentative themes. Through constant comparison, emergent themes, subthemes, and data extracts coded in relation to them were identified (Braun & Clarke, 2006; Ryan & Bernard, 2003; Strauss & Corbin, 1990). The second author (EO) studied and double-checked the data and the emerging interpretation to ensure objectivity of the results.

Ultimately, each extract of transcribed data was subjected to thematic analysis (Boyatzis, 1998; Lofland & Lofland, 1984; Mariano, 1995). As analysis progressed, some tentative themes were found to lack data to support them; others could be accommodated in other themes, whereas others deserved to be broken down. Bearing in mind the objectives of the study, theory and literature, data content, study context and underlying clusters of concepts, and relationships between codes, themes, and different levels of themes were noted (Glaser, 1992, 1998; Ryan & Bernard, 2003; Strauss & Corbin, 1990). Thereafter, more review and refinement of themes was conducted to ensure that they formed a coherent pattern (Braun & Clarke, 2006). The final themes are discussed in the Findings section, where we integrate them with literature and give theoretical interpretations. To ensure reliability, the study followed required procedures (Perakyla, 1998). For instance, during fieldwork we regularly checked technical equipment such as tape recorders to ensure that they worked reliably. Coinvestigators shared and cross-checked the interview transcripts. On one occasion, a respondent had to be reinterviewed (Ahern, 1999) by the principal author to obtain clarity in data. Throughout the analysis process, themes were clarified, changed, focused, and refocused.

Findings

Analysis and interpretation of findings identified four key themes in informal caregivers' experience with depression among physically ill patients. These include (a) caregivers' perceptions about depression, (b) barriers to caregivers' focus on depression, (c) resources and opportunities for managing depression, and (d) caregivers' perspective of consequences of depression, and are explored in detail below.

Caregiver's Perceptions About Depression in Their Physically Ill Patients

Depression: A Known But Unrecognized Illness

In all interviews, informal family caregivers exhibited the most concern about the physical nature of the patient's health problem. They did not report, and most likely did not recognize, a major depressive illness (MDI) in the way it is defined in the DSM-IV as an illness entity. Based on what informal family caregivers said, a decision to seek health care for a patient at a PHC center would be made after somatic signs and symptoms became noticeable and troubling. Although the caregivers mentioned signs and symptoms indicative of a current MDE in their stories, they did not say that their patients had a depressive illness. Instead, they recounted the physical aspects of health problems they had either noticed or were told about by their patients. We know from the literature that physical symptoms have been reported to mask depression (Alexander, 2001). The following comments illustrate this point:

> To tell you the truth . . . I thought that it was a simple fever that would go with a few tablets or injections. Her problem started like any other fever, with joint pains, going to bed even when not sleepy, [an] increase in body temperature and a feeling of dizziness She would be in her bed most times and say that she was not feeling well. Other than losing appetite for food and increased body temperature, there was nothing else that happened. She is taking her medication. Nothing much has changed. She is still unhappy, often sad and wanting to go to bed all the time. [44-year-old brother]

> About 2 weeks ago, she started having many complaints like constipation, fever, and lack of sleep at almost the same time. Her appetite for food reduced and she lost interest in the environment and the people at home. When I took her to a nearby clinic, they did not find malaria fever in her, which I thought the patient was suffering from. [40-year-old husband]

Because none of the patients had sought health care at PHC centers because of emotional problems, the informal caregivers could not associate depressive illness with the patient's physical illnesses. From stories elicited, most patients had sought health care from one health center to another, and from one traditional healer to the next, seeking relief of their suffering. The closest that caregivers came to identifying depression in their patients was when they constantly referred to a phenomena of *alowooza nyo* or *yeraliikirira nyo* (thinking a lot or worrying too much). In other studies from similar cultural and geographical settings, "thinking too much" was found to be a way of explaining depressive illness (Okello & Ekblad, 2006; Patel, Abas, Broadhead, Todd, & Reeler, 2001). The following quotations illustrate the worries, social withdrawal, inactivity, and inattentiveness that caregivers commonly found appearing in their patients during episodes of thinking a lot or worrying too much:

> I think her condition has made her to worry and think a lot. She sits there and thinks a lot. . . . This makes her situation worse. Maybe, with going to hospital for regular treatment, she may get a different perspective about life. She will know what is disturbing her. [46-year-old sister to a widowed patient from a rural setting]

> He has a lot of disturbing thoughts. He stays in the house for long. He just sits alone and you see his mind going astray. He thinks a lot. I feel really bad. His condition reminds me of my dead children. My husband died leaving me alone and I brought them up. In my old age and sorrowful state, what can I do? I don't have any assistance. Children who would have helped me died also. I do not have anywhere to run for help. [77-year-old mother of a patient in a rural, single-parent family setting]

According to caregivers, the main causes of thinking a lot or worrying too much in their patients included the looming loss of life opportunities associated with death among HIV/AIDS-positive patients, worries about vulnerability of children about to be orphaned in case of death, hopelessness, loneliness, and ceaseless pain:

> She has very many thoughts. She thinks a lot about her children and she does not have enough money. She loves her children very much. She feels tired of her sickness. She has started to refuse her medicine and she tells me that she is tired of the disease. Her eldest son promised to visit and before he did, we heard that he was in prison. The hope we had in him disappeared and this has affected her a lot. She sits there and thinks about her children. There are times when we feel we are failing her, especially after my husband lost a job. A patient like her needs special care, which is impossible without money. [38-year-old sister to a patient from a rural area]

> The only thing I see in her is thinking a lot. There are other family problems that could be disturbing her thoughts. My parents and brothers did not initially

> approve her as my wife. They claimed that she has bad manners and that she treats them badly. I felt bad because I could imagine she was going through a lot, especially after a miscarriage. I actually felt sad also. [30-year-old husband]

According to the informal family caregivers, patients who were thinking a lot or worrying too much also exhibited other strange behaviors. For instance, such patients were reported to have difficulties in sustaining a conversation, reduced problem-solving abilities, and a tendency to trivialize the seriousness of their problems with phrases like, "I will get better." Other "thinking a lot or worrying too much" symptoms that were reported, which are indicative of a depressive illness, included altered sleep patterns, appetite loss, slowness in activity, and intense sadness:

> The worst thing is that she does not eat. At the health center, she is given tablets but when they get finished, she again loses appetite. The sickness is worsening and she is now getting every illness that comes. I am a talkative person but she does not want to talk to me as she used to do. [44-year-old mother of a patient from rural family]

> I feel really bad because he sleeps in the house throughout the whole day and there is absolutely nothing he does for me these days. Not even talking! [28-year-old brother to a patient from a rural setting]

Caregivers' Perceptions of Etiological Factors

Informal caregivers' stories contained life events which they thought played vital roles in the etiology and course of what they understood to be "thinking a lot or worrying too much." They were able to mention circumstances in life which they thought predisposed, precipitated, and perpetuated thinking a lot or worrying too much in their patients. The mentioned life events fall in the categories of bereavement or grief, educational challenges, expenses for children's welfare, work- or job-related events, as well as health-related and legal circumstances. Accordingly, life events that predisposed the development of what was considered as thinking a lot or worrying too much in patients included death, broken relationships, financial problems at critical times, and work-related events:

> The patient becomes weaker because of thinking too much. When she thinks a lot about how to get money, she gets worried about how to look after her children . . . death of her husband started her problem . . . taking children to school became a problem. This worried her a lot. [50-year-old brother to a patient from a rural family setting]

> We experienced financial problems; especially after the patient lost a job. I get worried when I go to work fearing that the patient might commit suicide. After my work, I always have to check in the patient's bedroom to ensure that he is alive. He also separated from his girlfriend 3 months after he lost his job. [39-year-old patient's friend and neighbor]

In other caregivers' stories, we identified life events that precipitated thinking a lot or worrying too much in patients. These life events appeared to be the immediate circumstances that surrounded onset of the depressive illness. There are events or circumstances, like business failure or injury resulting from a fight, which are more likely to arise from a person's behavior. However, other life events ordinarily happen to all people and are independent of the person's behavior. Such events were thought to precipitate thinking a lot or worrying too much:

> Death of her aunt worsened her thoughts . . . but I think her condition is different now. . . . The death has nothing to do with it. Recently, she lost another *Ssenga* [aunt] who loved her a lot. Thereafter, she started thinking a lot about her. She would even dream that she is actually seeing her and this increased her thoughts. [28-year-old brother to a patient from a rural family]

> After the death of our child, that's when things started worsening for her. She got complications after birth and this is what affected her more. The death increased her thoughts which have been really disturbing her, and at times making her feel really like giving up and very sad. [30-year-old husband]

Other narrations by informal caregivers also contained enumeration of life events that appeared to perpetuate depressive illnesses. These events appeared to render resolution of thinking a lot or worrying too much less likely. The events instead acted to prolong the thinking and worrying after it had started:

> Maybe, the patient's problem resulted from drinking alcohol a lot. He over-drinks *waragi* [a local potent gin]. His over drinking came after the death of his wife. [72-year-old mother]

> *Mzee* [elderly person] is ever lively but whenever he thinks of his late son, you find him very sad and eventually the blood pressure rises because he used to love him so much. [38-year-old brother to a patient from a rural family]

Barriers to Caregivers' Focus on Depression in Physically Ill Patients

Concealment of Depression by Physical Illness

Effectiveness in caregiving is influenced by caregivers' knowledge of the patient's health problem and the associated complications. Informal caregivers did not deduce the presence of current MDEs in their physically ill patients. This is consistent with the expanding clinical literature suggesting that distress and medical ideas about depression confuses many people (Pilgrim & Bentall, 1999; Rogers, May, & Oliver, 2001). It was easier for them to enumerate physical complaints of their patients in a way that is consistent with commonly occurring physical illnesses in Uganda. Accordingly, complaints related to fevers, HIV/AIDS, sexually-transmitted infections, aches and pains, respiratory infections, allergic reactions (such as itchy skin), dental problems, hypertension, injuries, eye infections, joint pains, abscesses, and infertility, which are widespread in the country (East African Integrated Disease Surveillance Network, 2001; Muhwezi, Agren, Neema, et al., 2007; Uganda Bureau of Statistics [UBOS], 2006), were a common preoccupation and bother to the family caregivers.

The ease with which they described their patients' physical complaints is also consistent with the biomedical model of managing physical symptoms at PHC centers in Uganda. Besides, health workers at the level of PHC are universally known to poorly detect depression (Barkow, Heun, Ustun, & Maier, 2001; Klinkman, 2003; Staab & Evans, 2001; Valenstein, Vijan, Zeber, Boehm, & Buttar, 2001). On the basis of observable signs and not trying to diminish the significance of patients' mental health functioning, caregivers inferred that their patients were mostly bothered by the physical illnesses. They reported fevers (related to malaria) and HIV/AIDS to be the main reasons explaining their patients' decisions to seek help at PHC centers. One 28-year-old wife to a patient from a rural family had this to say:

> Looking at his condition and the people I see around in similar conditions, I have thought twice about his disease. In my words, I think he got HIV/AIDS. He has been getting fevers in evenings for over a year. It has been on and off. I know people in the community with a similar condition like my husband. They have HIV/AIDS also.

Given the chronicity and life-threatening nature of HIV/AIDS, a number of caregivers believed that it was the main cause of their patient's persistent afflictions. It is important to note that patients whose caregivers were interviewed had not sought health care for HIV/AIDS, but for other physical health problems. In Uganda, almost 30% of the adult urban population was estimated to be infected with HIV in the late 1980s, with the proportion falling to about 15% in the early 1990s and presently to about 6% (Shafer et al., 2006). A range of psychological and psychiatric problems, notably depressive and anxiety disorders, are known to manifest among patients with HIV/AIDS (Lippmann, James, & Frierson, 1993). Therefore, caregivers were perhaps justified to be overly concerned with physical aspects of patients' illnesses, some of which were HIV/AIDS-related because of predicable deaths and associated consequences, as embodied in the words of a 50-year-old brother to a female patient:

> Her husband died. About three months after his death, my sister fell sick also. I had to start taking her to the hospital and she started becoming very weak. She told me that she got infected with HIV. We do not have any hope that she will be fine as any other person.

It is also important to note that most caregivers viewed fevers in their patients as suggestive of long-standing illnesses, with HIV/AIDS being the most likely. The concept of *olusujja sujja* (feverish feelings) and malaria experienced by patients were not differentiated, and were used interchangeably to describe predominant symptoms:

> He has taken long with fever. It has been on and off. We treated the malaria fever using some tablets but it refused to heal until he came to the hospital. He has constant chest pain. I told him to go for blood testing but he refused. He smokes a lot, too. I think it increases his chest problems. I advised him to stop smoking and when he did briefly, he greatly improved. [30-year-old wife to a patient from a rural family setting]

In the context of medical pluralism, a number of caregivers' narrations revealed that along with getting their patients to seek help from PHC centers, they also pursued folk perspectives of illnesses that were seen as traditionally *Kiganda* (health problems whose cause, course, effect, management, and prognosis are believed to be enmeshed in Baganda culture) in nature, as earlier described (Okello & Neema, 2007). In the latter scenario, caregivers noted that the cause, course, cure, and management of the patients' illnesses lay outside the realm of modern biomedical practice. The persistence and multiplicity of unexplainable psychological and behavioral symptoms in their patients, and inability to improve after being attended to at PHC centers, seemed to reinforce their beliefs:

> I believe she has malaria but her joint pains scare me a lot. In fact, at some point, I thought she was bewitched because joint pains had become a common problem in our community. When she went to the hospital, she came with a different version of the story. Initially, I was adamant to let her go to hospital for a check-up. [46-year-old husband to a patient from a rural setting]

> I think it is a traditional illness. But some people are advising me to take her back to the hospital to know the right problem. I have never seen a person having a similar problem in our community who got relief from modern doctors. *Abasawo Abaganda* [native traditional healers sometimes called doctors] know what to do. [30-year-old husband to a patient from a rural family]

Other health problems that concealed patients' underlying depressive illness from caregivers included suspicions that patients had sexually-transmitted infections like syphilis, and complications associated with old age. Ultimately, caregivers perceived the physical dimension of illness to explain patients' decisions to seek help at PHC centers:

> She suffers from a disease called *kabotongo* [syphilis]. I don't know much about the illness but our grandfather said she suffers from it. It is in our family, grandfather says all of us have it, and he says he also had it. [35-year-old brother to a female patient, living with her in Kampala city]

> Being an elderly person, there are few days when she has no complaints. For over 1 year, she has had several complaints but started experiencing complete lack of sleep about 3 months ago. Even with sleeping pills, she couldn't get enough sleep and keeps talking of seeing her dead relatives when left alone to sleep. [39-year-old daughter]

Perceived Stigma Associated With Mental Illness

Even when caregivers identified indicative features of a depressive illness in their physically ill patients, they were uncomfortable with the "depression" label, which indicated stigma. Based on caregivers' views, depression in PHC patients should perhaps not be labeled as a mental illness. Feelings of exasperation were displayed whenever they were asked to talk about the mental health dimension of their patients' illness. Stigma is known to affect not only patients but their families, as well (Pejlert, 2001; Phelan, Bromet, & Link, 1998). It is possible that caregivers genuinely disliked associating their patients with any form of mental illness because it is loathed and misunderstood. Caregivers' views that epitomized the denial and fear of a possible mental illness in their patients included:

> If the person telling me that my patient has a mental illness is a professional, I may accept. But not these people around who may deceive to scare us.

> My patient having mental illness! I have never seen such illness in our family. It would defeat my understanding but I would take him to the hospital.

In addition, the process of negotiating access to basic primary care for a mental health problem has been noted to be complex. The process is obscured by difficulties of formulating and expressing the existence of a mental health problem in a way that is acceptable to primary care staff as a means of gaining access to the practitioner's consultation (Rogers et al., 2001).

A subtheme concerning stigma in the context of HIV/AIDS was common in stories of caregivers. In spite of knowledge generated through sensitization about HIV/AIDS, the associated stigma—whose consequence engenders depressive reactions among patients—was found to abound. A number of caregivers did not directly mention HIV/AIDS when referring to HIV/AIDS as the main health problem of their patients. HIV/AIDS-related stigma is known to be emotionally draining and a precursor to depressive illness among HIV patients (Ankrah, 1993; Kalibala & Kaleeba, 1989; Muller & Abbas, 1990). The words of a 34-year-old female friend to one of the patients from a rural setting illustrated the perceived stigma associated with HIV/AIDS thus:

> The patient's health problem . . . I think it is HIV. Most people don't want to tell facts; they call it fever, mostly malaria and all other sort of things. People still do not want to make others know that they have HIV. I do not know why, maybe they fear bad comments.

Other caregivers narrated presence of unexplained aches and pains experienced by their patients, which are commonly disguised ways to avoid mentioning HIV/AIDS as the problem. They talked in general and unspecific terms about the need for their patients to go for a blood test. In the context of HIV/AIDS-related stigma, suggesting a blood test indicates suspicion of HIV/AIDS infection:

> Her joint pains scare me. At some point, I thought that she was bewitched. It's not long ago when she started developing joint pains. These pains have actually disturbed her . . . she should have a blood test . . . that is the problem. [46-year-old husband to a patient from a rural setting]
>
> She has been complaining of chest pains and constant fevers for some time now. These have been on and off for about a year now. I think she should have a blood test. [33-year-old sister to a patient, with whom she stayed in Kampala City]

Poverty as a Barrier to Caregiving

As a resource, caregivers showed a commitment and resolve to meet the patients' overt physical needs, such as food and shelter. Most of the caregivers were from rural areas in central Uganda where people are relatively poorer, with a monthly mean per capita expenditure of 32,500 Uganda shillings (equivalent to about US$20; UBOS, 2005). Therefore, many caregivers reported that they struggled to care for their patients under a lot of financial strain and stress, issues which are known to undermine caregiving (Arksey & Glendinning, 2007; Glendinning, 1992; Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005; Howard, 2001). This view is well illustrated in the quotations below:

> I leave him at home and go to work . . . or to look for food and money. I dig in other people's gardens to get food. When I succeed, we eat well, when I don't, then it's really tough for us. At times, I get some money and buy things like soap or even paraffin. In other cases we sleep in darkness when we have no paraffin. You know, I am just a woman, surviving single-handed with no job. [28-year-old sister]
>
> I have a lot of challenges. I do not have any job. He does not work also. When he, for example, wants sugar in a drink or even to feed well . . . or to buy the prescribed medicine, I have no money to buy them. [30-year-old wife to a patient from a rural family setting]

It is vital to note that physically ill patients with an underlying depressive illness might respond poorly to treatment, especially if the latter is disregarded. Many caregivers reported that they managed to cope with patients' illnesses through hard work and sacrifice, because caregiving is expensive. A number of them were in despair and worried about what to do for their patients. The lack of information about patients' depression and alternative treatments to seek, hopelessness, poverty, the prolonged patients' sick roles, and disrupted work routines were hurdles that hampered coping. Some caregivers gave up their jobs to create time to care for the patient:

> The patient's treatment has become a problem. He had set up a small business but now that he can't work, the business is doing badly as I have pulled out some money to help him. It is me as his wife to provide care for him. There isn't much that I personally have done for him because I am just a woman and have no other relative to help me look after the patient. [26-year-old wife of a patient from an urban family]

Many times, caregivers are not only economically poor but they are also frail because of advanced age, mundane lifestyles, and insidious illness about which they are unaware.

Resources and Opportunities to Manage Depression in Physically Ill Patients

Coping With Unrecognized Depressive Illness: Caregivers' Perspectives

Caregivers expounded on alternative ways through which they coped with requirements related to depressive episodes in their physically ill patients. In most cases, they assumed informal counseling roles to alleviate suffering, discomfort, and pain of their patients. They tried as much as possible to be emotionally and physically close to their patients, encouraged them to take medications and eat food, ensured that patients accessed leaders of their religious faiths for prayers, and did housekeeping tasks like cooking, cleaning, and washing clothes, as well as shopping and giving patients company at different events. Caregivers' counsel to patients ameliorated self-pity and blame and promoted a positive attitude to life:

> The most important thing is trying to be near her as much as possible . . . *kumu buda buda* [give her hope and encouragement]. I try and bring to her what she wants and I try to be there for her. [36-year-old husband to a patient from Kampala City]

> I give her food and money to go to hospital if I have it. I have tried to counsel her. I constantly tell her to stop self-pity, and to stop thinking a lot and blaming herself. I also tell her to try to have a positive mind and think positively about her condition. I keep reminding her to take her medicine regularly. [50-year-old mother of a patient from a rural family]

Caregivers reported that they were able to endure caregiving pressure better if they received support from other people. Communion with families facing similar circumstances and involvement in church activities are important sources of comfort and support (Pejlert, 2001). Some of the caregivers were receiving remittances from wider, extended family networks and friends. This acted as a buffer that cushioned resource deficiencies:

> At times, we get special assistance in [the] form of money from our relatives like uncles, aunties, etc. . . . which help to push us for a little while. It's really hard because these relatives also feel stressed because of our demands. [33-year-old sister to a patient with whom she stayed in Kampala City]

The availability of social support networks as a resource was not only beneficial to caregivers but also directly to the patient. Caregivers reported that patients' perceptions of being cared for, loved, esteemed, and valued was very important in enhancing well-being. Social circumstances that caregivers associated with well-being in their patients included receiving visitors, family reunions, and being involved in religious activities:

> When our sister who lives in a neighboring country comes to visit her, she feels much better and improves a bit. When she goes back, the patient looks very low in spirit. [35-year-old brother to a female patient in Kampala City]

> At times, her friends come and encourage her and when there is a gospel song on the radio playing, she listens and feels hopeful. In a way this gives her some joy and happiness. [36-year-old husband to a patient from Kampala City]

It is important to remember that caregiving increases the requirement for social support from friends, family members, workmates, and professionals (Neufeld, Harrison, Hughes, & Stewart, 2007), and from the study; it is only professionals who seemed to be absent from the social support networks.

Challenges to Caregivers' Coping

In many cases, the inability to understand what lay behind most of the patients' suffering was a real challenge to caregivers. Some patients were not willing to take necessary steps to find out the possible reasons for their ill health. Although this could protect against psychological breakdown, it rendered caregivers helpless, inadequate, and indecisive about the course of action to take:

> I tell her to go to the hospital and get treatment. My patient needs to test her blood and understand what she is suffering from. She cannot just keep silent when fever is on and off . . . she should get tested and we know what she is suffering from . . . unfortunately, my patient has consistently refused to go for blood testing yet it is good because she has to know what is affecting her . . . saying that she is sick all the time does not help. We do not know what her real disease is. Fever is on and off and it does not go away completely. She should get tested, to receive counseling. [36-year-old sister to a patient from a rural family]

Lack of adequate social support, rejection, and fear of implications of the illness seemed to make it difficult to avail patients with the necessary care. Certain signs and symptoms of physical illness in some patients overwhelmed their caregivers, to the extent of setting in motion stigmatizing reactions. Some caregivers could not comprehend the fact that they could contribute to their patient's depression, especially in the attitudes they exhibited and the type of care they gave. Highly expressed emotion is known to impact negatively on a patient's functioning (Hooley, 1986). Consequently, current MDEs seen among patients could have been a result of strains in relationships within the patient's environment:

> She does not know how she looks like. Her skin has deteriorated. I have a food stall where I sell food and tea. She goes to serve customers. Some have openly complained about her looks. My business is suffering. I have a challenge of telling her without annoying her and feeling that she is discriminated against. I was thinking of using her colleagues to tell her for me. She has been making and selling pancakes but people have started refusing to eat them. [38-year-old sister]

The Role of Protective Life Experiences

It is important to note that informal caregivers identified life experiences that acted to protect or shield their patients from debilitating emotions. These circumstances appeared to promote self-confidence and improve self-esteem in physically ill patients who met the criteria for major depression. The experiences appeared to facilitate recovery and positive coping with the problems associated with thinking a lot or worrying too much:

> When the patient's blood pressure lowers to [a] normal level. When friends and religious ministers visit her. When there is enough food for the whole family. When the crop harvest is good, the patient feels a bit better. When church members come and visit us at home. When our children get school fees to go to school. When we don't have any stressing issue in our family, we are just happy. The patient also enjoys going out to watch local actors/musicians. [39-year-old daughter]

> When he meets friends who had similar problems like he has but eventually got even better jobs than the ones they had before, he feels happy. When he meets friends who assist him financially, he feels a bit better. When he takes an application to a potential employer and he is reassured with a promise for a job. [39-year-old good friend and neighbor]

According to caregivers, a number of life experiences engendered well-being in their physically ill patients who were also depressed. Stimulating life experiences like proper nutrition, controlled pain, compassionate care from health centers, remission of illness symptoms, and financial stability were described as important in patients' lives. Having enough to feed the patient in terms of quality and quantity came up as central in protecting against thinking a lot or worrying too much. Informal caregivers' assessment was that patients got relief and felt better after accessing health care from relevant health workers:

> When she gets money, you see her happy but when she has no money, you find her seated alone and in deep thoughts. Whenever she goes to the hospital, she comes back with an improvement in her condition. I normally tell her to go to the hospital regularly to know what is actually bothering her. When she goes to the hospital with a fever, she feels better after treatment. After a time, the fevers and other disturbances come back to bother her. [30-year-old daughter to a patient from a rural family]

> When she is not in pain, she happily joins her colleagues in conversation. When she is in pain, she cannot even converse and this increases her sadness. With food like milk, she feels better. When she has enough food, she feels much better. [46-year-old sister to a widowed patient from a rural setting]

Consequences of Depressive Illness: The Caregiver's Perspective

According to caregivers, thinking a lot or worrying too much in their physically ill patients was reported to affect the functioning of both the patient and the family. Negative impact was reported to be much more apparent in disruption of ordinary social functioning and economic activities. Symptoms associated with thinking a lot or worrying too much, such as slowness in activity, poor concentration, and persistent fatigue were reported to affect the economic output of the patient. Patients' inactivity was reported to result in loss of income, which presented hardships to the family. In some cases, family structure and aspects of family functioning like composition, decision making, social interaction, and access to health care had been fundamentally affected by the illness of a family member. For instance, illnesses affected family functioning by altering choices regarding where to stay, and for how long, and prompted patients to leave their confiding and trusted relatives living far from health centers to have easy access to health care.

Presence of an additional person in receiving households, in the form of a patient who could not contribute in meeting household expenses, was reported to constitute a heavy burden. Health care–related costs, as well as losses arising from giving up jobs or missing out on employment opportunities to be available to look after the patient, made the financial burden to the caregivers astronomical.

The most direct impact of thinking a lot or worrying too much in PHC patients on family well-being included the reduced ability of the patient to participate in income-generating activities. In families with limited resources and multiple health care demands, tough choices had to be made:

> Her sickness has increased my responsibility especially during those times when her pains are intense. I have to look after the children when she is sick and make sure they are okay yet this is her responsibility when she is okay. It has been a challenging experience with regard to caring for her. Every patient needs care, and that care needs money. It has been hard for me. As you can see, my income is not sufficient and I have children to look after and yet they also fall sick often. At times I feel very sad, worried and disheartened, because I feel deep inside my heart that I am not doing enough to look after these people who need my assistance. [46-year-old husband to a patient from a rural setting]

> I don't move away from home just like that yet most things need money. When I move, I force her young

> sister not to go to school. She has to stay at home with her. At times, we wake up when I am feeling weak and I can't dig. Then we end up going hungry. We do not eat when I do not work. We also have to sleep in darkness when I don't get money to buy paraffin. [30-year-old husband to a patient in a rural setting]

According to caregivers' narratives, thinking a lot or worrying too much about their physically ill patients was found to be synonymous with current MDEs. Caregivers managing this problem reported experiences of fatigue, worry, restricted activity outside the home, and financial constraints—issues that were also raised in a study by Rose and colleagues (2002). Many caregivers reported that they felt apathetic, helpless, hopeless, worthless, sad, and indecisive, and experienced poor sleep as a result of day-to-day caregiving for their patients. These reactions trigger a series of emotional experiences ranging from shock, frustration, confusion, depression, and sadness to worries and fear in many caregivers (Karp & Tanarugsachock, 2000). Caregivers' reactions are illustrated by the following comments:

> I did not feel very sad at first, I knew it was a bit of malaria fever and it would get better. When I realized that her condition was deteriorating and related it with the circumstances under which her husband died, and I realized there was trouble, I felt really bad. There are days when I even cry due to my sister's sickness. It has been terrible for me. She has been helping me a lot. She is a good woman and to know she is going to die is bad. She has been very helpful to me. She knows how to look after people. She is good. [46-year-old sister to a widowed patient from a rural setting]

> When she told me, I was engulfed by sadness deep inside my heart. I was not amused. My sister's sickness was life-threatening. But when a calamity happens and you have nothing to do about it, you have to be firm that God will take charge. [50-year-old brother to a patient from a rural family]

From the study, it appears plausible that caregivers of physically ill patients who also had concurrent MDEs experienced forms of family transformations as they struggled to adjust to changes imposed by the physical illness with emotional consequences. They had to come to terms with the reality of the patients' illness and accept it as their burden (Badger, 1996). Similar to another study, there were notable consequences of caregiving that included precariousness in financial status, cutbacks in social activities, diminished friendship networks, embarrassment to talk about patient's depression, consciousness of stigma, and the strenuous acceptance of more patient-related responsibilities (Fadden, Bebbington, & Kuipers, 1987).

Discussion

Managing depression associated with physical illness is a ubiquitous scenario that informal family caregivers confronted on a day-to-day basis. Similar to what was found in another study (Burns, 2000), the fact of caregiving being strenuous and burdensome has been well elaborated in this study. Many families have no choice but to take upon themselves the task of caring for loved ones who are sick (Chentsova-Dutton et al., 2000). An investigation of ways in which the caregivers grappled with unidentified depressive afflictions in their patients, which professional health workers label as depressive episodes, was long overdue. Hitherto, little had been documented about caregivers' perceptions of current MDEs among physically ill patients presenting in Central Ugandan PHC centers in particular, and perhaps in other developing societies in general. This research was undertaken to fill this gap.

Notwithstanding the physical or emotional dimensions of illness in the patients we studied, there was no distinction in caregiving. After a help-seeking visit at health centers, patients were found to derive solace in the care provided largely by family members at home, as previously observed (Sethabouppha & Kane, 2005). In addition, caregivers did not recognize clinical depression as an illness entity among their patients, though they enumerated its diagnostic symptoms. Concealment of depression in physical illnesses was found to render its identification by caregivers and patients difficult, which undermined appropriate caregiving. Similarly, stigma associated with the label of depression—which is a known type of mental illness—made caregivers uncomfortable. Many caregivers struggled to care for their patients under financial strain, which tends to undermine caregiving, whereas others displayed caregiver burnout (Arksey & Glendinning, 2007; Glendinning, 1992; Hartley et al., 2005; Howard, 2001).

After probing, caregivers described bothersome symptoms in their patients, such as thinking a lot or worrying too much, which is consistent with a DSM diagnosis of major depression. Expressions, feelings, and behavior like altered sleep patterns, appetite loss, slowness in activity, and intense sadness were identified by caregivers in their patients. These features are diagnostic of a depressive illness (American Psychiatric Association, 2000). Though they never directly associated their patient's physical illnesses with a depressive illness, caregivers were able to point out physical and cultural issues which they perceived as a bother to their patients. These include HIV/AIDS, malaria, chest pains, and traditional Kiganda illnesses, to mention a few. Inability of caregivers to recognize depressive symptoms in patients had been reported in another study that looked at care for depressed patients in primary care (Gask, Rogers, Oliver, May, & Roland, 2003).

A number of caregivers were not sure about the treatment and care to give their physically ill patients who had concurrent depression. In meeting nutritional needs and transport costs to health care facilities, giving counsel to ameliorate patients' self-pity and promoting a positive attitude in life, caregivers' interventions appear to have been consistent with the biopsychosocial model of health and illness. This was in terms of patients affecting and being affected by the interaction with their caregivers; the complexity of the social world in which patients live; the influence of society in labeling, attribution, and management of the health problem; the apparent caregivers' trivialized recognition of depressive illnesses; and the role of the family in dealing with stressors (Kalibala & Kaleeba, 1989; Okello & Musisi, 2006; Sarafino, 2002; Sarafino & Armstrong, 1986).

Although caregivers had difficulty recalling life event experiences that patients had encountered in the 6 months prior to the interview date, after detailed probing they were able to identify those which they associated with the health of their patients. The identified perceived psychosocial stressors can be conveniently grouped as predisposing, precipitating, and perpetuating factors (Kumar, Hatcher, & Huggard, 2005). Predisposing and precipitating life stressors thought to be associated with thinking a lot or worrying too much in patients included but were not limited to deaths, broken relationships, financial problems at critical times, and work-related events, whereas those that perpetuated it included misuse of alcohol and worrisome thoughts. This finding is consistent with findings from elsewhere which confirm associations between life events and depressive illness (Broadhead & Abas, 1998; Broadhead, Abas, Sakutukwa, Chigwanda, & Garura, 2001; Brown, Harris, & Hepworth, 1994; Leskela et al., 2004; Ndetei & Vadher, 1984; Patton, Coffey, Posterino, Carlin, & Bowes, 2003; Rafanelli et al., 2005; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004). A number of caregivers could not identify the depressive dimension in their patient's illnesses and seemed to believe that once the physical dimension of the illness could be professionally managed by health workers, the patient would be fine. Caregivers' ability to introspect into probable life events associated with their patient's illness was rather low.

Even if caregivers did not identify depression as the overt problem of their patients and were unsure about what to do, they revealed a number of resources and opportunities to start with in holistic management of depression. Their ability to meet patients' basic needs for food and shelter, and willingness to facilitate access to health care is important. Caregivers showed that they readily and willingly boosted their patients' self-esteem through informal counseling. Religious faith and spirituality in the form of prayers and listening to religious music are resources that soothed patients, a fact reported in another study (Etowa, Keddy, Egbeyemi, & Eghan, 2007).

In spite of the burden of care, caregivers' availability and closeness to patients is an indispensable resource. Their commitment to encourage patients to turn up at health centers for treatment, procure drugs, and even consult traditional healers on behalf of patients is evidence of availability. In Uganda, like elsewhere in the developing world, the family is responsible for much of the nursing and health care, both in and out of the hospital (Kalibala & Kaleeba, 1989; Muller & Abbas, 1990). Illness and disease place heavy burdens on the family as a whole and the caregiver in particular. Though informal family caregivers seemed to cope in fulfilling their roles, they were still burdened by care obligations, inadequate finances, and the impact of ailments, an observation that has been made in other studies (Hartley et al., 2005; Sethabouppha & Kane, 2005).

The main challenges that caregivers faced in managing physically ill patients with indistinct depressive symptoms included the inability to discern treatments to seek, hopelessness, depletion of financial resources, the patient's inability to function well, and disruption of daily family routines. Similar to studies from developed countries, our findings reveal that in spite of caregivers' availability and commitment, caregiving is associated with heavy financial burdens, as well as considerable physical and psychological vulnerability (George & Gwyther, 1986; Robinson, 1989).

Limitations

Whether it was poverty or a misconception that researchers could have been emissaries of humanitarian organizations, respondents' reception was often cordial and anticipatory in nature. Even after self-introductions by researchers, in which the emphasis was on the purpose of the visit, most caregivers still projected poverty as a central theme in patients' lives. There could have been attempts to please the researchers. Respondents seemed to expect a lot from researchers' visits and this could have affected the quality of data that was collected. However, researchers had to assure respondents about who they were and the purpose of the research.

One cannot make generalizations from the study because the focus was on one ethnic group, the Baganda. Future research can do better by comparing perceptions of caregivers in different ethnic and cultural groups. It would have been better if this study had compared patients' perceptions with those of their caregivers; however, comparison was not the objective of the study. Although researchers elicited diagnostic symptoms of current MDEs from caregivers, it was not easy to ask about depression as a distinct mental illness entity. A number of caregivers perceived any insinuations about mental illness negatively. Researchers were able to get meaningful data only after describing depressive illness in terms of thoughts (i.e., worrying thoughts, a lot of bad thoughts, sad thoughts, sadness in the heart, etc.) and general distress.

Implications

The study demonstrated that depression was perceived by caregivers as not just as an illness but an illness of thoughts. This reflects the way of thinking, feeling, and being which has been found to permeate caregivers' perceptions of depressed patients, their lived worlds, and the future (Katon et al., 1997). It seems plausible that current MDEs in physically ill patients seen at PHC centers might not be presented by patients or their caregivers as a reason for consulting health workers for treatment. This has implications in management of depression at PHC centers, which we think should be crafted on a chronic care model. The model demands that formal, ongoing support is given not only to the patients but also to the informal caregivers as well, to prevent burnout (Duncan & Reutter, 2006).

To most caregivers, the predominant belief was that health workers have the ability to miraculously ameliorate patients' suffering and discomfort. It therefore makes sense if treatment of patients by professional health workers is given alongside counseling and advice to caregivers. Several studies have shown the importance of giving caregivers adequate, relevant, and easily understood information about their patients' diagnosis and treatment, and available support options if they are to effectively play their role (Greenwood, 2002; Meeker, 2004; Morris & Thomas, 2001; Wackerbarth & Johnson, 2002). Sensitization and empowerment of health workers is needed, because they are better positioned to support informal caregivers who manage the multiple stressors, strains, and hassles associated with depression among the physically ill on a day-to-day basis. Health workers' involvement would reinforce the role played by informal caregivers in ensuring adherence and compliance with different management options. As professionals, health workers should be enabled to appreciate caregivers' needs for information on care and problem solving.

Caregiving for a physically ill person with depressive illness was found to be very stressful, often resulting in caregiver burnout. The experiences of sadness, despair, hopelessness, frustration, worries, and fear faced by caregivers in the care of physically ill patients with current MDEs indicates that they also have emotional problems that should be addressed (Chentsova-Dutton et al., 2000). A study in the United States found that being a caregiver and experiencing mental or emotional strain is a risk factor for earlier death (Schulz & Beach, 1999). Therefore, caregivers deserve psychological support, although some might attempt to resist such attempts on the premise that they do not need it, that it would not do them any good, or that their attention is focused on the ill relative—thereby restricting them exclusively to his or her care (Chentsova-Dutton et al., 2000; Mittelman, Roth, Coon, & Haley, 2004). As suggested in other studies, the supportive and reassuring role to caregivers by community nurses and other professionals like community psychologists and social workers appears to be highly needed (Ashworth & Baker, 2000; Wiles, 2003), especially in resource-constrained countries like Uganda. Home visits by professionals from the mentioned categories provide the most viable opportunities to execute such a role and promote as well as strengthen networking among caregivers in the community.

Conclusions. Although caregivers could not verbally label a current MDE as specified in DSM-IV, they were able to identify symptoms indicative of depression in the sample. Caregivers' recognition of current MDEs among their physically unwell patients might have been imperfect but the illness remains a real problem. Within the discussed limitations, caregivers recounted their beliefs concerning probable causes and presentation of current MDEs. They also perceived consequences of current MDEs on their individual patients and on themselves. Other than provision of treatment for physical symptoms of illness, we found that there was little, if anything, being done about current MDEs among the physically ill patients in PHC centers. Though most of the care was for physical symptoms and was sought from health centers, home-based management still stood out as a fall-back position. Important to note is that even when caregivers coped with depressive illness in physically ill patients, they were burdened by their caregiving roles. The fact that they deserve help and support by the mental health services has been documented (Scazufca, Menezes, & Almeida, 2002).

Caregivers deserve to be sensitized about the mental health implications of physical illnesses so they can seek appropriate care for their patients. Professionals need to recognize the experiential expertise of caregivers, involve them in decision making, and respect them as partners in management of subtle, emotional disorders like depression that tend to underlie physical illness (Walker & Dewar, 2001). They deserve supportive services not only targeting the physical illness in their patients but also the depressive dimension. Such services have the potential to improve not only the quality of patients' lives but also the prognosis of identified illnesses. This is possible especially because caregivers were able to describe the linkage between some life events in their patients' illnesses.

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