

A STUDY OF FAMILY CARING; CARERS' EXPERIENCES USING RESPITE CARE SERVICES

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INTRODUCTION

Since its inception in the mid 1970s in Australia, home and community based care has received increasing public attention. This is partly due to the deinstitutionalization movement of the late 1960s and the 1970s, which resulted in a significant increase in families' responsibilities for caring for their disabled members^{1),2)}. Currently, family members provide most of the health care for the elderly and because of rising health care costs and limited nursing home beds, more families will need to assume carers' responsibilities. According to figures supplied by the Commonwealth of Health, Housing and Community Services³⁾, it is estimated that half of the moderate to severe cases of dementia and most of those with mild dementia are cared for in the community.

People with chronic mental illness experience some limitation in the carrying out of daily living tasks and require assistance in order to maintain their lifestyle. The confused and disturbed elderly, in particular, require more care and attention than a healthy oriented elder person. In this regard, respite care can play an important role in terms of reducing the carers' responsibilities and maintaining their physical and emotional strengths so that they can better provide quality care when the patients come back from respite care services^{1),4)}. Originally, respite care was developed to prevent burn-out caused by the family members' exhausting

care roles, and mainly focused on the families of developmentally disabled and mentally retarded individuals.

However, the needs of people with chronic mental illness and their carers, who are being overloaded by their caring roles have not been adequately explored⁵⁾. Moreover, little is known about actual effects of respite care specific to carers of individuals with chronic mental illness and only recently has the respite care model been extended to carers of psychiatric patients, indicating the need to develop research in this field. The study of respite care, therefore, has special relevance with respect to social policy in developing respite services for people with chronic mental illness. The purpose of this study is to describe the caring experience of families of people with chronic mental illness who are using respite care services.

Definition Of Terms

- Carers; those who have primary responsibility for the provision of care for people with chronic mental illness.
- Chronic mental illness; a significant level of mental disability as a result of a condition which continues over an extended period whether intermittent or continuous. For the purpose of this study, this includes schizophrenic disorders and dementia/Alzheimer's disease.
- Deinstitutionalization movement; public mental health policy in which mentally and developmentally disabled individuals are discharged from institutions and into community settings, thus reducing new admissions and treating people in these community settings.
- Respite care; within the field of mental health, any service or group of services designed to provide temporary periods of relief and/or rest for caregivers away from the patient⁶⁾.

REVIEW OF THE LITERATURE

The main elements found in the search of the literature included the

effects of family caring, the carers' needs, and the impact of respite care on the carers. The etiology, diagnosis and management of schizophrenia and dementia/Alzheimer's disease were not included in this literature review as the focus of the study is on the family members' experiences of caring.

1. Caring Effects and Carers' Needs

Research on the effects of caring on the carers of individuals with chronic mental illness is well documented in the nursing and allied literature of the last decade. The consequences of providing care are many and most studies discuss them with respect to carer "burden" and "stress"^{2),7),8),9),10)}. These articles suggest that the burden associated with providing care makes carers vulnerable to health and emotional problems. This evidence has begun to play an important role in developing respite care services¹¹⁾.

For instance, MacCarthy et al.⁸⁾ assessed the burdens and needs of the carers. Objective carer burdens identified were problems with own mental and physical health, restrictions on social life, housing problems, money worries, problems with children in the house hold, and unemployment. The needs of the carers were identified by standardized assessment in terms of respite care, separate residence, marital welfare, staff contact information and advice, emotional support, and child care. The most common needs of the carers identified were staff contact information and advice, emotional support, and respite care.

The findings from this study, which identified the restrictions on social life and problems with carers' mental health are also consistent with several other studies in this area¹¹⁾. Scharlach and Frenzel¹²⁾ pointed out the experience of being limited to in-home activity as the most common and severe burden of caring. Other dimensions of the burden of caring include depression^{13),14)}, guilt, and feelings of not loving enough, or not doing enough¹⁰⁾. In terms of the needs of the carers, DeAngelo¹⁵⁾ identified major needs of elderly family carers, which included intermittent respite care, financial and housework aid.

As evidenced by several studies^{16),17)}, social support has been discussed for buffering the pressures on the family that lead to burn out or stress. Carers who suggested they had enough social support were higher in well-being than those who reported requiring more social support. According to Robinson¹⁸⁾, carers of Alzheimer's patients tend to need social support at a time when social support may be low. Using self-help groups like Carers Association and ARAFMI (The Association of Relatives And Friends of the Mentally Ill), which supports carers with similar situations, also provides relief and normalization.

2. Respite Care Services

There have been various forms of respite services developed since its inception. The types of respite care can be distinguished by the location of service, which can be either in-home or out-of-home, and by the carer's purpose to use these services, for instance for a special family occasion, periodic holiday, or response to emergencies^{2),6)}. The effectiveness of respite care is controversial. Several researchers reported on the positive effects of respite care, such as relief of carers' burden, improved quality of life, and better relationships between carers and care recipients following respite care services^{12),19),20)}.

Conversely, other studies found that respite services made no statistically significant changes to depression, stress or burden of carers^{6),21),22),23)}. In a study conducted in Australia, Wells and Jorm²⁴⁾ used a randomized controlled survey that evaluated a special nursing home unit for dementia sufferers and compared it with periodic respite care in the community. The authors reported that after admission of the dementia sufferers to full-time care in a nursing home, the psychological problems of their carers were significantly reduced, whereas carers from the respite care continued to have a high level of psychological problems.

Studies conducted in America discussed the relationship between respite care and its effect on long-term institutionalization. Scharlach and Frenzel¹²⁾ noted some families used respite care as a transition from home

care to long-term institutionalization whereas Lawton, Brody and Saperstein⁶¹ reported that the respite care delayed institutionalization.

Among the studies reviewed, some interesting results were found. Although respite care services provided physical relief for the carers, some carers had feelings of guilt, loneliness and depression while the care recipients were away from home. These feelings were closely related to whether or not the care recipients agreed to using respite care services^{12),25)}.

3. Difficulties With Current Studies

From this preliminary review of literature, several knowledge gaps regarding respite care were identified. In spite of an increasing number of empirical studies that have attempted to evaluate the actual impact of respite care, the benefits of respite care are vague and controversial. This is largely because of the paucity of studies from which to generalize information regarding the effectiveness of respite care. Moreover, none of the studies investigated the actual experiences of caring for people with chronic mental illness who are using respite care services from the perspective of the carers. In order to grasp the practices of caring, qualitative research such as ethnography, phenomenology and grounded theory offers a perspective usually not accessible through traditional quantitative techniques²⁶⁾.

RESEARCH QUESTION

The research question asked was: How do carers experience the reality of caring for a relative with chronic mental illness using respite care services? This led the researcher to the use of phenomenological methods in order to seek an understanding of individual experiences and reflect on the meaning of respite care. The problem investigated for this study started with several anticipated questions which were reformulated during the data collection; What is it like caring for someone with chronic illness?; Does the experience change with time, under what circumstances?;

What are the consequences to the carers if there is a disagreement between them and care recipients about using respite care services?; How do the carers perceive the effectiveness of respite care through their experiences?; What are the carer's feelings while the care recipient is away on respite?

METHOD

1. Research Design

This research followed the design of a qualitative study using the Giorgi method, which is based on the philosophy of phenomenology. This exploratory qualitative study was designed in order to acquire experiential understanding of the phenomenon and to uncover the meaning of the phenomenon investigated. This was gained by interviewing carers of people with chronic mental illness who are using respite care services and are willing to share stories of their experience in a natural setting. The findings of this study were presented with a descriptive-analytical interpretation which provided an understanding of the phenomena. In order to clearly show the structural definitions of this phenomenon, the context and data samples of the study were confidentially included.

2. Population - Purposeful Sampling

The sample was drawn from carers of people with chronic mental illness who have been using a respite care service in the Hunter area, Australia. The subjects were carers of people who have been diagnosed as having chronic mental illness, which includes schizophrenia, major affective disorders, and dementia/Alzheimer's disease. The sites consisted of a community center, which mainly provides rehabilitation programs and one respite bed only to people with serious mental illness, and several nursing homes providing respite beds for people with dementia/Alzheimer's disease. The staff of the 'Residential Rehabilitation Team' and 'Aged Care Assessment Team', by which respite beds were arranged, were asked to distribute information and consent forms to the carers. Then, the carers

were asked to send the consent form back to the researcher if he/she wanted to participate. Approval was sought from the organizations to proceed.

Four carers consented and took part in the research. Those four participants were considered relevant for this study given the constraints of time, resources, and the relative inexperience of the researcher. Omery²⁷⁾ asserts that the importance of the phenomena is not established by the frequency of their occurrence, but rather by the selection of informants who can share information about their culture and by the researcher's judgement of the method. All participants were female and living with their ill relative at the time of the research. Of the four participants, three were daughters of the person with Alzheimer's disease and dementia, and one carer was the mother of a young son with schizophrenia. The average age of the carers was 53 years and the length of time they had been caring for their ill relative varied from six to ten years

3. Ethical Considerations

All subjects taking part in the study were fully informed of its purpose and assured that their anonymity would be maintained during audio-taping, analysis, and publication of the results. Also, the participants were advised of their right to withdraw any time and their right to refuse to answer any question without penalty in any way. This was achieved by gaining informed consent and return telephone calls from the participants.

4. Data Collection

Once the study protocol was reviewed and approved, the participants contacted the researcher by telephone and a brief explanation was given. An appointment was scheduled for interviews at a place and time convenient for the participants in a relaxed atmosphere. It is crucial to select the participants who have no objection to talking and describing their feelings and experiences because data can be directly affected by their willingness.

Data were gathered through semi-structured interviews and each carer was interviewed twice, lasting from 3/4 to one hour. Time spent before and after each session for warm up and on closure usually added another half an hour to the session. The interviews were tape recorded and transcribed verbatim. A copy of transcribed data was shown to the participants in following interview session for its completeness, with an invitation to make any deletions, additions, and/or corrections to increase validity of the data collected. The researcher also read each transcript to determine if any additional reflections or questions were required to add clarity or completeness.

Once the demographic data were solicited directly, the interview focused on the carers' experience in caring for their loved ones. It had been planned to include observation to see interactions between carers and care recipients at their home and respite care centers during their admission and discharge process. However, soon after the first interview, the researcher found that it was impossible to use observation because the participants were not able to make an appointment when their care recipients were at home and not all participants took their care recipients to the respite care service.

5. Data Analysis

Data analysis for this study focused on thematically disclosing the meanings of lived experiences from the participants' perspective through rigorous study of transcribed descriptions using Giorgi modification of the phenomenological method²⁸⁾. The analysis involved the following steps, which set forth the process of 'intuiting, analysing, and describing', with the description followed by clarifying uncertain meanings from the descriptions.

Firstly, the researcher listened to and read at least three times each participant's audio-tapes and their four verbatim transcripts, respectively, to acquire a feeling for them, and then went back to the participants for

elucidation of details.

Secondly, the meaning units in each transcript were differentiated and demarcated followed by a more refined level of differentiating the meaning units, which involved a process of identifying the underlying natural descriptive statements within the meaning units.

The next step was deciding which components of each participant's statement were relevant for each meaning unit. Redundancies in the units were eliminated and the relevant statements were regrouped, using direct quotes from significant statements. The three meaning units, demographic data, carer's perceptions on the nature of disability and relationships with family, were excluded from further analysis when they were compared with the original transcripts and the other meaning units as they assumed less importance. Some of them were, however, used for the description of the participants. Refer to Table 1.

Fourthly, each meaning unit was intuited and reflected on to disclose themes and transformed into concepts. Burden and perceptions of being a carer were put together, creating a theme *"Caring for a loved one"*. Four meaning units related to respite care: impact of respite on care recipients, carer's perceptions on respite, effectiveness of respite, and difficulties followed by respite, were considered closely interrelated and thus formed into one theme called *"Life saving break"*. The meaning unit, carer's concern and wishes, was subsumed into the meaning unit of *"Coping and managing"*. Perceptions on institutionalization and support from relatives and community were renamed *"Inevitability of institutionalization"* and *"Looking for support"* respectively when their context was carefully examined.

The last step was the integrating and synthesizing of the emerging themes that resulted in a complete description of the phenomenon. In addition, it was expected to communicate to other researchers about the findings and to validate each theme and its interpretation. However, this was not feasible due to the time limitation.

Table 1. Examples of regrouped meaning units and statements

MEANING UNITS	SIGNIFICANT STATEMENTS
Demographic data	"no, Greece. I've got an Australian husband" "J is the only one in my family who has the problem"
Perceptions of being a carer	"they come first before anyone else" "I can get very frustrated, especially when he has some idea and I can't move him"
Carer's perceptions on the nature of disability	"It's only the brain, she is a touch wood, she has been healthy, she eats very well" "one of those people you've got to break things to gradually"
Burden	"you've got to do everything" "it's tiring, fair bit to do, always something to do"
Impact of respite on care recipients	"she really didn't know whether she was here or there" "he likes that little bit of independence"
Carer's perceptions on respite	"break for mum away from us all the time" "came down and gave everybody time to get themselves back together"
Effectiveness of respite	"we've just done that little bit that we couldn't do that before" "felt refreshed and I'm ready to tackle it all again"
Difficulties followed by respite	"it took me a while to get back into action" "I used to have to keep my self busy to stop worrying about him being down by himself"
Perceptions on institutionalization	"I never wanted to have her in a nursing home" "just like him being in gaol or in something"
Relationships with family	"they miss out on a lot, but they understand" "he knows that's the best place for her"
Support from relatives and community	"I haven't got any family that I could turn to or get my support that way" "they are so far away system"
Carer's concerns and wishes	"more respite?" "The time will come when he is able to go out into the community"
Coping with difficulties	"I help a friend of mine as she has a shop" "the constant struggle to cope"

DISCUSSION OF FINDINGS

Each carer had a different life experience and lifestyle. Despite these differing experiences common themes did emerge in the examination of the interview data. Finally, five themes emerged from the data: *"Caring for a loved one"*, *"Coping and managing"*, *"Looking for support"*, *"Life saving break"* and *"Inevitability of institutionalization"*.

Caring for a loved one

Carers express various kinds of emotions in caring for a disabled relative at home for a long period. From the beginning until now, the carers have had a fear of the unpredictability and uncertainty of the disorder. They feel angry, frustrated, embarrassed and guilty that their loved one has that disability.

"Can't relax because you are never quite sure what's going to happen next".

"You can get all those emotional things, you try not to, but it's just built up".

Caring for a loved one at home leads to an unending list of problems, which includes overwhelming physical work for both care receivers and other family members, giving priority to the care recipients and family carers, and giving priority to the care recipient over the rest of the family as well as one's own life. It is clear that the carers have been continuously frustrated and stressed from recognizing that they are the only one who has full responsibility in caring for the disabled relative as well as having to run a home. From that they see themselves confronted constantly with negative choices in which decisions must be made with no desirable alternatives. These findings are virtually the same as the previous research on carers' needs and burden²⁹⁾.

"The one looks after them ends up worse than the ones cared for".

"They come first before anyone else and you couldn't go anywhere and couldn't do anything because there had to be somebody at home with mum".

This results in fear of own health breakdown, physically and mentally, and actually the carers have suffered from ill health and physical

disability. However, they give themselves self satisfaction or assurance that they have looked after their loved one for a long period of time.

"I feel good that I've looked after mum for that long".

As was suggested by Nolan and Grant²⁹⁾, for those carers their own needs have been almost entirely less important than their care recipient's and the carers express frustration at missing out and being unable to see any kind of future.

Coping and managing

There is a constant struggle to cope with seemingly everyday events. The carers have developed several ways of managing difficulties and coping with stress. For example, expressing their emotions by having a good cry or chat with a friend, changing their own environment and getting away from home for few hours, getting a casual job outside of the house, smoking, or going out with a close friend.

"It's just something to change me[my] brain a bit".

Learning to manage difficulties by experience is another way of managing, for example, switching off until the care recipient calms down and then having a conversation later on or keeping eye on the care recipient.

"You will learn to handle it".

Commonly, the carers take a difficult situation as it comes and try not to worry beforehand. They accept their situations by thinking that there are a lot worse difficulties or diseases than theirs or their care recipient's.

"I'll just worry about those things when it happens, treat all when it comes".

They also use a self defence mechanism, repression, to cope with stress by wishing for something which is virtually impossible to achieve, for example, hoping to get a cure for the care recipient, although they already know the disease is incurable.

"Hopefully the time will come when he will be able to come down and live somewhere full time".

Looking for support

Obviously, the carers feel overwhelmed by caring for their disabled family member and so they are constantly looking for support from their

relatives and from their neighbours or friends. The carers, however, do not expect much support from their family who are living together as the family members have already been in a difficult situation and have experienced many disadvantages due to their disabled member.

"They couldn't help, couldn't be here for 24 hours a day with us".

Major support provided by friends or neighbours is that the carers are able to talk about difficulties and problems with them, which is considered a kind of stress solving method. Each carer shows quite different perceptions in terms of degree of satisfaction with community health systems and/or self-help groups. However, what they are expecting from the health services is almost the same, for instance, getting easy access to services, staff's caring attitudes and receiving information from the health service team.

"Nobody there to advise to tell you what's going on".

"When it first happened there wasn't really a spot for him anywhere"

"They sent us out a special nurse to look after mum and dad, they are beautiful".

4. Inevitability of institutionalization

The carers feel bad that they are not doing their best as they have considered using a permanent nursing home or institution for their care recipient. However, when they come to terms with the breakdown of their own physical and emotional well-being and eventually reach the point that they can not manage or cope with the difficulties any more, they reluctantly let the care recipient go to a nursing home or similar situation. Decision making on using a permanent institution depends heavily on the health of both carers and care recipients, quality of service provided by the institution, other family member's opinions, and lack of support from others.

"I never wanted to have her in a nursing home, I wanted her to be here forever".

"As long as they are good, as long as I know that she's getting well looked after".

"She was happy there and I was happy then".

When they have to send their ill relative to an institution permanently, on the other hand, the carers feel relieved as they have long been waiting

for relief from the strain caused by caring responsibilities.

"I was in dream and it happened, time came, what a shock"

The theme of inevitability of institutionalization indicates that avoidance of institutionalization is not necessarily desirable and should not be regarded as a standard measurement of providing good care for their ill relative. A study by Dellasega²³⁾ also suggests that if admission to a permanent institution is desired, the decision should be respected, and both the carer and care recipient, then, prepared to cope with possible stressors caused by admission.

Life saving break

Using respite care services can be a life saving break for the carers. For the carers, respite care means "break" and "sanity". The carers express a great satisfaction with respite care provided and recommend any carers who are in a similar situation should use this service. After using respite care, the carers feel refreshed and ready to provide care again as they need the time to get back into the routine. It gives time to do things that they can not do while the care recipient is home, for example: going shopping, visiting friends, going on a holiday and so on.

"It's good for anyone looking after anyone's got this problem, they should go for respite, it does help"

"If you want to go shopping or go and visit friends that you never see for years then you can do those things"

In addition, one of the greatest positive effects of respite care expressed is the increasing independence and socializing effect on the care recipient.

"He gets to meet other people, which is the main thing, the socializing part of it"

The carers experience a guilt feeling that they have a rest or good time without their care recipient, but it is a temporary feeling as the carers think that they deserve that break. There is a strong indication of need to provide adequate information regarding respite care services. The carers feel strange and worry, in particular for the first time of their experience using respite care, due to simply not knowing about what is going to happen to their ill relative.

"I used to have to keep myself busy to stop worrying about him being down by himself"

"I started to feel guilty but then I thought, no, because I

deserved it to have that break and holiday"

Despite some minor problems caused by using respite care services, the carers strongly believe that there should be more respite care service available. Moreover, they perceive that without respite they would become exhausted to the point of illness and institutionalization of their care recipient might result.

"If they could have more respite it would be great, especially, for people that they have got to wait for years to get into a nursing home"

Respite is viewed as a necessary health care service to provide the carer with a period of restoration of strength. The findings related to this respite care are supported by many previous empirical studies that examined effectiveness of respite care, reporting carers' overall positive perception of the respite program⁶⁾. In addition, the findings suggest that, as Zirul, Lieberman and Rapp³⁰⁾ state, the decision to choose whether the care recipient should or will live at home relies upon the availability of comprehensive respite services including accessible residential options. Besides, according to a summary from the Group for Advancement of Psychiatry³¹⁾, which consisted of letters from readers with a mentally ill family member living at home, the family members expressed that their needs include receiving information related to illness, professional advocates and assistance in relation to using the community health system, and opportunities to share their guilt, confusion, and anger. Thus, it is crucial to inter-relate those needs with respite care programs in order to accomplish the goal of respite care for both the carers and care recipients.

LIMITATIONS

The findings from this study had several limitations in regards to the design, methodological credibility and subjectivity. In the phenomenological methods, the ability of researcher to conduct the study is crucial because the researcher plays the role as an instrument to collect and analyse data. The researcher, as a relatively inexperienced interviewer and person with a non-English speaking background and different cultural views, might have had an inadvertent affect on those informants with whom rapport and trust was sought, although the researcher's experience in interviewing techniques improved as experience was gained. The sample size was small

and a larger sample size would enable more comparison of cultural differences or different types of disabilities. The subjective nature of the study, which was focused on the carer's perspective and used only interview method, could be criticised, however, this criticism can be defended when considering the nature of phenomenological research^{32),33)}.

RESEARCH RECOMMENDATIONS

Further phenomenological studies need to be done with carers from other cultural background to provide a broader base for understanding the experiences of carers in using respite care services. Other areas of inquiry that arise from this study are: -a longitudinal study to elicit the experiences of carers over time would be valuable in observing the deterioration of the care recipient, the way the relationship is altered and the extent and intensity of involvement, a comparative study using a larger sample to look at men and women separately to discover how gender differences and how the different types of disabilities that the care recipient has alter their experiences in using respite care. It is recommended that further research be done to assess exactly what type of care is being provided and the effectiveness of these interventions in assisting carers to maintain their roles.

CONCLUSION

This qualitative study uses an exploratory descriptive approach to facilitate the discovery of how carers experience the reality of caring for a relative with a chronic mental illness and to gain an understanding of how nursing can best offer help. Based on what carers experience in caring for their loved ones at home and in using respite care services, it is necessary to provide acceptable, affordable and accessible respite care. The present study, in this regard, has added new understanding and carers' perspective to the nature and meaning of respite care experiences as well as their caring experience. The five themes from this study: "Caring for a loved one", "Coping and managing", "Looking for support", "Inevitability of institutionalization", and "Life saving break", go beyond the previously studied questions concerning degrees of family carers' burden and strain, which address the question of what happens to the family carer and

surpass the previous research simply focused on the degrees of effectiveness of respite care services.

It is considered important for nursing to discover the problems experienced by carers of people with chronic mental illness. By developing strategies to facilitate the use of outside resources to improve management of their relatives' illnesses and associated problems successfully, institutionalization, which is often the result of exhaustion of coping and tolerance levels may be minimized³⁴⁾. Providing a comprehensive and integrated knowledge regarding the nature of carers' experiences would expand nurses' understanding of the context of respite care and lead to the eventual improvement of nursing intervention for its health care consumers. Moreover, considering the growing population of people with dementia/Alzheimer's disease and the increasing public concern towards community health, educational and supportive respite programs for family members who assume responsibility for home care can benefit from knowledge of the carer's perspective on respite care portrayed in this qualitative analysis of their interactions.

This study offers beginning knowledge basic to interpreting the meaning associated with their experience. Therefore, the implication of this study is critical to contribute to developing community mental health nursing, because community nurses are in a key position to help design systems of care and, particularly from a nursing point of view, respite care can be regarded as a nurse initiated, psycho-educational intervention. Nurses can accomplish this by forming supportive relationships with the family to provide counselling, education, and encouraging informal supports in the neighbourhood.

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가족 간호 연구; 임시 위탁 간호 제도 이용에 대한 가족 간호자들의 경험

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> Abstract <

본 논문은 치매 혹은 정신분열증을 앓고 있는 환자를 간호하는 가족들 개개인의 관점으로 본 그들의 체험을 기초로 한 연구이며 오스트레일리아에서 실시되었다. 1970년대 중반부터 시작된 가정과 지역사회 중심의 간호는 국민들의 고조된 관심을 받아 왔으며 이것은 1960년대 말과 1970년대의 탈수용화 운동의 영향을 직접적으로 받았다고 할 수 있다. 현재 오스트레일리아에서는 많은 가족들이 노인 환자를 가정에서 돌보고 있으며, 지역사회 중심의 간호 제도는 이러한 환자들에 대한 가족들의 책임을 증가시키는 주된 요인이 되었다고 할 수 있다. 만성정신 질환을 앓고 있는 사람들은 일상생활을 해 나가는데 많은 제약을 받으며 그들의 삶을 유지하기 위해 도움을 필요로 한다. 특히 혼란에 빠져있는 정신장애를 겪고있는 노인들은 더욱 더 많은 관심과 도움을 필요로 한다.

이러한 점에서, 임시위탁간호제 (respite care service) 는 가족 간호인들의 장기 간호 역할로 오는 체력 소모를 감소시키고 그들의 신체적 정신적 건강을 유지하는데 중요한 역할을 해 왔으며 궁극적으로는 더욱 더 향상된 간호를 제공할 수 있다는 점에서 관심을 받아 왔다. 원래 임시위탁간호 제도는 가족 간호자들의 힘든 간호 업무역할로 인한 고초를 줄이기 위해 만들어졌으며, 주로 정신박약아와 정신지체를 갖고 있는 환자를 돌보는 가족들을 중심으로 발달되었다. 그러나, 만성 정신질환자의 가족 간호자들의 욕구는 무엇이며 특히 임시 위탁 간호제가 이들 가족 간호자들에게 실제적으로 어떤 영향을 미치는지에 대한 연구는 미약했다고 할 수 있다. 더군다나, 이러한 임시 위탁간호제는 그 중요성에도 불구하고 최근에야 만성 정신질환자들의 가족들에게 도입되어 이 분야의 연구의 필요성을 명백히 해 주고 있다. 본 연구의 목적은 이러한 가족 간호자 개개인이 임시 위탁간호제도를 이용할 때 얻어지는 간호 체험을 묘사하여 그 이해를 높이기 위함이다.

본 연구는 간호자들의 실제체험을 추출해 내기 위해 질적 연구 방법을 도입했으며 탐색적 묘사법으로 기술되어 졌다. 치매 또는 정신분열증을 앓고 있는 가족을 돌보는 4명의 가족 간호자들이 참여했으며 그들은 각각 2회에 걸쳐 인터뷰되었다. 인터뷰를 통해 녹음된 자료는 글로써 그대로 옮겨졌으며 참여자들의 경험을 묘사하

는 주제들을 반영하기 위해 현상학에 기초를 둔 Giorgi 방법에 의해 분석되었다. 만성 정신질환자들의 간호와 입시위탁간호제의 이용과 관련된 참여자들의 체험은 5개의 주제로 추출되었으며 그것들은 “사랑하는 가족을 위한 간호” (caring for a loved one), “적응과 대처해 나감” (coping and managing), “지지를 구함” (looking for support), “병원 수용의 불가피함” (inevitability of institutionalization), 그리고 “구조와 같은 휴식” (life saving break)으로 묘사되었다. 이 주제들은 만성질환이 가족들에게 미치는 영향에 대한 단순한 조사에 중점을 둔 기존 연구들의 결과에 한 단계 더 나아간 차원의 시각을 제시했다는 점에서 다르다고 볼 수 있으며, 또한, 본 연구를 통해 만성 정신질환자들 및 그 가족 간호자들을 위한 입시 위탁간호제도를 발전시키기 위한 정책과 관련지어 그 의의가 크다고 할 수 있다.