

行政院國家科學委員會專題研究計畫 成果報告

參與早期療育之發展遲緩兒主要照顧者生活品質相關因素探討

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摘要

本研究目的在探討遲緩兒主要照顧者的壓力及生活品質，研究設計方面，同時應用量性及質性研究方法設計，量性方面採用橫斷式相關研究設計，以方便取樣方式取的樣本共 116 位，質性方面，則以立意取樣取得樣本共 20 位。結果發現，家庭收入與生活品質有顯著關係，社會支持則與生活品質及壓力顯著相關。對一個家庭來說，照顧發展遲緩兒是一項挑戰，未來可針對主要照顧的需求及需求來源做進一步的探討，以此可提供這些家庭更具體的幫助。

關鍵字：發展遲緩，主要照顧者，早期療育，生活品質

Abstract

The purpose of this exploratory study was to assess strain and quality of life among primary caregivers of developmental delayed children. This study used both quantitative and qualitative methods. In the quantitative part of the study, a cross-sectional, correlational design was used. A total of 116 participants were recruited through a convenience sampling procedure. The qualitative part recruited 20 participants using purposed sampling. Results of the study showed that family income was related to quality of life. Social support had strong relationships with quality of life, and with caregiver's strain. Taking care for the children with developmental delay is a challenge for a family. Further studies that focus on the caregiver's needs and available resources in the society can offer more practical solutions in helping these families.

Key words: developmental delay, primary caregivers, early intervention, quality of life

Background and Significance

Raising a child with developmental delay is a great challenge for a family. Although services from medical, education, or welfare systems may offer some assistances to developmental delayed children and their families, these children are primary living at home, and their families take most responsibilities in taking care of them. Most of studies that related to children developmental delays emphasized the outcomes of the children. Little research has focused on the children's caregivers. As the family-centered care has become one of core concepts in early intervention, nurses in the early intervention team should not disregard the children's primary caregivers' needs.

Developmental delay is defined as "The child with retarded development means the child who are allegedly or expected abnormal development in respect of cognitive development, physiological development, language and communication development, psycho-social development or self-governing skills that have been judged and confirmed by the accredited medical institutes under health authority" (Children's Bureau Ministry of Interior, 2004). The number of developmental delayed children had been increased from 9299 in 1998 to 13231 in 2003, and a total of 12442 children with developmental delays were recruited under case management system at the end of 2003 (Ministry of Interior, 2004). The early intervention is a multi-disciplinary service that is governed by local and central authorities. A total of 24107 children with developmental delays received early interventions in various institutes in 2003 (Ministry of Interior, 2004).

Benefits of early intervention in children with developmental delays have been well documented in literature. However, little has known about caregivers of children with developmental delays. In considering issues related to caregivers of children, most studies in Taiwan were focused on children with cancer (Chiang, 2002; Chiang & Lo, 2002; Hsu, 2003; Lee, Gau, Tseng, & Lo, 2000) or with asthma (Chiang, 1999; Gau, 2003). Studies that have emphasized the caregivers of children with developmental delays pointed out the caregivers', majority of them were mothers, difficulties and strains in taking care of their developmental delayed children (Chen, 2003; Chiang, 1999; Hsu, 2002; Tsai, 2003). Nevertheless, none of these studies had examined the caregivers' quality of life. To sum, quality of life among caregivers of children with developmental delays may be affected due to their participating in caregiving roles. In addition to the delayed children's needs, health care providers should also extend their considerations and services to these children's primary caregivers.

Research Purpose

The purpose of this exploratory study was to assess strain and quality of life

among primary caregivers of developmental delayed (DD) children. Further, the study also examined relationships between caregivers' strain and quality of life, and correlated factors, namely, children's number of types of delay, frequency in therapeutic programs, caregiver's demographic characteristics (age, education, income, employment status), and perceived social support. The figure illustrates the relationship between quality of life and strain, and the identified study variables. In addition, a qualitative research method was used in order to understand the caregivers' lived experiences. The research questions were:

1. What is the quality of life of primary caregiver's with developmental delayed children?
2. What is the strain of primary caregiver's with developmental delayed children?
3. What is relationship between the types of delay and the caregiver's quality of life/strain?
4. What is relationship between the frequency in therapeutic programs and the caregiver's quality of life/strain?
5. What are relationships between the caregiver's demographic characteristics and his/her quality of life/strain?
6. What is relationship between the caregiver's perceived social support and his/her quality of life/strain?
7. What is relationship between the caregiver's quality of life and strain?
8. What are the lived experiences of primary caregivers of developmental delayed children who are enrolling early intervention programs?

Literature Review

Early Intervention and Caregivers

A child's developmental delay is problematic because it affects not only the child, but also the whole family, and further increases economic burdens for a society. Studies have shown that early intervention services were benefits to developmental children in terms of language abilities (Hsu, Lee, Kuo, & Liang, 1996; Smith, Groen, & Wynn, 2000), behavior problems (Matsuishi et al., 1998; Smith, et al., 2000), intelligence (Blair, Ramey, & Hardin, 1995; Ramey, & Ramey, 1998; Smith, et al., 2000), and social skills (Goodman, 1994).

Since most of developmental delayed children are living at home, their families, especially parents play an important role in caregiving. However, results of involving parents in early intervention are complicated. Beelmann and Brambring (1998) reported that using different types of parent involvements, such as co-therapist and parent counseling, could implement the successful of interventions. Similarly, in a qualitative study of interviewing 9 pediatric occupational therapists, participants highly valued parent-child relationships and commonly focused on these relationships

in therapies (Mayer, White, Ward, & Barnaby, 2002). Meanwhile, these therapists also indicated that the early intervention services facilitated the parent-child relationships. Other studies also revealed that early intervention services increased parents' perceived well-being (Hendriks, De Moor, Oud, & Savelberg, 2000), and released family's burden of economic (Huang, 2001).

However, the early intervention services also increased challenges for parents. For instance, Leiter's (2003) study showed that not all mothers were willing to add the therapeutic care to their roles as parents even they actually did therapeutic work with their children. In Huang's (2001) study, participants felt anxious because they were not clear about the real purpose of early intervention. To sum, caregivers' may experience both positive and negative feelings about early intervention services. Further studies are needed in order to have a better understanding about the caregivers' point of views about early intervention.

Studies Related to Caregivers

Many studies have examined informal caregivers' needs in terms of their roles in providing care. Support is the most common need that caregivers mentioned (Chiou, Hsu, & Wu, 2003; Hsu & Chiou, 2004; Kuo, Lin, & Lee, 2003). Studies that assessed the caregivers' social support also found that social support had significant relationships with caregivers' family function (Lin, Ou, & Wu, 1997; Shin, & Tam, 1996), with feelings of burdens (Kao, Lu, Yeh, & Liu, 1999; Liu, Hwu, & Lee, 1998), and depression (Tsai, 2003). In addition to social support, caregivers' also identified the needs of economics (Chen, 2004; Chiou, et al., 2003), information resources (Chen, 2004; Chiou, et al., 2003; Hsu & Chiou, 2004; Kao, et al., 1999), and professional interventions (Chen, 2004; Hsu & Chiou, 2004).

Burden was a common variable that researchers have focused in their studies of informal caregivers. In a study of caregivers of stroke patients, Liu et al. (1998) found that the caregivers' levels of education, their own health status, economic status, and the relationships with patients were related to their feelings of burden. Later, a longitudinal of 41 caregivers of metastatic cancer patients, the researchers also found that factors related to caregivers' burden included patients' illness status, caregivers' ages, levels of education, incomes, and periods spending in caregiving role (Hu, Chen, Chen, Lin, & Lin, 2001). Results of another earlier study identified 5 factors related to caregivers' burden, namely, family function, patients' status, caregivers' health, social support, and number of persons involving in the caregiving role (Kao, et al., 1999). To summarize these studies, factors related to caregiver's burden were caregivers' demographic characteristics such as age, education, economic status, health, the care receivers' (patients) illness status.

Caregivers' Quality of Life

Quality of life, is another concept that has been examined in many studies related to caregivers. In fact, in a study of 243 caregivers of dementia patients, Cheppell and Reid (2002) suggested that research may emphasize the caregiver's quality of life instead of burden. Haas (1999) performed a concept analysis of quality of life. Accordingly, the concept "quality of life" was defined as "a multidimensional evaluation of an individual's current life circumstances in the context of the culture and value systems in which they live and the values they hold. QOL is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions." (p. 219)

The relationship between patient's health status/illness status and the caregivers' quality of life has been well documented (Boling, Marcrina, & Clancy, 2002; Erickson, et al., 2002; Gau, 2003; Murphy, Fitzpatrick, Cruz-Rivera, Miller, & Parasuraman, 2003). Although studies have shown that qualities of life among parents with chronic diseases children were lower than those parents without sick children (Gau, 2003; Guethmundsson, & Tomasson, 2002). Some caregivers showed positive changes in quality of life while participating in caregiving's roles (Bond, Clark, & Davies, 2003; Yamamoto-Mitani, et al. 2004).

In conclusion, literature has shown that families of children with developmental delays had faced challenges in their life. These informal caregivers' quality of life may be affected by playing the caregiver's role. Factors related to the quality of life among caregivers of developmental delayed children need further study.

Research Method

Design

This study used both quantitative and qualitative methods. In the quantitative part of the study, a cross-sectional, correlational design was used to study levels of quality of life among caregivers with developmental delayed children. Further, relationships between caregivers' quality of life and strain, and related factors were explored. These factors include the child's status (degree of developmental delay, length of attending early intervention programs), the caregiver's demographic characteristics (age, education, income, employment status), and perceived social support. In addition to analyses of descriptive data, correlation and regression statistics were used in analyzing relationships among variables.

For the purpose of understanding the participants' lived experiences, a phenomenological method was used for the qualitative part of this study (Creswell, 1998). The researchers conducted semi-structured in-depth interviews by asking participants two open-ending questions. First, what was your lived experience being a primary caregiver for a developmental delayed child? And what was your lived experience that your child attends early intervention program? Participants' responses to

these questions were recorded using tape recorders (or digital recorders), and then were transcribed into written materials for data analyses.

Population and Sample

The population of this study was primary caregivers of developmental delayed (DD) children who were enrolled in early intervention programs in middle Taiwan. A convenience sampling procedure was performed in the first step (collecting quantitative data). In addition to 30 participants joined the pilot study, 126 subjects agreed to participate the study. Ten of them were eliminated due to much missing data. Thus, a total of 116 participants' responses were used in the study. In the second phase of the study, the qualitative data collection, a purposive sampling procedure was used to recruit participants. A total of 20 participants were interviewed.

Instrument

The study used self-report written questionnaires to collect quantitative information. The questionnaire included 3 scales and demographic information sheet. These 3 scales were: Quality of Life (QOL), Social Support (SS), and A Short Form of Questionnaire on Resources and Stress (QRS).

Demographic Information

Questions in this section covered two parts, the primary caregiver's and the developmental delayed child's information. The caregiver's demographic data included age, education, marital status, number of children, the relationship with the child, time spent in taking of the child, employment status/working hours per week, personal and family income, and family structure. The major information related to the child was the types of developmental delay, types of therapy were taking, the frequency of therapies, and the travel time for taking therapies.

Quality of Life

The participants' quality of life was measured using World Health Organization Quality of Life – Brief Form (WHOQOL-BREF) Taiwanese version, (台灣版世界衛生組織生活品質問卷簡明版) (The WHOQOL-Taiwan Group, 2004). The scale includes 28 questions that cover 4 domains, physical health domain, psychological domain, social relationships domain, and environment domain. Each item has a score range of 1 to 5. The range of total score is from 28 to 140. High scores indicate high quality of life. The coefficient alpha of the WHOQOL-BREF Taiwanese version was .91 (The WHOQOL-Taiwan Group, 2004). In this study, the coefficient alpha was .84.

Social Support

In the study of caregivers of dementia elder people, Tang (1991) developed a Social Support scale including 3 components (physical, emotional, and informational support), a total of 16 questions. The current study used a 20-item SS scale which was modified by Chen (2000). The subjects were asked each question in three domains, levels of needs,

levels of sufficiency, and resources of supports. Each question had a score range of 0 to 4 in the levels of needs and the levels of sufficiency. A higher score indicated a higher level of social support. In a study of 127 mothers with mental retarded children, Tsai (2003) reported a coefficient alpha of .91 in the sufficiency domain of the Social Support scale. The current study revealed a coefficient alpha of .94 for the domain of needs, and .92 for the domain of sufficiency.

Strain

Huang (1999) developed A Short Form of Questionnaire on Resources and Stress (QRS) to assess resources of stresses among mothers with disable children. The original scale included 48 items. This study used QRS that modified by Lin (2004) to assess the primary caregiver's strain in taking care of her/his DD child. The modified QRS had 52 items that classified into 5 subsets. Each item had a score range of 0 to 4. The range of total score is 0 to 208. A high score indicates high level of strain. The coefficient alpha in Lin's (2004) study was .95, and was .96 in this study.

Ethical Concern

After the potential participants agreed to join the study, the investigators would contact with the participants and explain the purpose of the study to them. Meanwhile, an information letter with a written consent form was given to the participant. The consent form included information related to the study and the rights of the participants, such as a statement that the potential participants may decide not to complete the questionnaire; a statement about confidentiality; and a statement that a decision not to participate will not affect the potential participants' relationships with the early intervention programs where they are enrolled. In addition, in order to protect the participant's privacy, the questionnaire would not include the name of the participant and the child.

Result

Quantitative

Demographic Information of Participants

A total of 116 primary caregivers joined the study. The ages of them from 23 to 62, with an average age of 34.03 ($SD=5.84$). Most of them were female (male=9). Table 1 shows the demographic characteristic of participants. The average age of the DD child was 54.2 months ($SD=14.17$) with a range of 12 to 72 months. Other demographic characteristics of the child are shown in table 2. Among 116 children, 32 of them had one type of development delay. Most of them ($N=21$) were language development delay. Nineteen children had two types delay, mainly ($N=12$) were language combined with cognizance delay. Twenty-nine had three types delay, 12 of them combined motor, language, and cognizance delay. Thirteen children had four types delay, and 23 had 5 types delay.

Descriptive Analysis of Quality of Life, Strain, and Social Support

The average score of quality of life was 82.2 ($SD=12.46$), with a range of 50 to 125. The mean score of the strain was 85.12 ($SD=33.33$), the highest score was 163 and the lowest was 13. In terms of social support, the average score of the need was 49.54 ($SD=12.65$), and the score of sufficiency was 36.94 ($SD=11.26$).

Factors Related to Caregivers' Quality of Life

There is no significant relationship was found between the caregivers' quality of life and children's number of types in developmental delay ($F=1.34, p=.26$), and frequency of therapies ($F=.30, p=.91$). In consider the caregiver's demographic characteristic, no significant relationships were found between the quality of life and age, education, and employment status. However, the caregiver's quality of life was different when taking family income into account ($F=3.68, p<.05$). In addition, quality of life was significantly related to the caregiver's social support, both levels of needs ($r=-.31, p<.05$) and levels of sufficiency ($r=.40, p<.05$). Further, the caregiver's quality of life was correlated to the strain significantly ($r=-.48, p<.05$).

Factors Related to Caregivers' Strain

Results of the study show that the caregiver's level of strain was significant related to the child's number of types of delay ($F=9.49, p<.05$). There is no significant relationship between strain and the frequency of therapies. In considering caregivers' demographic characteristics, no significant relationships were found between strain and education level, employment status, and family income. Interestingly, the caregiver's age had negative relationship with the strain ($r=-.22, p<.05$). Means, the older age the caregiver was, the lower strain she/he had. Significant relationships were found between strain and social support, both the level of needs ($r=.57, p<.05$) and the level of sufficiency ($r=-.43, p<.05$).

Qualitative

Twenty primary caregivers participated in the qualitative study. Except one participant was the DD child's father, all others were mothers. Ages of these participants were from 24 to 46 with an average of 33.9. A total of 20 transcriptions were collected from in-depth interviews. Nine major themes were generalized from the informants' descriptions of their experiences and feelings. They are:

1. Feel guilty for the child's delay and did not begin therapies in the first place.
2. Reorganize family structure and family roles.
3. Preparing for the child's future life.
4. Living space and time become limited and lack of flexibility.
5. Help families and the child to adjust unusually concerns from society.
6. Want to learn knowledge of early intervention and assistant skills.
7. Feel sorry but still actively arrange therapies for the child.

8. Adjust the shortage of family economic.
9. Actively looking for friendly education environment.

Discussion

Results of the study showed that, in terms of caregiver's demographic characteristic, only family income was related to quality of life. The higher income the family had, the better quality of life the caregiver's had. This result was similar to previous studies (Chien et.al., 2003; Erickson, et. al. 2002; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Lin, Yu, & Chang, 2001). Even under insurance and social welfare coverage, intervention programs for the DD child are still heavy economic loadings. It is not surprised that family with lower income had worse quality of life. Also, similar to Hamda, Ohta, & Najane's (2003) study, the social support had strong relationships with quality of life, and with caregiver's strain. Further study can be done to identify particular resources that are helpful for each need. As previous study showed that parents who had high stresses in taking care their sick children, they would have worse quality of life (Austin, 1996; Wang, 1995). Results of this study show that the primary caregivers' strains had strong negative relationships with their quality of life. However, except social support, the factors related to quality of life (income) are different to the factors related to strain (number of types of delay, and age). Further analysis that involved other factors about the children and the caregivers' demographic characteristics may be helpful in explaining the relationship between strain and quality of life.

This study collected rich qualitative information that can help healthcare providers have better understanding about the feelings and experiences among informal primary caregivers of developmental delayed children. Results of the study reveal that family with DD children need to adjust their lives. To the primary caregivers, mostly were mothers, they were worry about their children in terms of future education and lives. Some of them even had ambivalent feelings about the therapies. Meanwhile, they involved in the intervention programs actively.

Conclusion

Taking care for the children with developmental delay is not an easy task for a family. Informal caregivers need all help they can receive from all possible resource. To recognize their need and provide assistant are healthcare professions' responsibilities. Further studies that focus on the caregiver's needs and available resources in the society can offer more practical solutions in helping these families.

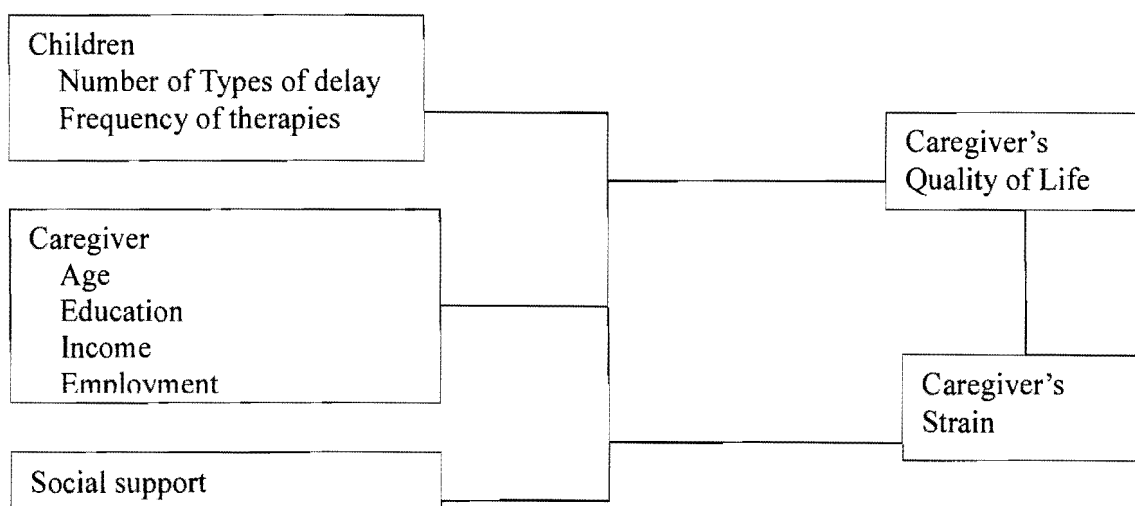
Table 1: Demographic Characteristic of Participants (N=116)

Variable	Levels	N	%
Gender	Female	107	92.2
	Male	9	7.8
Education	Illiteracy	3	2.6
	Elementary	5	4.3
	Junior High School	15	12.9
	High School	55	47.4
	College	36	31.0
	Graduate	2	1.8
Employment status	Full time	42	36.2
	Part time	14	12.1
	No	60	51.7
Number of children	1	14	12.1
	2	64	55.2
	3	33	28.4
	4	5	4.3
Other DD child at home	No	93	80.2
	Yes : 1	20	17.2
	2	3	2.6
Assistant in child care	No	41	35.3
	Yes	75	64.7
Family income per month	20000 and under	19	16.4
	20001-40000	62	53.4
	40001-60000	23	19.8
	Over 60001	12	10.3

Table 1: Demographic Characteristic of the DD Child (N=116)

Variable	Levels	N	%
Gender	Female	41	35.3
	Male	75	64.7
Education	No	34	29.3
	First year in kindergarten	16	13.8
	Second year in kindergarten	23	19.8
	Third year in kindergarten	42	37.1
Frequency of therapy per week	1 and under	22	19.0
	2	32	27.6
	3	36	31.0
	4	16	13.8
	5	7	6.0
	6 or over	3	2.6
Time spend in travel to therapy	Less than 60 mins	53	45.7
	60-120 mins	46	39.7
	120-180 mins	11	9.5
	180-240 mins	4	3.4
	Greater than 240mins	2	1.7

Figure: Research Structure



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計劃成果自評

1. 以原研究目的來看，自變項與依變項的關係除支持系統外，其餘大部分未發現顯著相關。
2. 壓力與生活品質的關係明顯，但其各自相關的因子卻不盡相同，此一現象需進一步研究以釐清整個相關因素的關係。
3. 質性部分豐富的資料，需進一步仔細分析。
4. 本研究結果預計投稿學術期刊。