

Awareness, utilization and influencing factors of social supports for main informal caregivers of schizophrenia patients: a cross-sectional study in primary care settings in Beijing, China

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Abstract

Background: Main informal caregivers of schizophrenia patients in Beijing are increasingly called upon to provide home-based care due to the increasing number of schizophrenia patients. This study aims to investigate the further needs of social supports for main informal caregivers of schizophrenia patients and to analyze the influencing factors on awareness and utilization of social supports in Beijing. The results of this study could potentially act as reference for health professionals to implement appropriate and effective support programs.

Methods: A mixed-methods approach was used in this study. Individual in-depth interviews with 10 main informal caregivers from the urban districts of Beijing were conducted to identify the caregivers' perspective on social supports and their further needs. Meanwhile, awareness, utilization and influencing factors of social supports for main informal caregivers were investigated using questionnaires in 6 urban districts in Beijing.

Results: Most caregivers in in-depth interviews expressed that they had negative experiences with respect to obtaining social supports, and they emphasized that more support would be needed in terms of financial support, respect, and rehabilitation institutions. Quantitative results showed that although the government provided multi-channel resources for schizophrenia patients and their families, awareness and utilization of the resources such as rehabilitation, employment, and health services were relatively low, which were less than 10.0% and 5.0% respectively.

Conclusions: The awareness and utilization of social supports are low for main informal caregivers of schizophrenia patients. More services and improved public attitudes are needed for schizophrenia patients and their caregivers.

Introduction

Schizophrenia is a mental disorder characterized by hallucinations (auditory, visual, olfactory, or tactile) and delusions [1]. As a progressive disease, schizophrenia not only increases the risk of disability and dependency, but also affects the patients' main informal caregivers' lives. Globally, the population of schizophrenia rose from 13.1 million in 1990 to 20.9 million cases in 2016 [2]. China has a large schizophrenia population in the world, the pooled prevalence of schizophrenia from 1990 to 2016 was 0.42% [2]. There were approximately 16 million patients with mental illness in 2019 in China, of which schizophrenia patients accounted for about half, and the incidence of schizophrenia in urban areas was significantly higher than that in rural areas [3].

The burden of schizophrenia is substantial, particularly for middle income countries [2, 4]. Most schizophrenia patients are supported by their main informal caregivers at home [5]. Main informal caregiver has been defined as the person belonging to the patient's informal support system who takes care and is responsible for the patient, and commits most of his or her time to that task without receiving any economic retribution [6]. Main informal caregivers rely on a variety of strategies to confront the

consequences of psychological instability of schizophrenia patients [7]. Social supports can be defined as having reliable people available to assist in meeting material resource and psychosocial need, which encompasses emotional, instrumental, informational, appraisal, social companionship and affectionate support [8]. Schizophrenia has been recognized as a disorder devastating for the patients' families. The symptoms of schizophrenia may act as a stressor, causing main informal caregivers' mental health to deteriorate. It has been suggested that social supports help people stay mentally healthy in stressful situations and protects people in various pathological states [9, 10].

As potential interventions, social supports have been paid more attentions in recent years. The effect of non-pharmacological interventions for main informal caregivers of schizophrenia patients and its application in clinical practice were demonstrated [11]. In some western counties, social supports for caregivers were more focused on a community-based multidisciplinary expert group. The content of social supports mainly included health education, psychological intervention, behavior management, mutual support group, consultations, day care, etc. The most important aspect of social supports is to help families acquire necessary knowledge and skills by providing health education, and seek out the most appropriate management approach for the patients [12].

Social supports are essential for the recovery of patients with schizophrenia. In China, social supports have been extensively studied in mental health disorders. However, little evidence is available for main informal caregivers of patients with schizophrenia. The potential reason is the main informal caregivers have low rate of the awareness and utilization of social supports [13].

As the capital of China, there were 79 thousand people with severe mental disorders in Beijing in 2019 [14], most of whom were schizophrenia patients, and the number is still growing. This study aims to investigate the further needs of social supports of main informal caregivers of schizophrenia patients and to analyze the influencing factors on awareness and utilization of social supports in Beijing. The results of this study could potentially act as reference for health professionals to implement appropriate and effective programs for main informal caregivers.

Methods

According our preliminary findings, caregivers of schizophrenia patients had a minimum daily care time of 2 hours and duration over 6 months. The potential reason was that most of the patients who recovering in the community were in non-severe situation or in stable phase.

Main informal caregivers of schizophrenia patients diagnosed by mental illness specialist hospitals, for both quantitative and qualitative investigation in this study, were approached by the inclusion criteria as follows: (1) minimum 2 hours of daily care and duration over 6 months; (2) willingness to participate the study; and (3) being able to answer the questions clearly and logically.

Data collection

Questionnaire survey

There are six urban districts and ten rural districts in Beijing. There were 18.65 million people in the urban districts, accounting for 86.6% of the resident population in Beijing in 2019 [15]. We carried out a cross-sectional survey in all the six urban districts from March to July 2019. A two-step sampling approach was used to minimize selection bias. First, 27 community health service centers (CHSCs) managing patients with schizophrenia were chosen from 6 urban districts by purposive sampling method. Second, all the main informal caregivers from the 27 CHSCs who met the inclusion criteria were invited to participate in the study, total 370 caregivers were recruited. The caregivers were investigated using a questionnaire. Written informed consent was obtained from each participant prior to the investigation. There were three steps in developing the questionnaire. First, question lists were developed by collecting and extracting information from literature references. Second, several experts in related areas were invited to review the questionnaire and a small scale preliminary investigation was conducted. Third, the questionnaire was modified according to the opinions of the experts and preliminary findings before the formal investigation.

The final questionnaire comprised three parts. The first part collected the caregivers' demographic information. The second part assessed the social supports for caregivers by the Social Support Rating Scale (SSRS) [16] with 10 items. The scale was widely used in immigrants, college students, workers, patients, patients' caregivers, etc. to assess social supports for its ease of use. In the caregivers of children and adolescents with schizophrenia, the Cronbach's α coefficient of total and subscales of SSRS were 0.818, 0.793, 0.881, and 0.836 respectively, which demonstrated high reliability and validity [17]. The 10 items are conceptually divided into three domains, including objective support (three items), subjective support (four items), and support usage (three items). Objective support reflects the degree of actual support received in the past. Subjective support reflects the perceived interpersonal network that an individual can count on. Support usage refers to the pattern of behavior that an individual utilizes when seeking social supports. The total score of the SSRS ranges from 11 to 60, with the objective support domain from 1 to 20, the subjective support domain from 7 to 28, and the support usage domain from 3 to 12. Higher scores indicate more social supports. The SSRS is a tool used to assess social supports and provides a measure of support, which is both ordinal and discrete in nature. Data of this type lend itself to analysis using ordinal logistic regression (it models the odds of being in a more sufficient support category, that is, the odds of having fair/sufficient support versus less support or sufficient support versus less/fair support). The third part collected the caregivers' awareness and utilization of social supports.

Individual in-depth interviews

In-depth interviews with caregivers were conducted from March to May 2019 by interviewers who received training and guidance in conducting qualitative interviews. The interviews were structured and contained predetermined topics and associated probes. These predetermined topics were chosen by the research team to elicit, in an open-ended fashion, an exploration of caregivers' attitudes. The topics were what

kinds of supports or resources have been obtained and what further supports are needed in order to provide better care for the patients. With a mix of sex, age and experience, a total of 12 main informal caregivers were enrolled from the 370 caregivers who completed the questionnaires by stratified proportional sampling approach. Written consent was obtained from the participants with full explanation of the purpose and procedure of the study. Confidentiality of data and personal information was assured to the participants.

Data analysis

Data of questionnaires were imported into Excel 2016 and were checked by two researchers in the team. Descriptive statistics were used to describe the demographic and socioeconomic characteristics of the caregivers. Normally distributed continuous variables were described by mean value \pm standard deviation (SD) and categorical variables were described by proportions. Independent t tests and analysis of variance (ANOVA) were used to analyze the mean differences in total and subscale scores by different demographic variables. Linear regression analysis was performed to identify potential related factors followed by a final ordinal regression analysis to measure the correlation between the total scores of SSRS and potential related demographic variables. All analyses were conducted using the IBM Statistical Package for Social Science Version 20.0 for Windows. All the tests are two sided, with statistical significance setting at 0.05.

All interviews were audio recorded with consent from participants. Digital recordings were stored in a password-protected, secure system. Audio-taped data were transcribed verbatim. Transcripts were reviewed and analyzed by seven members of the research team. To bring a wide variety of knowledge and preconceptions to the analysis process, the team comprised professionals with different research backgrounds, including a professor and a lecturer of general practice, four graduate students and a general practitioner. The team members read all the materials through for several times to apprehend the whole sense and then independently coded the transcripts to identify themes by condensing and summarizing the contents. When no new topics were identified, data saturation was considered [18]. The point of information saturation was reached at the tenth interview in our study.

Results

Of the 370 questionnaires administered, 363 questionnaires were returned (response rate 98.1%); 7 declined because they did not want to talk about their experiences. The mean age of the caregivers was 64.6 ± 11.5 years old. More than half of them were aged 61 years old and above. 35.5% of the caregivers received high school or higher education. Detailed socio-demographic information of the caregivers is described in Table 1.

Table 1 Characteristics of caregivers who completed the questionnaires (n=363)

Characteristics	n (%)	Characteristics	n (%)
Gender		Relationship with patient	
Male	154(42.42)	Spouse	112(30.85)
Female	209(57.58)	Parent	151(41.60)
Age		Child	31(8.54)
≤50 years old	38(10.47)	Brother or sister	64(17.63)
51-60 years old	90(24.79)	Other Family relative	5(1.38)
61-70 years old	127(34.99)	Caring years	
≥71 years old	108(29.75)	≤5 years	7(1.93)
Ethnic group		6-10 years	52(14.33)
Han	331(91.18)	>10 years	302(83.20)
Others	32(8.82)	Insurance	
Education		Basic medical insurance for urban employee	221(60.88)
Primary school or below	36(9.92)	Residents' basic medical insurance	104(28.65)
Middle school degree	121(33.33)	Others	38(10.47)
High school degree	129(35.54)	Number of chronic disease	
College degree	51(14.05)	No	4(1.10)
Bachelor degree	22(6.06)	One	242(66.67)
Master degree or above	4(1.10)	Two	69(19.01)
Religious or not		Three and above	48(13.22)
No	328(90.36)	Hours for caring patients per day	
Yes	35(9.64)	≤6 hours	173(47.66)
Marital status		6-12 hours	140(38.57)
Unmarried	11(3.03)	> 12 hours	50(13.77)
Married	299(82.37)		
Divorced	17(4.68)		
Widowed	33(9.09)		
Others	3(0.83)		
Employment status			
Employed	123(33.88)		
Retired	213(58.68)		
Unemployed	26(7.16)		
Others	1(0.28)		

Twelve informal caregivers of schizophrenia patients from 6 CHSCs in urban districts were selected for interview. Only 10 caregivers were interviewed; and the other 2 declined with no reason. Most caregivers were either spouses (6/10, n=6) or children (3/10, n=3) of the patients (see Table 1 for additional characteristics). The average age of the caregivers was 65.43 ± 11.39 years old, while the average age of the schizophrenia patients was 47.07 ± 10.45 years old. The demographics of the patients and the caregivers are described in Table 2.

Table 2 Characteristics of interviewed caregivers and care recipients

Items	Caregivers (n=10)	Care recipient (n=10)
Mean age	65.43 ± 11.39 years old	47.07 ± 10.45 years old
Sex		
Female	7	2
Male	3	8
Self-reported general health		
Excellent/very good	0	N/A
Good	0	N/A
Fair	3	N/A
Poor	7	N/A
Relationship		
Spouse	6	N/A
Child	3	N/A
Other family relative	1	N/A
Marital status		
Married	9	8
Widowed	1	2
Education		
Elementary school	0	2
Secondary school	6	3
Higher education	4	5
Disease status		
Stable phase	N/A	5
Relatively stable phase	N/A	3
Unstable phase	N/A	2

Scale scores

The mean score of the scale was 27.33 ± 6.45 . The distributions of total scores and subscale scores are shown in Table 3.

Table 3 Distribution of SSRS scores (total scores and subscale scores) of caregivers

Scale	Mean \pm SD	Minimum	Maximum
SSRS	27.33 ± 6.45	12	46
Objective support	6.70 ± 2.14	1	16
Subjective support	14.56 ± 4.15	7	27
Support usage	6.07 ± 1.92	3	11

Correlation analysis

There was no significant difference in the score by whether the caregiver was religious or not ($P > 0.05$). There were four factors positively correlated with the total SSRS score, i.e. age, education, marital status, and hours for caring patients per day ($P < 0.05$). Correlation analysis between SSRS scores (total scores and subscale scores) and general characteristics of caregivers are shown in Table 4. An additional file shows this in more detail [see Additional file 1].

Table 4 Correlation analysis between SSRS scores (total scores and subscale scores) and potentially related factors

Factors	Total score	SSRS	Objective support	Subjective support	Support usage
Gender					
Male	27.05±6.27		6.77±2.16	14.47±4.03	5.81±1.78
Female	27.53±6.59		6.65±2.12	14.63±4.25	6.26±2.00
t	-0.708		0.559	-0.360	-2.237
P	0.479		0.577	0.719	0.026
Age					
≤50 years old	29.08±6.11		7.08±2.19	15.68±4.38	6.32±1.69
51-60 years old	29.54±6.71		7.13±2.20	15.90±4.40	6.51±1.96
61-70 years old	26.33±6.41		6.36±2.15	14.31±3.97	5.65±1.97
≥71 years old	26.03±5.84		6.60±1.99	13.33±3.69	6.09±1.81
F	7.304		2.812	7.742	3.884
P	0.000		0.039	0.000	0.009
Ethnic group					
Han	27.35±6.46		6.74±2.18	14.53±4.12	6.08±1.89
Others	27.03±6.53		6.31±1.60	14.84±4.52	5.88±2.24
t	0.269		1.075	-0.405	0.590
P	0.788		0.283	0.686	0.556
Education					
Primary school or below	26.17±5.45		6.61±2.22	13.47±3.08	6.08±2.18
Middle school degree	26.09±6.17		6.29±2.05	14.18±4.05	5.62±1.81
High school degree	27.95±6.92		6.93±2.21	14.80±4.42	6.22±1.94
College degree	28.08±6.13		6.82±1.94	14.80±4.08	6.45±1.82
Bachelor degree	30.73±6.43		7.64±2.28	16.23±4.54	6.86±1.83
Master degree or above	26.50±3.11		5.75±1.26	15.75±4.03	5.00±0.82
F	2.804		2.287	1.601	2.984
P	0.017		0.046	0.159	0.012
Religious or not					
No	27.34±6.30		6.76±2.12	14.57±4.07	6.01±1.87
Yes	27.20±7.88		6.17±2.26	14.46±4.93	6.57±2.29
t	0.120		1.543	0.153	-1.395
P	0.904		0.124	0.879	0.171
Marital status					

Unmarried	27.91±5.05	6.73±1.74	14.45±3.14	6.73±1.95
Married	27.94±6.41	6.84±2.08	15.04±4.16	6.07±1.91
Divorced	23.53±8.32	5.53±3.17	12.24±4.55	5.76±2.33
Widowed	23.52±4.30	5.97±1.85	11.45±2.43	6.09±1.79
Others	27.33±4.04	7.67±2.08	14.67±2.08	5.00±1.73
F	5.283	2.753	7.417	0.662
P	0.000	0.028	0.000	0.619
Employment status				
Employed	28.45±6.64	6.98±2.12	15.21±4.48	6.25±1.81
Retired	26.85±6.41	6.60±2.12	14.28±3.97	5.97±2.00
Unemployed	25.69±5.20	6.08±2.17	13.65±3.83	5.96±1.78
Others	34.00	10.00	17.00	7.00
F	2.576	2.455	1.867	0.677
P	0.054	0.063	0.135	0.567
Relationship with patient				
Spouse	27.58±5.54	6.78±2.06	14.90±4.33	5.90±1.91
Parent	26.66±6.06	6.50±1.95	13.95±3.83	6.20±2.04
Child	26.48±6.54	6.84±2.31	13.87±4.05	5.77±1.56
Brother or sister	28.55±6.72	6.92±2.57	15.48±4.27	6.14±1.70
Other Family relative	31.40±10.24	7.20±2.28	17.60±5.90	6.60±3.05
F	1.665	0.628	2.718	0.684
P	0.158	0.643	0.030	0.604
Caring years				
≤5 years	27.14±7.38	7.14±2.34	13.71±4.57	6.29±1.50
6-10 years	26.44±6.55	6.13±2.35	13.96±4.03	6.35±2.02
>10 years	27.50±6.45	6.78±2.09	14.69±4.18	6.02±1.91
F	0.591	2.217	0.824	0.672
P	0.554	0.110	0.439	0.512
Insurance				
Basic medical insurance for employees	27.86±6.79	6.86±2.15	15.00±4.30	6.00±1.98
Residents' basic medical insurance	26.88±5.67	6.72±2.08	14.04±3.82	6.12±1.67
Others	25.47±6.17	5.74±2.00	13.45±3.87	6.29±2.18
F	2.584	4.543	3.441	0.404

P	0.077	0.011	0.033	0.668
Number of chronic diseases				
None	27.50±11.56	6.75±1.89	14.75±7.89	6.00±2.94
One	27.80±6.41	6.81±2.19	14.83±4.11	6.15±1.92
Two	27.20±6.23	6.68±1.94	14.67±4.12	5.86±1.94
Three and above	25.10±6.27	6.15±2.13	13.00±3.88	5.96±1.85
F	2.362	1.314	2.662	0.478
P	0.071	0.270	0.048	0.698
Hours for caring patients per day				
≤6 hours	28.03±6.73	6.65±2.30	15.15±4.33	6.23±2.00
6-12 hours	27.31±6.04	6.89±1.80	14.42±3.99	6.00±1.68
> 12 hours	24.94±6.15	6.36±2.39	12.90±3.55	5.68±2.22
F	4.529	1.217	5.974	1.743
P	0.011	0.297	0.003	0.176

Ordinal regression analysis

We put gender, age, education, marital status, relationship with patient, main medical payment way, number of chronic diseases, and hours for caring patients per day into the regression models. The total SSRS score and the three subscale scores were dependent variables, respectively. The results revealed that insurance was a predictor of the SSRS scores. More details are shown in Additional file 1 (see Table 5).

Table 5 Ordinal regression analysis of social supports for caregivers

Independent variable	B	Wald	<i>P</i>	95% CI
Gender				
Male	0.379	1.055	0.304	-0.344~1.101
Female	0 ^a			
Age				
≤50 years old	0.971	1.780	0.182	-0.455~2.397
51-60 years old	0.993	2.867	0.090	-0.156~2.143
61-70 years old	-0.257	0.278	0.598	-1.210~0.697
≥71 years old	0 ^a			
Education				
Primary school or below	1.402	0.528	0.468	-2.381~5.185
Middle school degree	0.220	0.014	0.906	-3.418~3.858
High school degree	1.066	0.333	0.564	-2.558~4.690
College degree	0.891	0.223	0.637	-2.810~4.592
Bachelor degree	2.478	1.638	0.201	-1.317~6.272
Master degree or above	0 ^a			
Marital status				
Married	-1.526	0.481	0.488	-5.837~2.785
Divorced	-0.103	0.003	0.959	-3.986~3.781
Widowed	-1.843	0.775	0.379	-5.945~2.260
Others	-0.676	0.110	0.741	-4.682~3.329
Unmarried	0 ^a			
Relationship with patient				
Spouse	-1.812	2.138	0.144	-4.242~0.617
Parent	-1.999	2.545	0.111	-4.456~0.457
Child	-2.395	3.104	0.078	-5.059~0.269
Brother or sister	-0.955	0.610	0.435	-3.351~1.442
Other Family relative	0 ^a			
Insurance				
Basic medical insurance for employees	1.310	5.803	0.016	0.244~2.375
Residents' basic medical insurance	1.228	4.388	0.036	0.079~2.377
Others	0 ^a			
Number of chronic disease				

No	-0.080	0.002	0.964	-3.548~3.570
One	0.523	1.081	0.298	-0.463~1.547
Two	0.383	.434	0.510	-0.757~1.524
Three and above	0 ^a			
Hours for caring patients per day				
≤6 hours	0.196	0.146	0.703	-0.811~1.203
6-12 hours	0.261	0.253	0.615	-0.757~1.280
>12 hours	0 ^a			

CI: confidence interval

The caregivers' awareness and utilization of social supports

The top three items of social supports awareness were “patients could apply for disability certificate” (96.14%), “patients could obtain free psychotropic medications” (93.66%), and “patients could obtain regular medical examination once a year in the CHSCs (or stations)” (90.08%). The top three items of utilization were “patients could apply for disability certificate” (90.08%), “patients could obtain free psychotropic medications” (83.75%), and “patients could use the public transport and visit scenic spots for free” (76.58%). More details are shown in Table 6.

Table 6 The awareness and utilization status of social supports for caregivers

Items	Awareness rate (n%)	Utilization rate (n%)
Social security		
Patients could apply for disability certificate.	349(96.14)	327(90.08)
Patients could use the public transport and visit scenic spots for free.	295(81.27)	278(76.58)
For Beijing residents, patients could apply for basic medical insurance.	189(52.07)	126(34.71)
For Beijing residents, patients could apply for pension subsidy.	147(40.50)	95(26.17)
Warm home.	176(48.48)	49(13.50)
Single-child disabled family could apply for special support policies in Beijing.	54(14.88)	21(5.79)
Patients could apply for social insurance subsidy for disabled persons in urban areas.	46(12.67)	21(5.79)
Patients could participate in rehabilitation labor programs.	97(26.72)	21(5.79)
Patients could obtain financial assistance during participating in in rehabilitation labor programs.	54(14.88)	11(3.03)
Patients can participate in vocational training for disabilities.	68(18.73)	16(4.41)
Patients could obtain corresponding subsidies during vocational training.	47(12.95)	8(2.20)
Patients could be admitted to stay in a rehabilitation institution organized by the district.	58(15.98)	15(4.13)
Patients could obtain corresponding subsidies during they stay in a rehabilitation institution organized by the district.	29(7.99)	11(3.03)
Patients could apply for the reduction of individual income tax.	41(11.29)	11(3.03)
Patients could obtain tax incentives for Beijing disabled.	43(11.85)	9(2.48)
Patients could be admitted to stay in Beijing social welfare institutions for the disabled.	44(12.12)	10(2.75)
Patients could obtain corresponding subsidies during staying in Beijing social welfare institutions for the disabled.	29(7.99)	12(3.31)
Patients could get employment support in Beijing.	58(15.98)	3(0.83)
Patients could get support when they starting a business in Beijing.	47(12.95)	4(1.10)
Financial support		
Patients could obtain disability living allowance in Beijing (100 bucks / month).	288(79.34)	262(72.18)
Patients could obtain Beijing residents' home disability service (100 bucks /	219(60.33)	158(43.53)

month).

Patients could obtain minimum living allowances for Beijing residents.	283(77.96)	123(33.88)
Patients could apply for basic living allowance for severely disabled families.	108(29.75)	54(14.88)
Patients who lived in dire poverty could get support.	112(30.85)	49(13.50)
Medical support		
Patients could obtain free psychotropic medications.	340(93.66)	304(83.75)
Patients could obtain regular medical examination once a year in the community health service center (or station).	327(90.08)	230(63.36)
Patients could obtain support to reduce the burden of medical expenses.	199(54.82)	151(41.60)
Poverty severe patients could get psychiatric diagnosis and treatment subsidy.	109(30.03)	76(20.94)
Education support		
Patient's children could obtain subsidies when be educated.	46(12.67)	20(5.51)
Living conditions support		
Patients or their families are supported by welfare guarantees to improve living conditions.	115(31.68)	30(8.26)

Qualitative findings

Two dominant themes emerged from the insights of the caregivers: the support obtained, and further needs for social supports.

The support obtained

Three subcategories of support obtained were identified, including financial support, medical support, and information and education support. The caregivers expressed that external financial resources including medical insurance and free medication were provided to alleviate family economic pressure to a certain extent; medical resources from society alleviated the caregiver's burdens; health education and mutual support groups organized by community created opportunities for the caregivers to communicate with others, and mutual support groups help to alleviate psychological pressure of the caregivers. However, these types of support were sometimes unavailable for some caregivers.

We received 2200RMB subsidies per month from the government. The medications and the health examinations for him are free. (Caregiver 1)

If the patient has a sudden relapse, the general practitioners, and our neighbors would help me to prevent his violent behavior and take him to the hospital. (Caregiver 6)

The mutual support group is good, but I have no time to attend. I have to look after the patient... (Caregiver 10)

Further needs for social supports

Three subcategories of further needs for social supports were identified, including more financial support, being respected, and affordable rehabilitation institutions. Every interviewee hoped that the government could provide more types of free medications and expand health insurance coverage for patients; they indicated that families with schizophrenia patients are more vulnerable to discrimination in China, and hoped to create a non-discriminatory environment around them; and they agreed that more affordable rehabilitation institutions should be opened for schizophrenia patients.

My son does not have a job. We depend on my husband's retirement pension... the treatment fees for patient are too expensive. We hope to get more free medical service for patients. (Caregiver 5)

Sometime they call my son idiot and even beat him. I hope schizophrenia patients should be fairly treated. (Caregiver 4)

I heard of Daxing Farming Therapy Base. Patients could do agriculture work or take exercise there. The patients' daily life was taken care of by doctors and nurses. We would like to take the patient there, but we can't afford it. (Caregiver 10)

Discussion

In this study, nine caregivers of schizophrenia patients declined to participate. The possible reasons might be the stigma attached to schizophrenia. There is an overall low level of understanding of schizophrenia among the public. The stigma that might be attached to schizophrenia makes it difficult for people to discuss [19]. The most important caregivers in this study were family members, especially parents and spouses, and more than half of the caregivers were retirees. Due to societal roles and expectations, female caregivers are the main contributor of caregiving activities and responsibilities. Such situation is common as the caregiving responsibilities are often delegated to family members with the least economic value [20], resulting in early retirement, turning down a promotion, and losing job benefits.

To a certain extent, available services, resources, and support for patients and their family caregivers could relieve the burdens on caregivers [21]. The awareness and utilization rate of disability certificates ranked first in our study. Being recognized as disabled in China, people with mental disabilities are entitled to have welfare services such as medical care, rehabilitation, education, employment, and social security. Almost 90.1% of schizophrenia patients have applied for disability certificates, which makes the utilization of other social resources possible. The types of social supports provided for schizophrenia patients and their families in urban Beijing include medical care, living security, social security, rehabilitation, labor and employment, sports and entertainment, disability certificates, home services,

housing security, education and training. The caregivers' awareness of resources and their high utilization more focused on medical care, life security, social security, and housing security. The awareness and utilization rate of resources such as rehabilitation, employment, and health services were relatively lower, which was less than 10.0% and 5.0%. Although the government provided multi-channel resources for patients with schizophrenia and their families, the awareness and utilization of social supports were not optimistic. The underlying reasons might be: (1) the workforce of rehabilitation and social care professionals in China was insufficient [22]; (2) funding and other support from national and social institutions for mental illness were limited, and burdensome application procedures and unperfect quota allocations impaired the accessibility of various types of support [23]; (3) stigma and discrimination from the public and even mental health professionals [24, 25], and low insurance coverage with high treatment fees created barriers to mental health service utilization [26]; (4) the mutual support groups and psychological counselling provided for caregivers were often considered superficial and impractical [27].

Educating society to reduce or eliminate stigma and discrimination that might be attached to schizophrenia is one strategy. The public health system in China should be working hard on promoting the social awareness through mental health propaganda and education in communities, hospitals and schools to reduce or eliminate stigma and discrimination. Unlike some Western countries, China has relatively few nursing home institutions, while the existing ones are less affordable to many schizophrenia patient families. The breaking up of the traditional structure of extended families, greater participation of women in the labor force and growing geographical mobility will come to limit the ability of schizophrenia patients to rely entirely upon informal care. It is essential that government policies operate in a way which encourages informal care. Policy makers should emphasize services designed to support caregivers in providing care, bolstering their self-efficacy and coping repertoire, and enhancing their support network.

Insurance affected the caregivers' perception of social supports in our findings. Basic medical insurance for employees is designed for the employees of urban enterprises. Residents' basic medical insurance is designed for all urban and rural residents who are not enrolled in any insurance program. Both of them are the combination of individual accounts and social pooling accounts. But the percentage of reimbursement is higher for basic medical insurance for employees compared with this of the residents' basic medical insurance. Inequity in health financing affects the caregivers' usage of social supports. Broadening the coverage of healthcare insurance for severe mental diseases and providing more accessible financial protection for patients with severe mental diseases are important ways to support more patients seeking medical health services [28]. Gradually improving the medical insurance system is a very important aspect of the current medical system reform. The pooling fund should be increased so that it can better adjust to China's rapidly aging population and epidemiological transitions as well as protect the insured from poverty due to illness.

Strengthening the existing primary health care system may be an important measure to enhance the quality of life of caregivers, care recipients and other family members. Policy makers should allocate more resources for community care, train more community care workers and make referral process

effective [29]. There could be support groups for caregivers that run by social workers or volunteers; education sessions or sharing sessions with physicians on typical symptoms; and the establishment of family therapy clinics to which families could be referred for counselling. Regular home visits and establishment of day nursing/care or respite care to cater for the needs of schizophrenia patients to relieve the main informal caregivers by taking over their tasks of caring on a temporary basis are useful. Employment and social skills training for patients should be strengthened. Mental health professionals and policy makers should allocate sufficient resources to implement strategies identifying high-risk populations, provide vocational training and supported employment for patients seeking jobs.

Important aspects regarding social supports of caregivers were revealed in this study and it could serve as a basis for future community-based care. But it also had some limitations. First, a cross-sectional design of the present study did not allow the determination of causal relationships. Second, the caregivers' population in the 6 districts might not reflect the CHSCs in other parts of Beijing or other parts of China when generalizing the findings.

Conclusions

The awareness and utilization of social supports are insufficient for main informal caregivers of schizophrenia patients. More services and better public attitudes should be considered for schizophrenia patients and their caregivers.

Abbreviations

SSRS: Social Support Rating Scale; SD: standard deviation; CHSCs: community health service centers

Declarations

Ethics approval and consent to participate

This study was approved by the Medical Ethics Committee of Capital Medical University, Beijing, China. Written informed consent was obtained from each participant involved in this study. All participant information was kept confidential.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and analyzed during the current study are not publicly available to protect participant privacy, but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

MRW, LFC, GHJ, YW, FYW, ZLP and XQL contributed to the conception and design of this study. MRW, LFC and GHJ were involved in data collection. MRW, LFC, GHJ, YW, FYW, ZLP and XQL analyzed and interpreted the data. The manuscript was drafted by MRW and LFC and edited by XQL. The final version was reviewed and approved by all authors.

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