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ORIGINAL ARTICLE

Can Family Carer Groups Help People with Intellectual Disabilities? Applying Focused Ethnography Methods in Community Contexts of Northeastern Thailand

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ABSTRACT

Introduction: This study aimed to explore the experience of family carer groups caring for individuals with intellectual disabilities (IDs) in the community contexts of Northeastern Thailand. Materials and Methods: We applied a focused ethnography method with a purposive sampling technique to conduct 35 in-depth interviews (of 14 individuals with IDs, 12 caregiving parents and nine disability group leaders, respectively), which were audio-recorded and transcribed verbatim, then translated from Thai to English. We used content analysis to code the interviews and develop themes. To evaluate the reliability of the coding attempt, we employed data triangulation techniques. Results: Family carer groups seemed to provide benefit to people with IDs and their families by offering support related to information records, the recovery of health and occupational skills development. Conclusion: Family carer groups are an integral part of efforts to support people with IDs. Notably, these groups may facilitate the early formation of long-term parent carer plans, which can better optimise the care and health outcomes of people with IDs in Thailand.

Keywords: Family carer, Caregiving experience, Intellectual disability, Community context, Thailand

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INTRODUCTION

Family carers assume the key role of caring for people with intellectual disabilities (IDs) in Thailand today (1-2). However, Thai parent carers of people with IDs not only suffer from the effects of long-term caregiving but also need to cope the distress of people with ID. People with IDs require unique and/or comprehensive services related to health, personal circumstance, social relations, functional activities and community support (3). Individuals with IDs also need continuous assistance from a caregiver during daily living activities and when accessing primary health care and public facilities. Previous studies have suggested that people with IDs have distinctly poorer health outcomes, requiring a long time to recover their health, placing undue levels of stress both on the person with IDs and their parent or caregiver (4). Some scholars have contended that people with IDs show limited cognitive processes (e.g., memory, reasoning, rate of learning, ability to solve problems and perception) (5-7).

Researchers have reported that Thai individuals with IDs, such as children born with autism, experience developmental delays and are vulnerable to accidents, chronic illness and physical inactivity (1). A Thai survey suggested the common causes of IDs to be disease (30.07%), trauma during birth (19.51%), accidents (14.20%) and hereditary conditions (0.48%), with some cases having multiple causes (2.81%) (8). Increasing evidence indicates that people with IDs experience inequality in primary health care in terms of both access to it and the level of knowledge in family caregiving (3). A small number of studies have explored the experience of caring for Thai people with IDs from the perspective of parent carers, but the roles of family caregivers in meeting the needs of people with IDs are unclear. Based on previous studies, caregivers are critically important for the health and well-being of people with IDs (9), yet the experience of parent carers remains largely unexplored in Thai community contexts.

Many studies have focused on the roles of caregivers for people with IDs (3, 7, 10) at a national level (11), while fewer researchers to date have explored family carers (12) at the community level (13-15). To our knowledge, no study has yet investigated the caregiving views of parent carers in a community context. Our study adds to the literature on family carers of people with IDs (2, 16–18), as it is only recently that family carer groups of people with IDs have been described (19).

Although the body of literature concerning family carer groups of people with IDs is growing, the caregiving experience in Northeastern Thailand has not yet been explored. The present study specifically focused on people with IDs (7), family carers (19) and issues related to developmental delay (6). Through this study, we aimed to address the gap in the literature on family carer groups for Thai people with IDs by applying focused ethnographic methods in the community contexts of Northeastern Thailand. The research question guiding this study was the following: How do family carer groups help people with IDs in Northeastern Thailand?

MATERIALS AND METHODS

Design and setting

A focused ethnographic method was applied to explore the experiences of family carer groups for Thai people with IDs in Northeastern Thailand. We applied this method because we sought to answer a distinct question in a specific context (20) and this approach allowed us to integrate the pluralistic nature of family carer groups. Past studies have described focused ethnographic methods as the 'work of describing [the] context' related to a 'process of learning about participant experiences' to gain in-depth reflection (21). Specifically, this method facilitated reflection on issues and factors related to participants' experiences of caregiving, parent carers, group creations, health information and community carers (22).

The setting of this study was the Nakhon Phanom province in Northeastern Thailand. We recruited parents of people with IDs, focusing on the community context. Study participants belonged to different caregiving groups that addressed needs related to access to primary care, health services, public health, nursing and community care. Moreover, this study focused on the family roles, member support and acceptance, which can be explored through in-depth interviews using content analysis.

Sampling and participants

This study applied a purposive sampling method (23) to identify family carer groups of Thai people with IDs. A purposive sampling technique enabled us to validate a selection of group representatives at the community level (24). For this reason, we purposively selected 35 participants within the following four groups: (i) people with IDs, (ii) parents of individuals with IDs, (iii) ID group leaders and (iv) the public ID department. Tables I, II and III present the characteristics of the participants of this study.

In-depth interview questions

Face-to-face in-depth interviews lasting 30 to 40 minutes were conducted between 2019 and 2020 at the participants' home addresses. All interviews were conducted in Thai and transcribed, then translated into English. Participants were asked to reflect on their experiences with family carer groups for Thai people with IDs. The researchers used open-ended questions, such as 'can you describe your experience?' and prompting 'how' questions, being careful not to interrupt the participants when they replied (Table IV).

Table I: Study participant information (people with IDs)

No.	Sex	Age (years)	Cause of ID	Level of ID self-reliance		
				Mild	Severe	Profound
ID1	Male	30	Down syndrome	●		
ID2	Female	39	Developmental delay	●		
ID3	Male	6	Developmental delay			●
ID4	Male	40	Accident disability		●	
ID5	Male	2	Down syndrome			●
ID6	Male	8	Brain disability at birth			●
ID7	Male	60	Developmental delay		●	
ID8	Male	63	Developmental delay		●	
ID9	Male	27	Rubella in pregnancy			●
ID10	Female	20	Developmental delay		●	
ID11	Male	29	Developmental delay	●		
ID12	Female	2	Developmental delay			●
ID13	Male	20	Developmental delay	●		
ID14	Male	15	Brain disability at birth			●

N = 14, ID = intellectual disability

Table 2. Study participant information (parents or family members of people with IDs)

No.	Sex	Age	Parenting duration (years)	Relationship		
				Role	Functional care	Health problem
PD1	Male	63	30	Father	Protecting from accidents	No
PD2	Female	68	39	Mother	Protecting from accidents	Diabetes
PD3	Female	30	6	Mother	Living activities	No
PD4	Female	62	40	Mother	Living activities	Diabetes
PD5	Female	43	2	Grandmother	Living activities	No
PD6	Female	58	8	Grandmother	Living activities	Anaemia
PD7	Female	42	6	Grandchild	Living activities	No
PD8	Female	60	10	Sister-in-law	Cooking	No
PD9	Male	46	27	Mother	Living activities	No
PD10	Female	58	20	Mother	Living activities	No
PD11	Female	33	19	Mother	Living activities	No
PD12	Male	68	12	Grandfather	Living activities	No

N = 12, PD = parent or relative of the people with IDs

Data analysis

The details of the 35 in-depth interviews were analysed using content analysis (25). First, our research team developed a coding schedule. In this stage, we remained open to all constructs for initial coding. Secondly, we

Table III: Study participant information (group leader for people with IDs)

No.	Sex	Age (years)	Role	Characteristics of intellectual disability care
RD1	Male	44	Leader of intellectual disability centre	Coordinating networks, design and activity
RD2	Female	56	Leader of intellectual disabilities centre	Coordinating networks, design and activity
RD3	Male	48	President of intellectual disability association in Nakhon Phanom province	Seeking occupational skills, training, development and promotion for family of person with ID
RD4	Female	32	Private supporter	Supporting ID therapy, training programme
RD5	Female	55	Director of special education centre	Supporting facility for joint groups of families with ID members and funding
RD6	Male	45	Director of intellectual disabilities in Nakhon Phanom province	Supporting ID activities
RD7	Male	38	Director of social welfare organisation	Supporting ID activities
RD8	Female	48	Occupational nursing	Supporting health information, health literacy and first aid care
RD9	Female	58	Villager	Promoting ID activities

N = 9, RD = representative of disability group leaders

Table IV: In-depth interview questions

Order	In-depth open-ended interview questions	Main themes
IIQ1	Can you describe your experience when you joined the ID groups?	Joining group
IIQ2	Can you describe your experience in collecting your ID information records?	ID information records
IIQ3	Please describe how you recovered health of people with IDs?	Recovery of health
IIQ4	Please describe how you promoted occupational skills development among people with IDs?	Occupational skills development

shortened, synthesised and integrated initial categories into developing themes. Thirdly, we quoted verbatim statements related to themes, such as personal attributes, which were identified to develop coding for preconception. Finally, we selectively coded a list of statements from participants that reflected the concept of family carer groups of Thai people with IDs.

Data validity, reliability and triangulation

Content analysis was conducted following the four-step procedure to analyse complete in-depth interviews (26). The participants were assigned to one of three ID groups: individuals with IDs, parents or relatives of a person with IDs and ID group leaders or public sector service providers (ID1-14, PD1-12 and RD1-9), as seen in Tables I, II and III, for the process of data collection. After coding was completed, another review of the data was conducted to identify differences in the dataset based on occurrence rates of the various codes. To evaluate the reliability of coding, we employed data triangulation techniques, which reflects the origins of the term we denoted and what it should connote (27). The data triangulation method used inter-coder reliability to assess the reliability of the qualitative data, and we summarised how well coders agreed with each other when applying codes to the data (28).

Ethical considerations

Ethical approval was obtained from Nakhon Phanom University and followed guidelines outlined in the Declaration of Helsinki, the Belmont Report, The Council for International Organizations of Medical Sciences (CIOMS) guidelines and the International Conference on Harmonisation of Good Clinical Practice (REC of Nakhon Phanom University Reference No. HE05/63). Ethical approval was granted for the protocol 'The Disability Care Centre for Caregivers of Temporary Handicapped Persons in the Context of the Operation of Parents, the Mentally Handicapped, Nakhon Phanom Province'. All participants signed a consent form before participation after the researcher assured them that their responses would be kept confidential and that their identities would not be disclosed in the study reports. Participants were identified by numbers assigned chronologically.

RESULTS

The 35 interviews focused on the research question 'How do family carer groups help people with IDs in Northeastern Thailand?' Four themes were identified in the content analysis of the data: joint groups, ID information records, recovering health and occupational skills development. Table V provides a summary of example quotations and their respective codes and themes.

Joint groups

Participants reported that they had joined carer groups to access community support, member profits, health information and public collaborations. People with IDs illustrate the experience of the joint ID group of parent carers in community contexts. Participants also stated:

There is no one can refuse to join our ID groups of parent carers. You know, it is the only way we can learn how to take care of our members with IDs. If we join, they provide support for long-term care, treatment and caregiving for both physical and mental health. (PD3; ID4)

Becoming a group member is very useful to learn about health information, health literacy and public support. At first, we created our group because the public sector provides support to all members. Nowadays, we can help them; we learn how to help them through long-term caregiving. (PD10; ID10)

For our parent carers in the community, because we

Table V: Example quotation, codes and themes

Quotation	Coding	Theme
When we first created our group, we only had 10 families, but in the last five years 41 members have joined our group to help support people with IDs, health literacy and community participation. (RD2; ID3)	Group creation	Network creation
In our group, we collected all the information related to people with IDs, attributions for planning family care, type of ID and family environment. (RD3; RD5; ID11)	ID attribution	ID information record
The purpose of the ID group is to support our members by participating in social events, saving money, exchanging local products and selling, developing occupational skills and earning incomes. (RD9; PD9)	Group purpose	Group support
Our ID centre provides help to cover ID health development, physical therapy, social events and community activities. This centre is not only for the recovery of health and development, we also promote parent carers in social events, public collaboration and health care information. (RD6; RD7)	Health activities	Recovery health
"Our group was supported by the public sector of occupational skills training, seeking funding to support all members and promote the participation of people with ID in the community and employment. (RD4; RD8)	Training people with IDs	Occupational skills development

have no experience with how to take care of people with IDs, if we join the group, they support us in the long term. (PD6; ID14)

When we joined the groups, they helped us manage the stress [and facilitate] understanding [of] how we can live with them. If we aren't here, we would have to put our IDs somewhere; it is not social care. (PD1; ID7)

ID information records

We asked the participants how they collected their ID information records. Based on the data, we identified three themes: personal attributions, family care planning and types of IDs. The participants explained:

Our group has come up with the idea of personal attributions – these are very significant databases for our group and its members. This is because personal attributions can identify the characteristics of disabilities for nursing, health information and public support. (PD11; ID5)

If we have recorded all personal information, this may relate to the planning of family care in the long-term database. It is an important process for caregiving; it helps us know when to go to the hospital [and] how to plan care and recovery [of] health. (RD1; ID12).

Recovering health

Some participants suggested that family carers are important for recovering the health of people with IDs following their hospitalisation for medical problems. The participants highlighted the benefits of stimulating health development, undergoing family carer training and learning physical therapy. Some relevant quotes of participants are included as follows:

The primary parent carer is important for [the] recovery [of the] health [of the individual with IDs]. In our group, we focused on physical health first and then stimulated health development second. It is a nice way [to develop] caregiving experience for [the] parent carer, public facility and centre support. (PD5; ID1)

[The] recovery [of] health is a very important process for both parents and [the person with] IDs. You know, in our group, there are different ages and physical conditions. We adopted two processes: first, to recover after hospitalisation for medical reasons and, second, to provide caregiving [for] the long-term recovery [of] health in the family. (PD8; ID9)

Of course, it is a good thing to promote [heath] recovery [and] development. We use recovering health in clinics, hospitals and the family. This method can help us reduce physical and mental stress. (PD12; ID13)

In our group, recovery [of] health is not only [done] after hospitalisation; we [also] provide support to caregivers in social events and activities and promote occupational skills. (ID6; PD2)

Occupational skills development

Through family carer groups, the leader and the director of the ID provincial office believed that occupational skills development could assist long-term family carers. The participants agreed that concepts for occupational skills development of people with IDs would be improved, including skills training, job funding and hiring of parents of individuals with IDs. These benefits are illustrated by the following statements of the participants:

Occupational training is an important element in the way we develop our ID skills and self-reliance. It can improve skilled labour, increases their earning income, assists long-term career development and helps parent carers. (PD7; ID2; RD1)

Our group was supported by the public sector, occupational department and the private sector. They supported the job funding, training and labour skills for people with IDs to help themselves by earning incomes. (PD9; ID11; RD3)

Having support there all the time, they supported not only ID health but [also] hired parents with IDs to take care of their sons and daughters. For instance, in our group, parents of individuals with IDs were supported in developing an alternative career, such as producing handicrafts, cooking and [performing] home-based *work in the community*. (RD3; PD4; ID8)

Overall, our findings illustrate the importance of family carer groups (e.g., network creations, social supports, member benefits and health collaboration). These results also suggest that such groups provide vital assistance in terms of ID information records associated with ID personal attributions, family care planning and physical disabilities. Similarly, recovering the health of people with IDs, such as after hospitalisation, was enhanced by being a part of a family carer group. Finally, occupational skills development related to skills training, funding jobs and hiring parents of children with IDs may foster family caregivers in community contexts.

DISCUSSION

This study aimed to explore the experiences of family care groups for Thai people with IDs in community contexts in Northeastern Thailand. Our study shows that family carer groups can help to improve the long-term caregiving of people with IDs through offering the benefits of joint group networks, ID information records, the recovery of health and occupational skills development. This finding is supported by previous studies on IDs and the recovery of health (13, 29). Family carer group networks increase community support, public sector service provision and the health of people with IDs. Our findings also indicate that family carer groups can support access to health information records, health literacy, the recovery of health and occupational skills development.

We found that family caregivers of people with IDs who join caregiving support groups attain greater access to health information and public support. This benefit has also been confirmed in studies focusing on caregiving aspects related to work (16), informal caregiving experience (30), member support and maternal networks (14). This finding supports the work of (19), who point out that family carers may suffer both negative and positive outcomes when caring for a person with a chronic disability. Some scholars have discussed how group creations can foster well-being for the family carer, connection with public support and caregiving literacy (17). Our study found that family group creations encourage community support and social activities, which can help people with IDs.

Our study illustrates that carer groups facilitate access to ID information records associated with ID personal attribution, family care planning and physical inactivity. This finding is consistent with the study of (11), who indicated that national, community and individual records – which include ID data, care planning and ID systems – are important for future care planning. Some studies (31–33) noted that handheld health records for personal attributions can help in the recovery of health, evaluation, acceptability and care of people with IDs. Other studies (6, 11) also showed that ID medical records and precise preventative intervention for both family carers and caregivers.

We found that the recovery of health for people with IDs was correlated with medical caregiving and long-term family caregiving. This finding supports the work of (15) and (7), who illustrated that family carer groups for people with developmental delays can enhance the long-term recovery of health. Previous research (34) has suggested that the recovery of the health of people with IDs requires the involvement of supportive family carers who can address health-related conditions. It is important that family caregivers are linked with public health care support after hospitalisation therapy to improve the long-term recovery of the health of people with IDs. This finding is consistent with that of a previous study, which found that the recovery of health was aided by forensics, professional caregiver support and health care services (7).

Our study suggests that occupational skills development can help people with IDs through family caregivers. This finding supports the work of (35), who illustrated that improving the occupational skills of people with IDs increases family incomes, access to jobs and social welfare. In line with a study showing that people with IDs can develop job skills (36), our investigation found that occupational training, funding and access to jobs can help people with IDs. More recently, researchers have suggested that occupational skills development can help individuals with IDs and their families to learn new worker skills (37,38). Hence, by employing a focused ethnographic method to explore caregiving experience (39), our study highlights that family caregiving is an integral part of supporting people with IDs.

Importantly, this study is not without its limitations. First, this study conceptualised family carers and the caregiving experience for people with IDs for operational data collection. Second, the current study only applied focused ethnographic methods with in-depth interview questions. Third, qualitative data analysis was performed using content analysis for coding, categorisation and themes. Fourth, the findings of this study may not be generalisable to other contexts. Future research could explore the caregiving experience in greater depth by defining a theoretical framework, measuring variables and testing hypotheses in a larger study sample. To do this, however, researchers may need to create a reliable instrument for the development and validity of a family caregiving scale for people with IDs to provide more valid findings.

CONCLUSION

In conclusion, this study elaborated on the experiences of family carer groups for people with IDs in Northeastern Thailand. Our study aimed to answer the following question: ‘How do family carer groups help people with IDs in Northeastern Thailand?’ We concluded that family carers associated with a caregiving group benefit from ID members, profits, health information and public collaborations. Findings demonstrated such groups also supported access to ID personal attribution records related to personal attribution, carer planning and identifying ID physical health characteristics. This study highlighted that the recovery of health can help people with IDs after hospitalisation for medical problems and long-term health issues. We found that occupational skills development can help people with IDs improve their skills training, funding and access to jobs.

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