

บทสะท้อนจากการทำวิจัยแบบปรากฏการณ์วิทยาแนวอรรถปริวรรตเพื่อศึกษาประสบการณ์ ของญาติผู้ดูแลผู้ที่อยู่กับโรคจิตเวชในประเทศไทย

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บทคัดย่อ

ปรากฏการณ์วิทยาแนวอรรถปริวรรต (Hermeneutic phenomenology) เป็นวิจัยเชิงคุณภาพที่ใช้กันอย่างแพร่หลายในศาสตร์ทางการพยาบาล และทางสุขภาพสาขาอื่นๆ อย่างไรก็ตาม การนำรูปแบบการวิจัยนี้ไปใช้กับกลุ่มประชากรที่ไม่ใช่กลุ่มโลกตะวันตก เช่น ในประเทศไทยนั้น พบว่ายังไม่เป็นที่นิยมเท่าใดนัก และมีความท้าทายหลายอย่าง บทความนี้จึงเสนอความท้าทายที่พบจากการทำวิจัยแบบปรากฏการณ์วิทยาแนวอรรถปริวรรตในประเทศไทย ของนักศึกษาไทยที่ไปศึกษาปริญญาเอกในประเทศตะวันตก โดยได้อธิบายกระบวนการเลือกระเบียบวิธีวิจัยและการทำวิจัย เพื่อศึกษาประสบการณ์ชีวิตของญาติผู้ดูแลผู้ที่อยู่กับโรคจิตเวชในชนบทของประเทศไทย บทเรียนจากการทำวิจัยและข้อเสนอแนะสำหรับนักวิจัยในอนาคต และยังได้นำเสนอประเด็นสำคัญเกี่ยวกับความลำบากในการดูแลผู้ที่อยู่กับโรคจิตเวชของญาติไว้อย่างย่อ เพื่อเป็นข้อมูลพื้นฐานให้เข้าใจการสะท้อนถึงวัฒนธรรม และความเหมาะสมของการประยุกต์ใช้ระเบียบวิธีวิจัยที่มีต้นกำเนิดมาจากโลกตะวันตก เพื่อทำความเข้าใจประสบการณ์ชีวิตของคนจากต่างวัฒนธรรม

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Reflection on conducting hermeneutic phenomenological research into the experience of family caregivers of people with mental illness in Thailand

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Abstract

Hermeneutic phenomenology is a well-established research methodology in nursing and other qualitative health research. However, the use of this approach in non-Western study populations has not been widely undertaken in Thailand and presents some significant challenges. This paper provides a discussion of the challenges encountered by a doctoral student undertaking a PhD program in a Western country while conducting the research project in Thailand. The process of choosing a methodology and then using this methodology to research the lived experience of people caring for relatives with a mental illness in rural Thailand is described. The lessons learned from this research undertaking and recommendations for future researchers are also outlined. The study details and findings highlight the plight of family caregivers in rural-urban Thailand and are briefly mentioned as the background to the reflect on the

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cultural relevance and appropriateness of applying an essentially Western methodological perspective to understand the lived experience of people from another culture.

Key words: phenomenology, Thailand, experience, reflection, cultural relevance

Introduction

Effective research requires the use of the best-fit research methodology for the topic to be explored. The aim of this paper is to discuss the challenges encountered while conducting a research project using a Western developed methodology, hermeneutic phenomenology, in Thailand. The proposed study sought to explore Thai family caregivers' lived experience of the crises that may periodically occur in the course of providing care and support for mentally ill relatives. Little was known about this topic in the Thai context, thus quantitative methodologies were inappropriate for this project and it was essential to begin with a qualitative approach¹. Before effective services could be developed to support caregivers it was important that the gap in knowledge about the experience of the caregivers should be investigated and addressed. A clear understanding of crises from the caregivers' perspectives and their specific context is necessary so that mental health professionals can provide support that suits the caregivers' needs.

The intention of this paper is to present a personal reflection exploring my experience of conducting this study (first author). For the purpose of personalising this paper, a decision has been made to write this in the first person to indicate the intensely personal nature of this writing. The paper provides a discussion of the challenges encountered as a doctoral student undertaking a PhD program in a Western country while conducting a research project in Thailand. The process of choosing a methodology and then using this methodology to research the lived experience of people caring for relatives with a mental illness in rural Thailand is described. The initial plan for this study was to utilise participatory action research (PAR) before deciding to adopt a hermeneutic phenomenological approach to the study question. Brief details of PAR and the chosen methodology are included for readers unfamiliar with

these research methodologies. The lessons learned from this research undertaking and recommendations for future researchers are also outlined. The study details and findings highlight the plight of family caregivers in rural-urban Thailand and are briefly mentioned as the background to the reflect on the cultural relevance and appropriateness of applying an essentially Western methodological perspective to understand the lived experience of people from another culture.

Background - brief overview of study

The research study^{2,3} was conducted in rural-urban area, Thailand. It sought to answer the following research question: "What is the lived experience of Thai family caregivers in a crisis during their care for relatives with a mental illness?" Permission was granted to conduct the research from the Human Research Ethics Committee (HREC) of the University of Newcastle as well as from authorised persons in the area in which the study was conducted.

The participants were 12 consenting family caregivers of relatives with mental illness. They were recruited from the mental health and psychiatric unit in the community hospital and from the mental health and psychiatric clinic in the health centres. Most of them had provided care for a relative with mental illness for more than 10 years. They were farmers and wage earners with low incomes of approximately 2,500-5,000 baht/month/family (AUD\$ 80-180). They had limited formal education and had completed only two to four years of formal schooling.

In-depth interviewing was used to gain access to the lived experience of family caregivers caring for relatives with mental illness. There were 12 initial interviews and 10 follow-up interviews conducted with 12

consenting individual family caregivers. The interviews were guided by semi-structured open-ended questions focusing on experiences of providing care for mentally ill relatives and associated crises.

A follow-up interview was sought with all twelve participants. Ten out of the 12 original participants agreed to be interviewed again. In the follow-up interview, participants verified the preliminary themes emerged from the first interview. They were asked to comment on and validate key findings arising from the earlier interview. The interviews continued until further clarification and exploration of key issues were sought and the participants had nothing more to say around provided interview questions. All interviews were recorded using digital recording equipment. The recorded data were then transcribed verbatim by the first researcher and then confirmed by a professional translator. The transcripts were analysed and utilised to build themes that described the phenomenon of interest.

Personal reflection on challenges encountered

The intention of this paper is to talk about my (the first researcher) personal experience of conducting this research that explored the experience of care-givers of people with severe mental illness. The following sections present the personal experience of the researcher in carrying out the study.

Language

The initial challenge arose early, I am Thai. English is my second language. I quickly found that I had underestimated how difficult it was to study in an English speaking country. When I later chose to undertake my research using a phenomenological approach, the difficulties escalated as I tried to understand the complex philosophical concepts underpinning phenomenology. I struggled to understand technical terms such as 'essence', 'epoche', 'intentionality', 'Being', and 'owned-body'. To further complicate the task that confronted me I found that there were different variants of phenomenology; while these shared some similarities there were also important differences. I battled to distinguish the differences between transcendental phenomenology, existential phenomenology and hermeneutic phenomenology. Although I had previously

found my grasp of English to be satisfactory, when I encountered such specialist terminology, I felt as if I had returned to a status of novice-English speaker. I also discovered that many of my English-speaking colleagues if not familiar with phenomenology likewise struggled to explain the specific terms.

Choice of methodology

Yet another unexpected challenge arose during the first year as I contemplated the approach that would guide my research. Was the approach that I had initially chosen really appropriate? As a psychiatric nurse and nursing lecturer in the mental health area for sixteen years I felt I was very knowledgeable about care givers' experiences and needs during times of crisis. At that time my perspective as a nurse trained in and focused on problem solving led me to think that it would be better if care givers could share their experience with others in a group, so they could learn from each other how to deal with crises. I spent a great deal of time during my first year as a doctoral candidate developing a research proposal using a participatory action research (PAR) approach. I sought informal contact with my colleagues working in mental health in Thailand to make sure that this kind of research could be done in the Thai community where they worked. They confirmed that crisis situations occurred frequently and suggested that research should be done to ascertain what would help those affected to deal with crises more effectively.

PAR is an area of social research that is defined in multiple different ways, for example, 'Participatory research is defined as systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action of effecting change'⁴. Participatory approaches seek to actively involve the participants in the research process enabling them to co-create a deeper understanding from their insights and to thus influence and change social reality. Participants and researchers seek to 'fundamentally question and rethink established interpretations of situations and strategies'⁵. Action research may be conducted with participatory research or separately and focuses on using problem-solving activities to identify and implement solutions to specific issues or problems.

As I learned more about PAR, I began to question my initial choice; the amount of time required to complete such a project given the distance and language barriers, seemed too great to allow successful completion. However, the issue that concerned me most was the power imbalance between myself as a nurse and researcher and the people with whom I hoped to work in the course of the project. Care givers in the study site are socially and economically disadvantaged and have a low level of literacy. The cultural perceptions of the role of health professionals as 'experts, not be questioned' further troubled me as I contemplated trying to work with a PAR approach. These limitations concerned me as I wondered if the potential participants 'would come to join the group and fight for themselves or would they come to listen and do what I would tell them to do?'

A few months before the completion of my first year of studying, I realised that in fact I knew very little about what care givers experience while caring for relatives with mental illness in Thailand. I needed to shift far from my personal assumption of already 'knowing' to a stance of 'not knowing'. Research was indeed needed to identify how to help these care givers but as yet I did not know what specific crises they faced, and thus did not know how to develop an intervention to best fit their needs. At this point, I needed to step back and rethink the intended approach. How could I conduct a research project that would help me to understand the experience of care giving during a time of crisis? This seemed to be an essential pre-requisite to developing a sensitive and helpful intervention.

A period of anxiety and tension followed as I struggled to refocus and decide upon an approach that was applicable to the study question but also achievable within the time limitations imposed by scholarship and PhD requirements. Much time was spent discussing the options available that would answer the research questions with fellow students and my PhD supervisors and after much thought and further reading, I decided to use a phenomenological approach to explore with care givers' their experience of giving care to mentally ill persons. Briefly, phenomenology seeks the meaning of phenomena (an object or awareness within experience).

Humans are seen as 'being-in-the- world' through their consciousness. They describe the world by giving meaning to it. The meaning they make of the world appears to their consciousness. Interpretation of this consciousness of an object is created by experiencing it; for example through hearing, seeing, or smelling it. Thus consciousness cannot therefore be separated into subject and object⁶. The application of phenomenology to research is also seen as a methodological approach to investigate the phenomena and has been described as a rigorous, critical, and systematic approach⁷.

There are several methodological interpretations of the philosophy of phenomenology⁷. For effectiveness, the selected method must fit with the research question of the proposed study. It also has to relate to the theory underpinning and guiding the study. Hermeneutic phenomenology is a philosophy of the individual⁸ and focuses on a human experience as it is lived and aims to create meaning and gain a deeper understanding of lived experience⁹.

While phenomenology has been used to investigate the experience of many different groups of people by different disciplines in many countries, the idea of conducting a phenomenological study in Thailand was challenging for me. Given my earlier clinical experiences and assumptions, I was worried: 'would care givers talk?' From my previous clinical experience, Thai people are generally likely to answer "I don't know" to questions and tend to provide short answers only to health care professionals. I wondered whether I would be able to engage care givers in a frank discussion about their experience. I continued to think about how best to begin to understand the experience of carers. As one step towards possible engagement, I attempted to develop an interview schedule that would be suited to the rural Thai people I hoped to interview.

Another issue related to the interview process that required much thought was whether or not to use the term crisis. Finally, the decision was made to use the terms 'difficulty' and 'challenge' rather than crisis. This decision was made with the intention to avoid bias in the participants' telling of their stories. I was however concerned as to how participants might respond to these

terms. Are there equivalent words to crisis in Thai? Will these be understood by the semi-illiterate participants in the study? If the focus was limited to 'crisis' would I miss a broad understanding of the care givers/ experience.

Beginning of the research

Barriers

At the commencement of data collection, I went to the study site every day to be ready to provide eligible prospective participants with particular information about the research project. However, for the first few weeks, the care givers attending the health centres and the hospital were apparently not interested in the study. I was perturbed by this, as this seemed in contrast to the experience other Thai researchers with whom I had spoken who had readily recruited participants to their studies. While the information sheet and related documents were distributed by the local psychiatric nurse who was already known to potential participants, the participants appeared to be reticent to participate in the study. Only a few people expressed their willingness to be involved. This was perhaps because most of those approached were illiterate. They were afraid of signing documents that they did not understand. Even though they were given a detailed description of what participation in the study would entail, many of them seem to be overwhelmed by the information and needed reassurance that the study would not affect them in any way. One participant later told me that she took all the documents to her niece to read and then discussed the study with other relatives to make sure that the study would not affect her. These barriers meant that it took five months to recruit sufficient participants to reach data saturation for the study.

Great surprise!

Despite the initial experience of difficulty in recruitment, gradually participants agreed to become involved in the study. Indeed, most proved to be very eager to be interviewed after the initial period of reticence and once sufficient care givers agreed to participate in the study, carers proved to be very eager to be interviewed. The experience of interviewing the first participant recruited to the study continued throughout the interviews. She responded readily to the initial questions

and went on to give a detailed discussions of her experience of caregiving. Concerns regarding the use of terms such as 'difficulty' and 'challenge' proved unfounded. In contrast, to my experience as a clinician, participants talked at length, ranging widely over many aspects of their caregiving. Most shared their experiences willingly and were to later reveal that they felt that the burden of care giving had been relieved a little with the opportunity to tell their story.

On reflection, a number of reasons likely contributed to participants' willingness to tell their story. Each person was interviewed in a safe place of their own choosing. I carefully reiterated the purpose of the research and explained clearly their right to withdraw at any point. My task then was to listen to them with 'fresh ears'; as if everything I heard was new for me. Sometimes, it was difficult to keep the care givers focused on the research questions as they talked randomly about their experiences. When this occurred the interview schedule was used as a guide to return the conversation to questions focused on the lived experience of care giving in crisis.

Listening without judgment

As I opened my eyes and ears to 'what is it like for these carers?' I was taken aback by the intensity and duration of their experience of crisis. My prior assumptions gained from my own clinical experience and confirmed by consultation with other health care providers were that people had periods of calm and stability with occasional crises. It was not uncommon for me to hear health care providers judging the carers as having somehow precipitated the crisis because of a lack of care, or failure to bring the person to the hospital in a timely manner. I likewise had made the same judgements. However, the experience of the participants seemed at odds with the common understanding of crisis. As I listened, I became aware of how important it was for me to put aside my judgements and to listen to their story. In contrast to my previous beliefs, participants spoke about their experience of caring for relatives with a mental illness as an enduring burden of care-giving in which the initial shock continues to impact on them until the present day. Their stories changed my intention of exploring what I had assumed

would be episodes of crisis to rethinking of these carers' experiences more in terms of 'ongoing crises'.

Coping with emotional impact upon researcher

Looking further at what was required during the research process, helps to explain how this project impacted upon me personally. Following up on the initial interviews with each participant, I wrote a letter summarising the key points of that interview to each of the ten original participants who agreed to meet with me for a follow up interview. During the second interview, each of the participants was overwhelmed as they read or listened to the letter that reflected their story. They shed tears and spoke of how very thankful they were that someone understood what they were going through and recognised their efforts to provide care for their loved ones with mental illness. Individually they confirmed the summary and some of them repeated again what they had told me. The intensity of their reactions was unexpected.

As the researcher, I now found myself experiencing very mixed emotions. I was happy that I could help provide some release from the tension arising from care giving but sad to realize that they had been in a position of ongoing crisis for such very long periods of time. I felt sad, overwhelmed and powerless as I realised that their needs were so underestimated by mental health professionals who should have listened to them more carefully. As I told each participant that I could not meet them for further interviews as it was time to return to Australia to continue my study, they expressed their sadness and reluctance to end our meetings together. I then had to remind them of the timeframe for my data collection and my role as a researcher. While they appeared to understand most sought to prolong the final session as long as possible, finding it was very difficult to take their leave. I felt intensely the conflict between my professional role as a mental health clinician and my academic role as a researcher.

After the fifth month of data collection, my relief at finishing data collection was mixed with sadness and pain. On the one hand, I was glad to have obtained sufficient data to have reached saturation within the set time period and I was proud of the participants who as

informal experts had shared their experiences of care giving for loved ones with mental illness. On the other hand, their experience of ongoing crises raised many concerns for me. I now realised how difficult their lives were, so much more difficult than I had ever imagined. Such an intimate encounter with each participant had given me a glimpse of lives lived in a state of ongoing crisis with minimal resources to deal with the difficulties and challenges faced every day. Uppermost in my mind was hearing from most participants of their desire for death as an escape from the almost intolerable burden of care giving. At times I was filled with sadness as I thought about the participants, sometimes I felt overwhelmed by the enormity of the problems that they encounter and wondered how such difficulties could be dealt with in an effective way. I discussed the personal impact of doing such research with one of my PhD supervisors and at times sought additional support from the University counselling service.

Tedious process of retranslating English transcripts

I came back to Australia hoping that I could present the participants' experiences clearly enough for others so that they would understand these experiences the way that I now did. However, once again I encountered unexpected challenges. As I set about the process of thematic analysis with both the Thai and the English transcripts translated by a Thai professional translator, I sought to identify the key themes, the descriptions to support these themes and sub-themes presenting the lived experience of care givers. Very rapidly, I discovered the transcriptions were not accurate enough to enable me to portray accurately the meaning of the lived experience of care givers. As I was a student enrolled in an Australian university with Australian supervisors who cannot speak Thai, it was essential that the transcripts were accurate. I thus commenced retranslating all the English transcripts. I continuously consulted the Faculty of Health's learning advisor, at the University of Newcastle to check the correctness of the transcripts' English expression. The tedious process of retranslating was done carefully as I attempted to remain true to the Thai culture

and to the participants' language. My focus was to ensure the experience of care givers was clearly presented and accessible to an international readership. To my surprise and pleasure I found that when I presented the findings of the current study at the 1st European Congress for Social Society in Geneva, Switzerland, my audience seemed to understand my portrayal of the care giving experience.

Lessons learned

While I had underestimated the challenges that I would encounter in attempting this research project, the findings have deepened the knowledge and understanding of the experience of the care givers who so kindly participated in the research despite their apprehensions and concerns. The methodology chosen was fit-for-purpose and despite its Western origins I was able to implement it effectively in the research context chosen. The process of backwards and forwards translation was tedious, however, it forced me to become deeply immersed in the data. This enabled me to work closely with my English speaking supervisors to build a shared understanding of the data and to then contrast the findings from this project with reports from similar research undertaken in different countries and cultures. Completing the entire project in English has ensured that these findings are accessible to an international audience and has likewise strengthened my competency in English. Additional time and funding should be budgeted for in cross-cultural projects with requirements for backwards and forwards translation. It is essential that the researcher undertaking the direct participant contact be a native speaker of the same language as the participants. Where an interpreter is required to undertake the interviews, the risk of mis-interpretation and mis-representation of the participants' experience is likely to be much higher.

As a mental health professional with clinical expertise and training in counselling, my ability to engage a person therapeutically served me well when I came to undertake the in-depth interviews, however I had not anticipated the personal impact of undertaking this project. I would strongly recommend that clinician researchers factor into their project plan and budget provision for additional psychological support when the research question is examining areas where human

suffering and pain is likely to be a core feature of the findings.

Despite the significant challenges encountered, I would encourage other researchers to consider phenomenological methodologies where this approach is appropriate to address the research question. While surveys and questionnaires might seem simpler to administer and interpret, the richness of the data accessed using hermeneutic phenomenology provides a window into the experience of participants that is not achievable using paper-based tools. I believe that the findings from the research project undertaken provide a basis from which to proceed to participatory and action type research projects designed to address the ongoing level of crisis and excessively heavy caring burden carried by people such as those participating in this study.

Conclusion

This paper demonstrated the challenges of conducting hermeneutic phenomenological research as an effective tool for deepening understanding and awareness of a specific experience, the lived experience of Thai family care givers in crises during their care for relatives with mental illness. These challenges included the language, the methodology used, the participants' education level, the emotional impacts on the researcher, and the translation process. This outline of the challenges and experiences encountered while conducting qualitative research using phenomenological methodology, provides an insight into what other researchers seeking to utilise such an approach might anticipate. Such awareness can assist future researchers to factor in additional levels of support and funding to address the demands of using phenomenology in a trans-cultural setting.

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