



ภาวะวิกฤตในการดูแลผู้ป่วยจิตเวชของ ผู้ดูแลและการนำไปใช้เพื่อพัฒนาระบบบริหาร ในประเทศไทย

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บทคัดย่อ

ในปี ค.ศ. 2003 องค์การอนามัยโลกได้ระบุว่าสมาชิกในครอบครัวเป็นผู้ดูแลหลักสำหรับผู้ป่วยทางจิตเวชโดยเฉพาะโรคจิตเภท บทความนี้เป็นรายงานวิจัยเชิงคุณภาพที่ศึกษาประสบการณ์ของผู้ดูแลหลักที่อาศัยอยู่ในชนบทของประเทศไทย โดยเน้นที่ความเข้าใจประสบการณ์ช่วงภาวะวิกฤตในการดูแลผู้ป่วยจิตเวชซึ่งเป็นญาติ และภาวะวิกฤต ได้แก่ พฤติกรรมก้าวร้าว อาละวาด พยายามฆ่าตัวตาย หวาดระแวง ประสาทหลอน ควบคุมตนเองไม่ได้ หนีจากบ้าน เกิดเป็นพั๊กๆ แต่เกิดยาวนาน ภาวะที่ผู้ดูแลหลักต้องเผชิญ ได้แก่ ปัญหาทางการเงิน การแยกตัวจากสังคม และผลกระทบรุนแรงต่อสุขภาพกายและสุขภาพจิตของผู้ดูแลเอง ข้อค้นพบนี้มีความสำคัญและเป็นสิ่งท้าทายสำหรับบุคลากรทางการแพทย์ บทความนี้ได้ให้ข้อเสนอแนะเพื่อนำไปปรับปรุงการเรียนการสอนการบริการและงานวิจัยในอนาคต

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Crises in Care-Giving - An Enduring State: Implications for Service Development in Thailand

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ABSTRACT

In 2003, the World Health Organisation (WHO) identified family members as the main carers for people with mental illness. This paper initially provides a brief report of the findings of a qualitative study exploring the experience of family care givers in a rural area of Thailand. The focus of this study was to seek an understanding of the experience of crisis faced by carers as they looked after their relatives with mental illness. Contrary to expectation crises were not episodic events interspersed with extended periods of stability, but rather an enduring state. For care givers this burden resulted in financial hardship and social isolation and impacted severely on their own physical and mental health. These findings pose significant challenges to health care professionals and community services in Thailand. This paper examines the implications of these findings and makes recommendations regarding educational enhancements, changes to clinical practice and suggestions for future research.

Keywords: crises, care-giving, implication, Thailand

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Introduction

Thailand is one of the countries described by the WHO as being within the lower and middle income category¹. In 2011, there were more than 1.6 million patients diagnosed with mental illness out of a total population of almost 65.9 million². In 2007, Chisholm, Lund, and Saxena³ reported that only US\$1.20–1.25 per person was expended annually for significant health conditions (schizophrenia, bipolar disorder, depression and hazardous alcohol use) in Thailand. In addition, most mental health professionals work in urban areas and there is a severe shortage of mental health services in rural areas. In 2008, the shortage of mental health professionals in Thailand was demonstrated by the following statistics: Per 100,000 people there are 0.86 psychiatrists, 3.74 psychiatric nurses, 0.45 clinical psychologists, and 0.66 social workers⁴.

Typically, family care givers are involved in supporting relatives whose mental illnesses are persistent and long term. As such, the ongoing involvement of family care givers is an important, if often overlooked, component of the overall care provided for people with chronic mental illness. For many family care givers with relatives suffering from mental illness a poor understanding of the nature of psychiatric symptoms and treatments means that when crises such as flashbacks, suicide attempts or aggressive behaviours occur, they are shocked, distressed and find these difficult to manage⁵⁻⁷. Furthermore, delays in seeking help, for instance, presenting to the hospital, can mean that by the time health professionals become involved psychiatric symptoms have become severe and

the costs of hospitalisation, medications and other forms of treatment are much greater, than would have been the case, had help been sought earlier.

In order to identify more clearly the educational and support needs of care givers of relatives with mental illness, this study was undertaken in a rural-urban community in Thailand. Many of the participants were involved in subsistence farming while also providing high levels of care and support for their relatives. The study findings form the basis for the recommendations for future research and implications for health care services and educational providers outlined in this paper.

Background

Family care givers play an important role providing care for their mentally ill loved ones and are known to periodically face crises themselves. The existing literature has indicated a range of precipitating factors, such as medication non-compliance, running away from home, abuse of alcohol and drugs, suicidal behaviours, aggressive and destructive behaviours, self-harm or threat to others and unpredictability that lead to crises caused by mental illness^{5, 7-10} as well as how it is that family care givers can be drawn into crises during their care for their loved ones^{7, 11-16}. Most studies, however, have been conducted in Western countries. Although there are published studies focusing on the experience of crisis, the aim of these was to evaluate crisis intervention services which were already well established^{17, 18}.

Other research, including phenomenological studies, has focused broadly on the general

experiences of family care givers providing care for a relative with mental illness, particularly schizophrenia¹⁹⁻²⁴. The experience of crisis goes beyond family care givers providing support for loved ones diagnosed with high impact psychotic disorders such as schizophrenia. Indeed, the burdens of care giving and associated crises, may be experienced by family members providing care to loved ones experiencing any form of mental illness. Previous Thai studies have mainly focused on religious and cultural beliefs towards care giving^{7, 9}. The study reported in this paper was designed to address a gap in the literature and specifically examined the lived experience of family care givers in crisis during their care for relatives with mental illness.

The theoretical understanding of 'crisis' informing this study is presented briefly to enable the reader to more readily appreciate the reported findings. A widely accepted definition of crisis describes 'a state of disequilibrium'. When the tension or stressors that have precipitated the crisis diminish or recede, the person returns to their previous 'steady state'. Conversely, the tension may fail to resolve and in fact may increase and in order to return to and maintain a state of equilibrium, new coping strategies may be required. If the state of disequilibrium recurs repeatedly, the person's capacity to adapt may be challenged to the point that they experience mental and/or physical collapse; in everyday language, 'they may have a breakdown'²⁵⁻²⁸.

Generally, a crisis state is defined as time limited, lasting between one and six weeks²⁸,

however, for people with mental illness a state of crisis may persist for an extended period. The person may have recurrent crises throughout their lives as well as an ongoing sense of helplessness, loss of control, disruption to work, social interactions and family life. There is also a degree of perceived danger to self and others²⁹. It could be anticipated that for the people close to the person with a severe, prolonged mental illness, i.e. the care givers, there would likewise be a significant adverse impact.

A brief description of the research

Given the paucity of knowledge regarding this particular aspect of care giving, i.e. caring during crisis, this study employed a hermeneutic phenomenological approach, informed by van Manen's theoretical framework³⁰. Participants were recruited with the assistance of the primary health care workers in the study area. In-depth audio-taped interviews, using semi-structured open-ended questions, were conducted with 12 consenting participants. Follow-up interviews were undertaken with 10 of these participants. Additional data collection techniques included note-taking during interviews and maintaining a reflective field journal. Data analysis was conducted using a two-step procedure. The initial step involved a rigorous and systematic process of thematic analysis, checking and re-checking the fine nuances of the verbatim transcriptions. This was followed by a detailed interpretation of the phenomenon of interest. Ethics approval to undertake this study was obtained from the University of Newcastle Ethics Committee and

written permission to conduct the study was provided by the Chief of the Public Health Office of the Province within which the study was conducted.

Key findings

Contrary to the expectation of the primary author and the views of health professionals in the region in which the study was undertaken, the crises experienced by caregiver participants were not episodic events interspersed with extended periods of stability, but rather enduring states of ongoing crisis. For care givers this burden impacted severely on their own physical and mental health resulting in financial hardship and social isolation. The persistent difficulties and challenges experienced by care givers included

practical issues such as struggles to pay for care and to feed the family, the ill person’s threatening behaviours, social stigma, and their own emotional and physical difficulties. In describing these difficulties, participants spoke of the ways in which their lives had been ‘turned upside down’ and changed dramatically for the worse. Importantly, the findings clearly demonstrated the desperateness of living in ‘a state of ongoing crisis’. The thematic analysis of the data enabled a schematic representation of this experience of ‘living in a state of ongoing crisis’ organised under four key themes: ‘Out of control’, ‘So alone’, ‘Confusion and chaos’, and ‘No way out’. A comprehensive description of the full findings of the study is beyond the scope of this paper; however, the key findings are succinctly represented by the following figure.

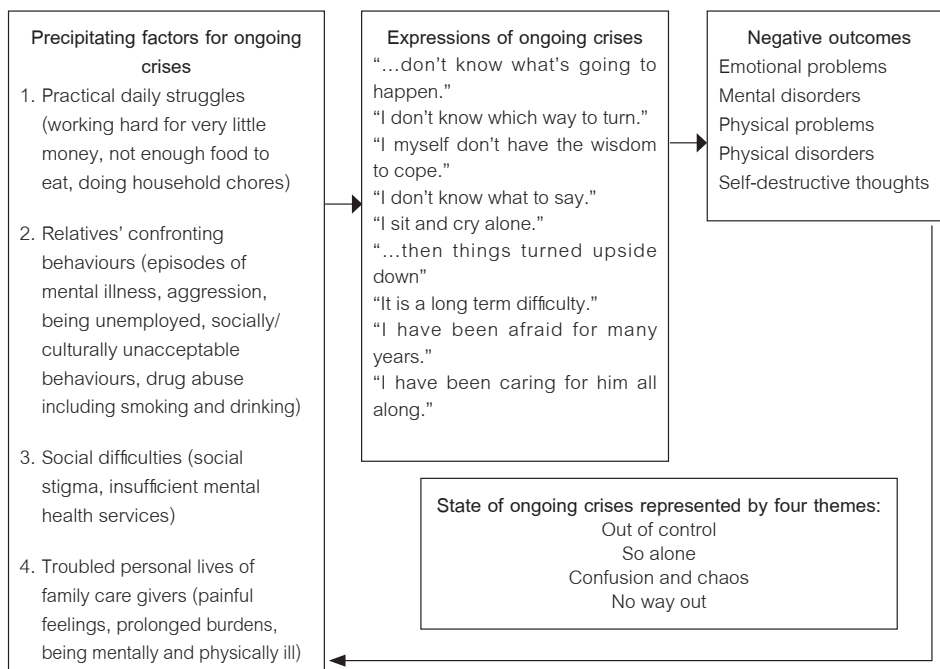


Figure 1 Factors contributing to care givers’ experience of living in a ‘state ongoing crises’

The study highlighted a number of previously unreported aspects of the experience of caregivers. Caregivers spoke of financial stressors related to accessing treatment and high treatment costs that resulted in a level of deprivation that can best be described as starvation. The long term and isolating nature of caregiving in the face of persistent crises led participants to describe the worst aspect of care giving as 'loneliness'. The persistent crises in combination with the level of stigma directed towards the ill loved ones and caregivers were key contributors to this sense of aloneness. Participants avoided talking to neighbours and described a reluctance to ask for assistance from community members or health professionals.

The level of stigma towards caregivers and their ill relatives further reinforced the sense that 'there is no way out' for the care-giver or the person with mental illness. The phrase 'No way out' bluntly illustrates the experience of living in a state of ongoing crisis for these caregivers who spoke frankly of seeing death as a desirable alternative to continuing with their current existence. As one participant said, "I would like to jump from a bridge to kill myself. I am tired of life" (Tong, p. 16). Caregivers also spoke of their current physical and mental issues and illnesses, with some participants themselves having received a formal diagnosis of mental illness such as an anxiety disorder or depression.

These findings deepen current understandings of crisis. A crisis has previously been described as

a situation of both danger and potential opportunity. People experiencing a crisis may return to a level of functioning post crisis that is consistent with their pre-crisis functioning or may indeed function at a lower or higher level after facing a crisis^{25, 28, 31}. In contrast to current perspectives, these findings provide a picture of a group of people whose experience is one of being in a state of ongoing crisis. The data suggests that rather than a return to equilibrium, caregivers' functioning fails to return to pre-crisis functioning and is instead epitomised by maladaptive responses and mental and physical illness as an outcome of the unrelenting nature of the care-giving role.

Implications

These findings suggest that in many instances, health care providers may have profoundly underestimated the level of burden carried by family members. As care givers related their personal stories of caring for a relative with mental illness, a picture of life lived in a state of ongoing crisis unfolded. The additional insights obtained from this study bring a deeper understanding of the needs of care givers caring for ill relatives. Although the Thai health care system provides a basic level of psychiatric treatment, the burden of care for people with mental illness falls primarily to family members. To adequately provide care for chronically ill relatives, care givers need ongoing [help, support and understanding] from social structures, community services and health care professionals. Importantly, the support from

health care providers must focus on meeting individuals' needs¹¹. The findings from this study point towards areas requiring the focused attention of health care providers, those responsible for policy and service development and educators of both the current and the future health workforce. The section of the paper that follows outlines possible actions that can be undertaken to address the needs of caregivers.

Educational enhancements for health professionals

Educational initiatives designed to enhance the capacity of the health workforce to more effectively support caregivers require a two-fold focus. Firstly, upskilling the existing workforce through the provision of focused educational programs is required, while attention is concurrently given to enhancing health professional curricula to ensure the future workforce has the skills required to support caregivers. Janosik³² and Kanel³¹, whose work builds on Caplan's crisis theory²⁸, assert that in order to help people successfully negotiate crises, health professionals need to have a better understanding of the hazardous events which cause people distress, how they experience those events and the overwhelming tendency to resort to customary coping mechanisms. With this understanding, health professionals are better equipped to change the way in which they practice. A number of examples of the initiatives designed to improve health professional knowledge are reported in the literature, including a focus on

the importance of mental health literacy which aims to improve knowledge and beliefs about mental disorders to enhance mental health care provided by professionals³³. The Canadian Alliance on Mental Illness and Mental Health³⁴ used key findings from previous research to develop a framework to improve the mental health literacy of health and mental health professionals, researchers, policy planners, consumers and family members. The findings of this current study indicate additional components to add to educational programs including a focus on the pressures family care givers of mentally ill relatives face day-to-day, the experience of living in a state of ongoing crises and the implications of this for care givers. These findings should serve as a guideline to enhance the understanding of mental health professionals concerning the experience of care givers in ongoing crises during their care for their mentally ill loved ones.

Strengthening clinical practice

Just as these findings have significant implications for the planning of future educational initiatives, they also have implications for the ways in which health professionals practice in the clinical setting. While it is essential for practicing health professionals to be aware of the overall difficulties and challenges that care givers of mentally ill relatives face, particular note needs to be given to care givers struggling to adapt in effective ways and experiencing major disorganisation in the period that would normally be expected to result in

resolution^{25, 27, 28}. Kanel³¹ suggests that health care providers need to provide crisis intervention for people who are in the midst of crisis because they are more receptive to suggestions and support than when they are in the steady state. Likewise, Gavois, Paulsson, and Fridlund¹² found that care givers needed support from health professionals during crisis. The provision of adequate support increases the person's capacity to cope effectively with difficulties and challenges and to adapt well to new circumstances. Appropriate support instituted in a timely fashion has the potential to enable care givers to achieve a higher level of functioning.

Recommendations from the World Health Organisation³⁵ emphasizing primary health care as an approach to strengthen health systems can be used to guide the development of crisis intervention for care givers. Providing help for mental health problems and disorders through community-based services should be seen as a priority as this approach has been reported to enable the largest number of people to access effective services, at an affordable cost, and in a way that minimises stigma and discrimination^{35, 36}.

In Thai rural communities, the village health care workers or community health workers serve as frontline personnel to provide primary care for the community. They provide basic help and support for people in the community including serving as educators, communicators, problem detectors, problem solvers, community organisers, and leaders of health³⁷. Given the limited availability of adequate numbers of mental health professionals

in Thailand, village health care workers provided with appropriate training and support could work collaboratively with health professionals to help care givers cope more effectively with crises.

However, infrastructure and funding to support these roles would be required to bring about improved help and support for family caregivers. This would include formal education and training around basic mental health issues including responses to crisis situations. A possible approach for increasing the competency of village health care workers could be the provision of training using the validated program Mental Health First Aid³⁸. This would need to be translated, validated, and modified for the Thai context. An initial crisis assessment tool should be developed to support the village health care workers in their primary health care roles. The tool should be accessible for use in either actual or potential crisis situations²⁵. The precipitating factors (see Figure 1) for the state of ongoing crisis which is frequently the experience of caregivers could be used as the basis for developing such a tool for the village health care workers. During visits to care givers in the community, such a tool could be used to assess factors which may precipitate crises and those considered to be at risk could be referred to health professionals for further assessment and support.

The process of developing such a crisis assessment tool for health care workers and health/mental health professionals could commence with consideration of the findings of this study. Lewis

conducted a study to develop a crisis assessment tool and suggested that a measurement tool helped clinicians justify treatment for people in crisis³⁹. It was recommended that an effective questionnaire should include questions related to the person's thoughts, behaviours, feelings and perceptions of the crisis situation. The findings of this current study have identified potential precipitating factors for crises, expressions of distress related to living in a state of ongoing crises, the effects of ongoing crisis on care givers, and their lived experience in ongoing crisis. These findings provide information that can form a solid basis for the development of a crisis assessment tool for use by health professionals and village health care workers in Thailand.

The development of a clinical pathway that outlines the appropriate response to assist the person in crisis would assist the implementation of a consistent response to-care-givers. Once the assessment process has been completed, clinicians would be encouraged to provide support that is tailored to individuals' needs. Those involved would also be encouraged to refer care givers and relatives with mental illness to receive help and support from a range of organisations. For example, the police can help care givers deal with legal issues. Local government officials can be encouraged to assist by providing a budget to serve the basic needs of people with mental illness as well as the development of employment projects for disadvantaged people. Monks likewise can be recruited to assist through the provision of community-based rehabilitation of people with

mental illness using as a model a programme already established in the Thai community³⁵. Finally, health workers require skills to facilitate consultation and referral to mental health professionals in secondary and tertiary care in a timely fashion as required.

Future research directions

Although the findings from this study are suggestive, there is a need for follow up research to investigate the types of support and intervention will be effective and feasible within the Thai context. The resources available for the provision of assistance for care givers of relatives with mental illness are very modest. Currently, a person with mental illness is paid a living allowance by the Thai government of 500 Baht per month (around US\$16)⁴⁰. Research on how this very limited budget might be spent to provide the best possible support for these people needs to be undertaken.

As mentioned previously, mental health professionals are a very scarce resource in Thailand. Further research needs to be carried out addressing how these available human resources can best be utilised in times of crisis to produce positive outcomes for family care givers. This research needs to incorporate an examination of what crisis intervention can be delivered by the village health care workers, health/mental health professionals, and local government officials to support these people to successfully survive crises and prepare more effectively for possible crises in the future²⁶.

Conclusion

This study has highlighted the desperate situation of care givers of relatives with mental illness who live in a rural under-resourced area of Thailand. The contribution to the Thai community made by this group of care givers cannot be underestimated and these findings require the focused attention of those responsible for service development, clinical services and education who have the potential to assist this neglected group within the community and to support them to provide care for their ill loved ones whilst maintaining their own well-being. An integrated approach to addressing this area of need is likely to yield the most effective outcome with efficient use of the modest health care budget available in this country.

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