Haematology Oncology Research Journal
ISSN: 2997-6677 |
Volume 10 Issue 2, April-June, 2022
Journal Homepage: https://ethanpub.online/Journals/index.php/E25
Official Journal of Ethan Publication

IMPROVING QUALITY OF LIFE: A COMPREHENSIVE STUDY OF HOME CARE SERVICES FOR INDIVIDUALS WITH DISABILITIES IN CHINA

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Abstract:
China presently accommodates a substantial populace of individuals with disabilities, comprising a minimum of 85 million people, of whom over 44 million are aged 60 years or above[1]. Individuals with disabilities, characterized by diminished health status, heightened susceptibility to complications, and limited economic resources, constitute a distinctive population facing notable health challenges. Consequently, these individuals warrant significant societal attention and support. In order to enhance care services and mitigate the health-related concerns of individuals with disabilities, the Chinese government, in collaboration with the Disabled Persons' Federation, has implemented a comprehensive array of measures [2]. One notable facet among these measures is the substantial growth observed in the home care service program in recent years[3]. These services have garnered considerable acceptance among individuals with disabilities owing to their less restrictive nature and personalized approach. In-home care services, rendered by proficient service providers, entail comprehensive assessments and provisions of living assistance, rehabilitation support, and psychological comfort, all within the confines of the individual's residence.

Keywords: China, disabilities, home care services, health challenges, healthcare, personalized care

1. Introduction

China presently accommodates a substantial populace of individuals with disabilities, comprising a minimum of 85 million people, of whom over 44 million are aged 60 years or above[1]. Individuals with disabilities, characterized by diminished health status, heightened susceptibility to complications, and limited economic resources, constitute a distinctive population facing notable health challenges. Consequently, these individuals warrant significant societal attention and support. In order to enhance care services and mitigate the health-related concerns of individuals with disabilities, the Chinese government, in collaboration with the Disabled Persons' Federation, has implemented a comprehensive array of measures [2]. One notable facet among these measures is the substantial growth observed in the home care service program in recent years[3]. These services have garnered considerable acceptance among individuals with disabilities owing to their less restrictive nature and personalized approach. Inhome care services, rendered by proficient service providers, entail comprehensive assessments and provisions of living assistance, rehabilitation support, and psychological comfort, all within the confines of the individual's residence.

Prior investigations concerning the utilization of care services by individuals with disabilities have predominantly focused on a limited sample size and have predominantly concentrated their efforts within centralized care facilities and economically prosperous metropolitan areas [4,5]. This study centered on a specific cohort of individuals with disabilities who were recipients of home care services within a particular Chinese county. The primary objective was to investigate the fundamental characteristics and health status of individuals with diverse types of disabilities. Further investigation involved a comparative analysis of the self-care capabilities and mental health status of individuals with disabilities residing in urban and rural regions. The findings derived from this study serve to

enhance our comprehension of the current state of home care service implementation, thereby offering valuable insights to guide future policy development and refinement endeavors.

2. Materials and Methods

2.1 Study Design

From January to June 2023, a cross-sectional study was conducted in Yancheng, Jiangsu, China, focusing on the health status of individuals with disabilities who were beneficiaries of home care services. For the purpose of this research and survey, we deliberately selected four specific regions, namely Dafeng, Funing, Yandu, and Yannan, to serve as the focal areas. Employing the comprehensive whole-group sampling approach, with communities as the fundamental units, a total of 23 communities were ultimately chosen. Trained investigators visited the residences of individuals with disabilities to administer one-on-one surveys, encompassing a comprehensive questionnaire consisting of inquiries regarding basic characteristics, disability status, and health outcomes. Our study obtained ethical approval from the Ethics Committee of Yancheng Funing Rehabilitation and Care Hospital.

2.2 Patients

The inclusion criteria are as follows: (1) age between 16 and 59 years; (2) first or second-degree physical disabilities, mental, or intellectual disabilities, as evidenced by a valid People's Republic of China disability card; (3) the questionnaire could be completed by either the patients themselves or their primary caregivers; and (4) voluntary participation and provision of signed informed consent.

The exclusion criteria: (1) currently not availing home care services; (2) experiencing communication difficulties and incomplete investigation process.

2.3 Measures and Variables

Basic status: the collection of personal information encompassed various details, such as age, gender, household registration, and education level. Additionally, disability-related information encompassed aspects such as disability type, degree, and cause of disability.

Health outcomes: (1) the Modified Barthel Index (MBI) was employed as the assessment tool to evaluate their activities of daily living [6]. The scale comprised ten distinct domains, contributing to a cumulative score of 100. Notably, a higher score on the scale is indicative of a greater level of independent living ability. A total score falling below 40 signifies severe impairment, 41-60 indicate moderate impairment, 61-99 suggest mild impairment, and 100 signifies a state of independent self-care. (2) the symptom check list 90 (SCL-90) was used to evaluate the mental health[7]. The scale encompasses a total of 90 questions, distributed among nine distinct dimensions, with each question being assigned a score ranging from 0 to 4.

2.4 Statistical Analysis

Data analysis was performed using IBM SPSS Statistics (version 24.0, Armonk, New York, NY, USA). Mean ± standard deviation was employed to describe normally distributed measurements. Differences between groups were assessed using the paired t-test for normally distributed data and the non-parametric test for non-normally distributed data. The chi-square test was employed for count data analysis.

3. Results

3.1 Basic Characteristics

A total of 342 individuals were eventually included in our study. Table 1 presents a comprehensive summary of the fundamental characteristics pertaining to people with disabilities. Of notable significance is the finding that more than 60% of individuals with disabilities in our study had attained a primary school education or below. This observation underscores the prevailing reality wherein a considerable majority of individuals with disabilities are deprived of opportunities for comprehensive education, consequently exerting a discernible impact on their economic standing. The primary caregivers for individuals with disabilities predominantly consisted of their parents, with an average age of 63.8 years. This observation suggests that accessing home care services is challenging, thereby raising concerns regarding the potential inadequacy of care quality.

Table 1: Basic characteristics of the disabled individuals.

Characteristics	Participants		Characteristics	Participants	
	n/mean	%/SD		n/mean	%/SD
Gender			Disability type		
Male	167	48.8	Physical	67	19.6
Female	175	51.2	Intellectual	110	32.1
Age(year)	43.8	10.5	Mental	117	34.2
Age group			Multiple	48	14.1
18-29	17	5.0	Disability severity		
30-45	147	43.0	Level 1	83	24.3
46-59	178	52.0	Level 2	118	34.5
Household registration			Level 3	138	40.4
Rural	193	56.4	Level 4	3	0.8
Urban	149	43.6	Disability duration (year)	32.5	14.8
Education			Causes of disability		
Primary school or below	212	62.0	Cerebrovascular and cerebral organic diseases	46	13.5
Middle school	99	28.9	Genetic and developmental malformations	165	48.2
High School or Technical Secondary School	31	9.1	Trauma	25	7.3
Junior College or above	0	0	Schizophrenia	65	19.0
Number of family members			Unknown cause or other	41	12.0
1	8	2.3	Comorbid chronic diseases		
2	43	12.6	Hypertension	28	8.2
3	129	37.7	Diabetes	17	5.0
4	157	45.9	Hyperlipidemia	13	3.8
≥5	5	1.5	Malignant tumors	4	1.2

Primary Caregiver			Hemophilia	5	1.5
Parents	210	61.4	Coronary heart disease	9	2.6
Spouses	73	21.3	Heart failure	3	0.9
Siblings	32	9.4	Epilepsy	6	1.6
Relatives	20	5.9	Age of primary caregiver	63.8	8.9
Others	7	2.0	Daily care hours	6.3	3.8

3.2 Health Outcomes of Disabled Between Rural and Urban Areas.

Table 2 displayed a comprehensive depiction of the self-care and mental health status of individuals with disabilities residing in both urban and rural areas. The MBI scores of individuals with disabilities residing in rural areas were found to be significantly lower compared to those in towns (p=0.021), particularly in the domains of using the toilet (p=0.031) and getting dressed (p=0.044). Regarding mental health, individuals with disabilities residing in rural areas obtained significantly higher scores than their urban counterparts across all dimensions assessed (p<0.001). Notably, higher scores indicate a greater presence of psychological issues, thereby suggesting that rural PWDs experience inferior mental health compared to their urban counterparts.

Table 2: Comparison of MBI and SCL-90 between urban and rural areas

Variables	Urban(n=149)	Rural(n=193)	p Value
MBI	97[80.5,100]	84[60.5,100]	0.021*
Bowel control	10[10,10]	10[8,10]	0.519
Bladder control	10[10,10]	10[8,10]	0.222
Personal hygiene	4[3,5]	4[3,5]	0.497
Self-bathing	4[2,5]	4[1,5]	0.204
Feeding	10[8,10]	8[6,10]	0.229
Using the toilet	10[8,10]	8[4,10]	0.031*
Stair climbing	10[5,10]	8[0,10]	0.152
Getting dressed	10[6,10]	8[6,10]	0.044*
Chair/bed transfer	15[12,15]	15[8,15]	0.341
Ambulation	15[12,15]	15[10,15]	0.774
SCL-90	37[0,94]	154[42,212]	<0.001*
Somatization	4[0,12]	17[4,30]	<0.001*
Obsessive compulsive	5[0,12]	15[1,29]	<0.001*
Interpersonal sensitivity	2[0,7]	12[0,24]	<0.001*
Depression	5[0,15]	18[3,33]	<0.001*
Anxiety	4[0,14]	14[3,25]	<0.001*
Hostility	3[0,9]	9[4,14]	<0.001*
Phobic anxiety	3[0,8]	11[2,20]	<0.001*
Paranoid ideation	1[0,6]	9[1,17]	<0.001*
Psychoticism	3[0,7]	14[0,29]	<0.001*
Other	3[0,10]	8[0,18]	<0.001*

* indicates a statistical difference. The numbers in square brackets indicate upper and lower quartiles.

4. Discussion

For individuals with severe disabilities, both formal care and home care represent fundamental and essential requirements [8]. Particularly concerning new-onset disabilities arising from acquired factors, access to both routine home care and regular formal care plays a vital role in enhancing the quality of life for affected individuals and mitigating the risk of potential complications [9]. A notable portion of individuals with severe disabilities encounter financial challenges, prompting the Chinese Government to institute welfare initiatives in the form of home care services to address the demand for formal care [10]. Nonetheless, China faces a substantial population of individuals with disabilities, and considerable regional disparities in development persist, leading to inadequate safeguarding of the quality of life and care requirements for individuals with severe disabilities.

We conducted a comprehensive survey encompassing essential information about individuals with disabilities within a medium-sized county. Remarkably, it was observed that all of the surveyed individuals are beneficiaries of unpaid home care services extended by the government. The educational attainment level of individuals with disabilities, as an aggregate, remains relatively low, resulting in challenges regarding employment opportunities and limited income generation[11,12]. Consequently, underprivileged families with disabled members frequently become the target beneficiaries of government welfare programs. Mental and intellectual disabilities represent a substantial proportion among the individuals we surveyed who have disabilities. In contrast to those with physical disabilities, individuals with mental and intellectual impairments not only experience challenges in self-care but also bear a heightened risk of causing harm to themselves or others, rendering family care more demanding and costly[13,14]. Accordingly, their increased vulnerability and specific needs align with the rationale for their prominence as recipients of welfare policies. Based on the survey outcomes, it is evident that over fifty percent of individuals with disabilities are predominantly cared for by their parents. Notably, the average age of the surveyed population is 43.8 years, while their primary caregivers exhibit an even higher average age of 63.8 years. Providing physical care for over six hours daily presents a formidable challenge for this elderly caregiver cohort, underscoring the considerable difficulties experienced by family members in their role as caregivers for individuals with disabilities. China is undergoing a significant demographic shift, transitioning towards an aging society characterized by a declining fertility rate and an increasing proportion of elderly individuals who themselves require care[15,16]. In the foreseeable future, parents serving as caregivers for disabled individuals will experience physical limitations or unforeseen mortality, significantly affecting the existing caregiving model for the disabled. Consequently, the Government's role as a guarantor will grow in importance, necessitating the gradual implementation of a comprehensive set of social adjustment measures.

A notable disparity in economic development exists between urban and rural areas. Consequently, we conducted a comprehensive investigation to elucidate the distinctions in the quality of life and mental health experienced by individuals with disabilities in these respective regions. On the whole, the selfcare capacity of individuals with disabilities is considered fair, even in the lower rural regions, where the median score surpasses 80, denoting a mild degree of functional impairment. Conversely, in urban areas, the median score for individuals with disabilities reaches 97, significantly higher than in rural areas. Notably, two essential subcategories, namely using the toilet and getting dressed, pose relatively greater challenges for individuals with disabilities, exhibiting comparatively lower completion rates. The distribution of resources in China has historically been characterized by disparities between urban and rural areas[17]. These discrepancies in health insurance payout ratios between the two regions may provide an explanatory framework for this phenomenon. Consequently, individuals with disabilities residing in rural areas encounter substantial obstacles in accessing quality medical care, both prior to the onset of illness and subsequent to the occurrence of disability. In light of these observations, certain intriguing aspects warrant close attention. As individuals with disabilities exhibit improved capacity in their daily activities, the range of welfare services offered by the government may extend beyond exclusive care and rehabilitation endeavors. The precise attributes of home care services demand further scrutiny through comprehensive data analysis and in-depth research.

The principal focus of this study rested on examining the disparities in mental health experienced by individuals with disabilities in urban and rural regions. Substantiating this concern, the scores on the SCL-90 questionnaire were notably higher in rural areas compared to urban areas, encompassing all nine subdomains assessed by the questionnaire. Similar disparities were also documented in the study conducted by Yu Xin et al[18], wherein the depression rate among elderly individuals with disabilities was found to be 67.44% in rural areas and 59.10% in urban areas. Subsequent investigations carried out by Tao TIAN revealed that older women exhibit more pronounced mental health issues[19], with marital status, education level, and engagement in social activities emerging as significant determinants. Moreover, the recent COVID-19 pandemic may also represent a significant contributing factor exacerbating the mental health challenges faced by individuals with disabilities[20].

A limitation of this study lies in the inadequate sample size of the survey, necessitating its expansion in future research endeavors. To augment our understanding, prospective investigations should focus on the specific service components of home care and assess their effects through longitudinal comparisons.

5. Conclusions

In conclusion, our study demonstrates notable disparities in the mental health status and self-care capabilities of individuals with disabilities who are beneficiaries of home care services, based on the distinction between urban and rural regions. Specifically, our findings highlight that the primary caregivers of individuals with disabilities tend to be older and experience a relatively lower quality of life, with this situation being more pronounced in rural areas compared to urban areas. Additionally, a substantial majority of individuals with disabilities manifest psychological issues that are often overlooked. As a result, there exists an urgent imperative to enhance the precision in identifying the unique care requirements of individuals with disabilities and develop more tailored and individualized care plans to address their needs effectively.

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