

## Original Article

# Responsibility and burden from the perspective of seniors' family caregivers: a qualitative study in Shanghai, China

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**Abstract:** Objectives: This study aimed to explore the experience of seniors' family caregivers with regarding the responsibility, burden and support needs during caregiving in Shanghai, China. Materials and methods: An exploratory, descriptive, qualitative design was used and a semi-structure interview was conducted. A convenience sample of 11 participants in two community service centers in Shanghai was recruited. Data saturation guided the size of the sample. The Colaizzi method of empirical phenomenology was used for interviewing and analyzing data obtained from 11 caregivers. Results: Three major themes were found: It is a hard work; It is my responsibility; Social support is not enough. Conclusion: The findings of the study are practical and helpful for health care providers to develop appropriate caregiver support services, to balance the responsibility and burden of caregivers, and to consider the factors influencing the utility of support services.

**Keywords:** Responsibility, burden, social support, family caregivers

## Introduction

China is the world's most populous country in old age. The current pace of population aging in China ranks first in the world, and the population 60 years old and over will be more than 400 million at the middle of this century. As the population ages, family caregivers play an increasingly important role.

Currently, more than 90% of the elderly in China prefer home care rather than nursing home. There are three reasons accounting for this: first and foremost, home care is consistent with traditional Chinese culture. Different from the western seniors, the senior in China pays more attention to the sense of security, family love, and belonging, which only can be gained from home. Secondly, it is well known that Chinese specially advocate loyalty and filial piety for thousands of years, traditional behaviors and social interaction are strongly influenced by Confucianism [1]. As a result, when one of the

family members gets old or sick, both the society and the family expect family members to undertake the responsibility [2]. Thirdly, the pace of aging in China exceeds the speed of economic growth; therefore, the government can not afford completely the cost of institutional care for such a large senior population. At present, only 1.16% of seniors can enjoy institutional care, while the remaining 98.84% of senior, whether willing or in desperation, are bound to home care. Nevertheless, home care is a cost-effective strategy to solve the problem of aging, therefore. It was accorded great importance by the Chinese Government. In a word, home care is the primary pattern of aged support. As a result, family caregiver became the major strength of long-term care, and becoming an urgent social problem need to be concerned worldwide.

The health status of the senior in China can not be optimistic. A nationwide survey [3] conducting around the health of seniors showed that

the prevalence of chronic diseases is 67.1%-81.6%, with 2 or more chronic diseases as high as 20.5%. Therefore, a considerable number of seniors would be taken care, long-term care and health care services for the elderly would be significantly demanded. Due to long-term, challenging, heavy care work, family caregivers suffer from heavy burden, which affect the caregiver's physical, mental, social life and quality of life [4-7] seriously. Therefore providing appropriate and sensitive support services for family caregivers who provide the bulk of care to home-dwelling elderly is becoming a public issue. Some countries implemented a series of caregiver support services, however, some studies [8-11] indicate that there are some gaps between services provided and service utilization, which means that some caregiver support services can not meet caregivers' needs and have a low utilization. Therefore, it is essential and urgent to understand family caregivers' experiences from their perspectives in order to explore the potential support needs.

Recently, numerous studies have been conducted to explore the experiences of family caregivers in western countries. Some studies have reported the experiences of Chinese family caregivers of seniors with special diseases, and most of them were conducted not in mainland China but in Taiwan, Hong Kong, and other regions. However, these studies mainly focused on the caregivers who take care of person with some special disease, such as dementia [12-14], stroke [15], dialysis [16], schizophrenia [17], cancer [18] and so on, and most of them were conducted not in mainland China but in Taiwan, Hong Kong, and other regions. To our knowledge, little is known about the experiences of family caregivers in mainland China, especially the experience of family caregiver of seniors under the specific Chinese cultural background. Therefore, there is a need to better understand. In this study, 11 caregivers were interviewed and the purpose was to draw public attention to the issues of family caregivers and provide information to the community health service providers, further to better meet the needs of caregivers.

### Subjects and methods

#### *Design*

The design of this study was based on empirical phenomenology conducting through inter-

views with 11 family caregivers of the elderly. Empirical phenomenology is useful to describe the commonality of a phenomenon across experiences, which are caregivers' experiences in this case. The commonality is regarded as the essential structure of the experience, therefore the key factors common across caregivers are elaborated. Face-to-face interviews involving interaction between the interviewer and the caregiver was used to understand the caregiver's situation as expressed in his or her own words. The interview outline was developed as guideline to the interview in order to avoid the omission of some important question and ensure the completeness and accuracy of data collection. A research question was formulated as follows in this study: What are responsibility, burden, and support needs of caregivers of senior in Shanghai, China? The study was approved by the corresponding ethics committees of the institutions involved (Second Military Medical University and the two community health service centers), and written informed consents were obtained from all caregivers before interviews. The participants were informed that the interview would last for about an hour, and that the whole interview process would be tape recorded. Participants were assured of the confidentiality of their communication and could withdraw from the interview anytime.

#### *Sample*

The population for this study composed of senior's caregivers in two communities, in Shanghai, China. The convenience sample of 11 family caregivers of seniors were recruited, the in-depth nature of the phenomenological interview method lends itself well to small sample size [19]. In order to determine the sample size for this study, we used the criterion of redundancy, which is met when themes identified during the ongoing data analysis are repeated and no new themes emerge. Participants selected for this study met the following inclusion criteria: over 18 years of age, taking primary responsibility for the care of senior aged 60 or over at home, the care work is unpaid, continuous care of not less than 3 months and 40 hours per week. The caregivers included had to be willing and able to describe his or her care experiences. The researchers

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**Table 1.** Characteristics of participants

Interview No.	Gender of participant	Age of participant	Relationship to the elderly	Time since admission	Education status	Employ a nanny	Family monthly income (RMB)
1	Female	66	Wife	1 years	Senior high school	No	1000~3000
2	Male	82	Wife	10 years	Primary school	Yes	3000~5000
3	Female	81	Husband	10 years	Senior high school	Yes	≥10000
4	Female	72	Wife	10 years	Senior high school	No	1000~3000
5	Male	82	Husband	5 years	Primary school	Yes	3000~5000
6	Female	70	Wife	20 years	College/university	No	1000~3000
7	Female	64	Daughter-in-law	1 years	College/university	Yes	3000~5000
8	Female	73	Wife	14 years	Junior high school	No	1000~3000
9	Female	76	Wife	40 years	Primary school	No	3000~5000
10	Female	52	Daughter	16 years	Senior high school	No	3000~5000
11	Female	57	Daughter	1 years	Junior high school	No	3000~5000

personally conducted the semi-structured interviews at a home setting.

### *Data collection*

The advertisement of the study was posted in the Community Health Center, and residents' committees also help researchers introduce this study to family caregivers. A convenience sampling was used to recruited participants, and an informed consent was obtained prior to each interview. The participants were made aware of the purpose of the study and their right to refuse to answer questions or opt out of the study at any time [20]. No participants dropped out during the interview. The interviews were undertaken in the caregivers' own homes or some convenient place for the caregiver by taking into account their availability so that they could confidentially answer the questions. After obtaining the informed consent, the researchers began with "As a family caregiver, what is your experience?" and audio taped thoroughly. Each semi-structured interview lasted 45-80 minutes and was conducted by two researchers, a researcher is primarily responsible for asking questions, and the other researcher is mainly responsible for observing and recording. Efforts were made to avoid distractions or interruptions during the interviews. Caregivers were clearly eager to tell their stories, and the interviews were not finished until they felt they had provided enough information of their experiences. During the interview, the expressions and behaviors were observed and noted to help researchers understand their care experiences comprehensively. The real names of the caregivers were replaced by the

code number to protect the privacy of participants. After each interview, the researchers would promptly write their own experience and reflection in order to align the next interview.

### *Reliability*

Various strategies were used to ensure credibility of the data collection and analysis process. Prior to data collection, the interviewer conducted a pilot study to ensure a consistent approach to the interview process. The tape recordings were transcribed verbatim solely by the researchers within 48 hours in order to assist interpretation and ensure accurate analysis. Notes and memos were written after each interview to record initial ideas as a memory aide [20]. The thematic content analysis was undertaken by the researchers solely, therefore the consistency between interpreters was not an issue. The derived list of categories was discussed with informants who could check the validity of the identified themes and their meanings. Using the input of informants at this stage helped ensure that the results were valid and applicable to the research population [21]. The researchers kept the copies of the complete interview transcripts and the original tape recordings to refer back to during the writing-up stage of the study in order to stay close to their original meaning.

### *Caregivers' profiles*

Key characteristics of participants in this study are shown in **Table 1**. All the participants were Chinese-speaking adults, not surprisingly 9 female and 2 male. The age ranged from 52 to

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**Table 2.** Overview of the themes and sub-themes emerged in the analysis

Themes	Sub-themes
It is so hard	a. Declining physical healthy status b. Sustained mental and emotional confusion c. No freedom any more d. Heavy economic pressure
It is my responsibility	a. Husbands and wives are accompanied till they are old b. Learn to be filial from Confucius c. Avoid bothering other family members as less as possible d. This is my destiny
There are gaps in caregiver support service	a. The information of support service is not smooth b. Some support service is limited c. Some support service is not accessible d. Reluctance of caregivers and resistance of senior

82, with mean and median ages of 70.5 and 72 years respectively. The average length of time spent on caregiving ranged from 1 year to 40 years, with a mean of 11.6 years. All participants were married except one. The education status of the participants included 3 at primary school level, 2 at junior high school level, 4 at high school level, and 2 at colleges/university level, which indicated that lower educational level of caregivers. All participants were retired excepting one on job. All caregivers had no religious affiliation.

### Results

Three themes are extracted as following: (a) It is a hard work; (b) It is my responsibility; (c) Support is never enough. **Table 2** shows the resulting three major themes categories and corresponding sub-themes.

#### It is so hard

Most caregivers described that the most important experience is that they suffer heavy burden, physical, psychological, social, economic, are subject to different degrees affected, and sometime they felt powerless. First and foremost, most caregivers complained that they felt run down, most of the seniors in this study have no ability to self-care, and therefore the care work is heavy and seriously affected the health of caregivers. Secondly, Caregivers always worried about the safety of senior and had difficult to communicate with them, thus, most caregivers experienced ongoing mental and emotional confusion. Thirdly, caregivers generally accompanied the senior 24 h a day

and 7 days a week and have no freedom at all. Fourthly, most caregiver usually paid for the high medical expenses of the elderly, together with the reduction of income due to the care work; as a result, economic pressure is heavy, too. Above in all, the care work itself is a hard work.

#### *Declining physical healthy status*

There are several reasons accounting for the healthy status declined. Firstly, most caregivers who are interviewed are old, it is worth noting that 9 were 60 years old or over, and two were over 80 years old. This phenomenon is consistent with the fact that the aging of the population leads to the elderly taking care of the elderly. Secondly, most of them had 2 or more chronic diseases themselves and need to be taken care. However, they had no choices but to take the responsibility of caring senior. Thirdly, the work of taking care seniors is cumbersome and complex, caregivers assume great physical labor. Therefore, the healthy status of caregivers declined. Although they would like to take good care of the elderly, but sometimes feel their strength does not match their wishes. *"I'm old too, my health status is declining, supposedly I should be taken care by others at this age, but he needs to be cared more than me, sometimes I felt tired, powerless...I am too old to provided better care to him."* (#1).

#### *Sustained mental and emotional confusion*

With aging, people's cognitive function declines, chances of accidents increase, and a variety of diseases appear; therefore caregivers always

look over their shoulders, difficult to feel at ease. In addition, taking care of seniors is long-term, cumbersome, complex, together with caregivers' strong sense of duty of providing better care to the elderly, however sometimes the caregivers had difficulty on managing well, therefore the caregivers were prone to worried, stuffy, powerless, sulking and other negative emotions, caregivers often suffered sustained mental and emotional confusion.

As the motor function, cognitive function and linguistic function of the elderly decline, the security of elderly faces a great threat. As a result, the caregiver worried about the security of elderly on the whole day. One caregiver expressed: "Since he has been sick, I have not slept well for only one night, always worried about that some accident would happen, and often waked up with a nightmare." (#2) // "...just afraid that he would have a fall or knock things over at home...while my heart always hunting." (#3).

Because the seniors always have a number of behavioral problems, such as bizarre behavior, obsessional characteristics, memory impairments, hearing impairment and other issues, sometimes caregivers had an obstacle to communicating with the elderly. When the elderly insisted on doing things in their own way, the caregivers did not know how to deal with it, although they would like to provide good care to the elderly, sometime they felt that they were incompetent. "I have a obstacle to communicating with her because she could not hear clearly. When I tell her something, she would misunderstand and stick stubbornly to her opinion..." (#7) // "After he was diagnosed as cancer, he was suspicious of something frequently...I have no way but to tolerate." (#3).

As a result of taking care of sick seniors year after year, physically tired, health declined, together with the loss of personal social life, caregivers often felt that their life was stuffy. "My life is bitter, stuffy, damned hard, my personal life was completely paralyzed...I living a life of bondage, I can't go anywhere...life is just like this day by day, I we didn't have any fun...we are suffering." (#4).

*I have no freedom anymore*

Another outstanding experience of caregivers is the loss of freedom, performance as strong

sense of time limited. Most of the care recipients were the elderly stroked, and they cannot manage the daily life activities by themselves. Therefore the caregivers must always accompany along and arrange the time according to the elderly, their own schedule are subject to different restrictions. "I have no freedom because I was banded, and can't remove another way..." (#6). This led to a series consequences, including social life was restricted, interests was given up, role conflict and even personal marriage was hampered. "I almost had no chance to visit my old friend...even if there is a party, I neither have time to attend." // "I danced, traveled before, since he was ill, I had to given up..." (#2) // "...I should take care of my mother who paralyzed in bed for my whole life, because my boyfriend can't accept this condition, so I was not married..." (#9). Because caregivers are often the spouses or children, they were not just caregivers, were also husband, wife, daughter, father, grandfather, grandmother and other multiple roles, should assume different obligations and responsibilities, would inevitably lead to role conflicts. "We are sandwich, now I look after my mother in law, but my own mother need to take cared too, as a daughter, I should went to visit frequently but I have no time...Now my granddaughter was born, I have no opportunity to see her." (#7).

*Economic pressure is heavy*

In this study, the medical expenses of care recipient is large, the elderly at least had been two diseases, taking two or more drugs, and most of them need regular services by community doctors (average cost is about RMB 500 yuan a month). Generally, the monthly medical cost about RMB 1,000 yuan, together with the income of caregivers reduced as the result of the care work, therefore caregivers experienced heavy financial pressure. "...We both have to take medicine and need a doctor's regular onsite services, all these need money...his pension ran out every month, and sometimes it is not enough...so we had to pinch and screw, save as much as possible..." (#9).

**It is my responsibility**

Another major experience of caregivers is strong sense of responsibility. For spouse caregivers, it is accepted that the husbands and wives to take care of each other, which was

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influenced by the culture of loyalty. For children caregivers, it is taken as a naturally given obligation to show filial piety to their parents, which was affected by the deep-rooted culture of Confucianism. Therefore, they avoided trouble other family member. However, some caregiver regarded caring the senior was their destiny and the only thing they can do was to accept the fact.

*Husbands and wives, be accompanied till they are old*

Among the caregivers, most of them are spouses because of two reasons: On the one hand, the marriage affection between them is deep, and they depend on each other. On the other hand, it is a cultural tradition in China that husband and wife take care of each other when they are old. Among the caregivers, almost all the spouse caregivers mentioned that, because they are couples, it is should be accompanied by each other till they are old. The spouses' mutual care is the best approach. This phenomenon is the inevitable result of Chinese loyal culture [22]. *"My greatest experience is that he should be dedicated to take care of, he deserved it."* (#1). *"...We are a couple, It is supposed to accompany each other...The elderly take care of each other is the best approach."* (#2).

*Learning to be filial from Confucius*

In addition to spouse caregivers, children are the other major source of caregivers. China is a country that specially advocates loyalty and filial piety [23-27]. Learning to be filial from Confucius, this is Chinese deep-rooted cultural tradition for thousands of years. As children, it is taken as a naturally given obligation to show filial piety to their parents. It is Chinese obligatory responsibility regardless of the health of themselves. *"I went to visit my father when he was in hospital, otherwise I was uncomforted regardless my poor health...Then it is so selfish to consider myself...we should be worthy of our own conscience. After all, our parents gave birth to us."* (#11).

*Avoiding trouble other family member as less as possible*

Some spouse caregivers are reluctant to bother their child. There are two reasons: First and

foremost, the modern society is competitive, children have their own life and work, spouse caregivers love their children so much that they avoid delaying their work, affecting their lives, hampering their development, and adding their burden. Second, the spouse caregivers had strong sense of duty; they are not at ease but taking care of the elderly personally. As long as their health conditions permit, they will try to take care of the elderly personally without complaint. *"I will not tell these to my children to affect their work...they would be in low mood if they remind that their father is ill at home."* (#3) // *"I can not be ease as long as my husband was cared by other person..."* (#4).

*This is my destiny*

Some participants believe in fate, which means that people doing everything was decided in fate, so they couldn't against the destiny but to accept the fact. *"I have no alternative but let my personal society life pass...This is my fate... so I can't do against it..."* (#6). In addition, Chinese people believe in Karma, there is justice in this world, one good return deserves another. It advises people to perform good deeds, and believes that will be published if do ill deeds. *"It is important to teach child by personal example as well as word and deed, now I honor and show filial obedience to my parents, my son will treat me just like these....I think dedicated to look after parents is accumulated virtue and treasure for ourselves."* (#7).

*There are gaps in caregiver support service*

There are gaps in caregiver support service was another experience that frequently mentioned. The structure of a Chinese family is becoming smaller since the implementation of birth control, function of the traditional pension weakening, so available resources within the family are short; caregivers often do not have alternatives to share the responsibility. On the other hand, community support services are not well to meet the needs of caregivers. There are four reasons accounting for this: Firstly, the information of support service is not smooth, thus some caregiver knew little about some existed support services. Secondly, some support service is seriously limited; Thirdly, because of the time is not convenience, distant is far away and money is lacked, some support

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service is not accessible for part of caregivers. The last but not least, caregivers were reluctant and seniors are resistant to use support services.

### *The information of support service is not smooth*

Currently, the community has undertaken a number of caregiver support services such as day care centers, community meals delivery and so on. The article takes Shanghai as example, the government led by the Ministry of Civil Affairs had carried out "six aid of home care services" including food aid, cleaning aid, urgency aid, bath aid, walk aid, doctors aid. Services form including in home services and day care centers. It is a practical project of Shanghai government. However, there are some seniors and caregivers never used or even heard of, trace it to its cause, on the one hand, these support services is short relatively, the coverage is small; on the other hand the information is not smooth, some caregivers never understand or heard of support services which had been carried out, this is a factors should not overlooked. "I wonder whether there are some institutes that can look after my husband temporally, just for a few hours...I learned that some support service is very good in the TV, such as volunteer services and day care centers, but these are not existed in our community" (#3). But actually, day care centers and volunteer services had carried out in the community of Shanghai. It can be seen that caregivers have a strong demand for support services, but because the information is not smooth, the utilization of support services is affected.

### *Some support service is limited*

The limitations of existing support services mainly reflected in two aspects. On the one hand, clients of the existing support services are limited. For example, government subsidies for home care services limit the age, income, census register of clients, it is undoubtedly removed the eligibility of some seniors. Such as one caregiver, although she is urgently demanded health care service for aged but was refused just because her husband was not eligible for the criteria of minimum living. *She complained: "We are also very difficult, but we are not entitled to those services (home care service)".* Nursing home and day care centers usually

refused some seniors who had serious disease and had no ability to self-care. *One caregiver complained: "No day care center would admit my husband, much less than day care center, even nursing home refuses, because he could not move, bowel and voiding must be helped..."* (#4). Thus the requirements of support services including age, income, living capacity exclude some people who had strong need in some extent.

On the other hand, Some senior and caregivers had a high quality requirements about some support service, they thought some support service was inconvenient, thus can not meet the individual needs the elderly and caregivers. Some caregivers said it is not free in nursing home and day care center. *"My wife had no freedom in nursing home and it is not convenience comparing to home..."* (#2). Some caregivers thought the quality of support service is poor. *"I won't go to volunteer service, although it is free, because its condition is poor and service quality is low"* (#3). There also some caregivers used some support service but quitted because the quality of service. *"We had used meals delivery, but because it is not delicious and some times it is cold, so now I do not use it any more"* (#7). Thus, many caregivers worried about the quality of service and coupled with a lot of inconvenience, therefore affect the usages of support services.

### *Some support service is not accessible*

The accessibility or convenience should be a notable feature of the community support services. The accessibility mainly reflected in distance, time and money, this is a factor hampering caregiver to use the caregiver support service. The inaccessibility of distance mainly means the site where support service is provided is far away from the resident of caregivers and seniors distance, but sometime the caregivers and seniors have difficult to move. *"The nursing home is far away, it is convenience for us to look after him, especially in the rainy day."* (#3)//*"If adult day care centers are close to my home, we would like to attend."* (#2) The inaccessibility of time mainly means that caregiver usually company the senior all day along and have no time to enjoy the support service. *"I have no time to take participate in the programmer which can teach us some care skill"* (#4). It was no doubt that inaccessibility of

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money is a frequently issue that mentioned by the caregiver. As expected, most caregivers concerned about the cost of support services, because it was a sufficient barrier to keep them from using services; Economic status often determines support resources of a family. Some caregivers thought that they would have enough support if they have enough money. *"Now my main pressure is economic stress... economic decides everything...We have no money to pay nursing home."* (#3).

### *The resistance of the elderly and the reluctance of caregivers*

The resistance of the elderly is the most frequently mentioned reason for caregivers not using community support services, second is the reluctance of caregivers. The reasons for the resistance of the elderly include the elderly would not accept care outside home, they were fearful or embarrassed, and refused or resisted in help from service providers. For these caregivers, the resistance of the care receivers was sufficient to discourage use of a series of support services. *"He refused to go to nursing homes...in the nursing home, he ate and drunk nothing for two days...He was afraid..."* (#9) // *"When I or my husband asked if she wished to go to nursing home, she shook her head, she preferred at home and take care by her own children."* (#7).

Several caregivers were found to be reluctant to accept help from support service providers. There are two reasons for this reluctance: one is that caregivers' feeling of responsibility, guilt, shame, and worrying about their elderly' safety, they can only be ease when taking care of the elderly by themselves. On the other hand, some caregivers worried about the quality of support services, the existed service providers can not provide high quality services and they were unwilling to accept "strangers" (service providers) to take care of elderly. *"There is not convenience in nursing home, sleep is not well too... food is not tasty...but she is free at home, so we would not let her go there."* (#2) // *"We worried and distrust if someone else takes care of him..."* (#11).

### **Discussion**

One finding of the study is that the work of taking care of seniors is a hard work, there are sev-

eral reasons accounting for this: (1) The care work itself is long-term, cumbersome, complex and challenging, which was found in the previous studies [28-30]. (2) Most caregivers are old, had reached the standard of senior in developed countries [31]. It is a common phenomenon that the elderly take care of each other in China. Moreover, most caregivers had chronic diseases. (3) The majority is female caregivers, consisted of spouses and children. This finding is consistent with many studies [32, 33], most caregivers are women worldwide. In the context of feudal culture of male-dominant for thousand years in China, women are subject to vulnerable groups. For these reasons, the experience of caregiver is hard and burdensome.

Another finding is that most caregivers regarding caring the seniors is their own responsibility. It is an inevitable result of advocated loyalty and filial piety for thousands of years. In these context, when a family member become old or have disease, it is accepted to live at home and be cared by family members, caregivers had strong sense of responsibility. The burden experience of caregiver was documented in the previous study frequently [34, 35], the responsibility experience was rare reported. Furthermore, it is controversial whether caring the elderly is a responsibility or a burden for the family caregiver in different studies. The finding in this study indicated that the relationship between responsibility and burden are two aspects. For some caregivers, filial obligation was found to be positively associated with caregiver's burden, the finding was supported by Foster [36]. It can be explained that when the sense of responsibility of caregiver is stronger, the wish of providing perfect care is corresponding more intense, therefore tremendous pressure and feeling of self-blame, guilt emerge and produce more suffering, especially when the caregiver can't achieve the initial wish for some reason. Gonzalez LA [37] pointed out the similar point. Nevertheless, filial obligation was found to be positively associated with caregiver's burden for some caregivers. It is natural for these caregivers to show filial piety to parents and it is a enjoyable thing rather than a burden.

However, the sense of responsibility affected the expectation of support service and support



seeking behaviors, which are barriers of health care services utilization. It is identified in the previous study [10, 14, 26, 33, 38]. Most caregivers in this study dedicated to care the elderly at home personally rather than sending the senior to some health care institutions, even at the sacrifice of their own lives. Most participants would take care the beloved personally as long as their health and energy permitted, usually had low aware and expectation of social support services, as a result, the utilization of support services is low. In addition, some participants believe in fate, and it is also a barrier of utilization of support services. The finding above provides direction for community nurses and other health professionals in targeting caregiver support service should regard the traditional cultural factors to meet the expressed need of caregivers.

In this study, the support is never enough. In addition to cultural factors as mentioned above, other factors of low perceived of social support were identified in this study, including some support that urgently needed is not available, Some support service is not accessible, Some support service was not be afford. This finding involved the availability, accessibility, and affordability of caregiver support service and indicated that there is a gap existed between support service provided and utilization. It is similar to the finding of Whittier et al [9] also was identified by Chen [11]. These findings are practical and helpful for future caregiver services and program development that should consider the availability, accessibility, affordability of the support services. Firstly, services needed by family caregivers must be available in their community. Secondly, these services must be accessible. Support services must be located conveniently within a reasonable amount of time. Service accessibility applies not only to physical location of services, but to the structure of service delivery as well and working hours must be considered. Thirdly, services must be affordable to caregivers. Caregiver consideration of the affordability of services will not only include financial costs, but also costs in terms of time, effort, potential loss of confidentiality, and potential family conflict. These suggested that there is a need for support service providers to enhance efforts to improve the service network for supporting family caregivers.

In this study, the experience of family caregivers suggested that the whole society should pay more attention to the issues of caregivers and appropriate support should be provided. The support should include material support, emotional support, informational support, economic and policy support. The support which urgently needed should be given priority. The results indicated that, among burden experience of caregivers, emotional pressure is less mentioned than physical pressure. Therefore most participants identified that they need physical support more urgently than emotional support. It can be explained by the theory of Maslow's needs [39]. Physical demand is at the lowest level of demand, when it is not met, psychological needs will not arise. China is still a developing country, the health care system is not perfect, therefore, the need of caregivers still focuses on physical part, and emotional needs are relatively low. For caregivers, health declining and feel powerless is the most prominent experience. Another outstanding experience is loss freedom, this finding was consisted with several qualitative studies [40-43]. This suggests that health service providers should first take measures to help caregivers ease the physical stress and burden. In addition, larger economic pressure is another outstanding experience that most caregivers mentioned, but the finding of Winslow [26] mentioned that the issue of economic is talked less. This shows that the health care system in China is not sound enough, so the appropriate policy and financial support are urgently needed under the present conditions. In some western countries, there are some policy supports including caregiver subsidies, tax exemptions and caregivers paid leave policies, but are rare in China, therefore, there is an urgent need for Chinese government to develop relevant policies.

However, the following limitations were identified in this study: Firstly, The sample was convenient and small, and qualitative research method was used, therefore, the generalization cannot be gained. A larger sample size and quantitative research methods need to be considered in further studies. Secondly, this study is conducted in two communities in Shanghai, and the research region is limited. Future studies should be conducted in a broader region even nationwide.

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### Disclosure of conflict of interest

None.

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