

The Use of Online Services in Stress Management for Caregivers of Adolescents with Mental Disabilities

—Social Support as a Theoretical Perspective

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ABSTRACT

Research has demonstrated the relatively high levels of psychological stress among carers of people with mental disabilities. Among them, young people with mental disabilities aged 14 and above face a sharp reduction in benefits and services, and their carers are even more overburdened. The stress level of caregivers is not only related to their well-being, but also has a great significance in improving the situation of young people with mental disabilities. Using social support as a theoretical perspective and emotional support as an intervention point, this study conducted a social work practice and intervention study with the target group using pre and post measures, semi-structured interviews and group work. Five carers of young people with mental disabilities from the M Mental Disability Family Support Centre in W were selected to participate in an online emotional support group, which was assessed at the end of the group from the PSTR scale pre-test and post-test and feedback from the group members. According to the results, the participants' psychological stress scores decreased significantly, while they also gave positive feedback about being supported. Therefore, the intervention can be considered effective and able to contribute to the alleviation of psychological stress among caregivers of young people with mental disabilities.

Keywords: *Mentally challenged carers, social support, psychological distress*

1. INTRODUCTION

People with mental disabilities include people with autism, intellectual disabilities, Down's syndrome and cerebral palsy. China has a large number of people with mental disabilities who are mainly cared for within the family[1]. According to the survey data in the "Research Report on the Current Situation and Needs of People with Mental Disabilities in China" in August 2008, more than 99% of the parents directly stated that they were facing mental stress problems[3]. This shows that carers of people with mental disabilities have many supportive needs that need to be seen. For young people with mental disabilities, their family carers are one of the most important links to the outside world and to society[4]. Responding to the needs of carers can therefore be beneficial not only for the carers' own well-being but also for the good development of the cared for, i.e. the mentally challenged group[5].

Today, China has a number of policies and practices in place to support the mentally challenged and their

families. However, policy coverage and formal support for young people with mental disabilities who have reached the age of 14 but are still under 18, as well as for those who have just turned 18, is still incomplete[6]. The Shenzhen Autism Research Association mentioned in its "Research Report on the Current Situation and Needs of Older People with Mental Disabilities and Their Families" that there is a "cliff effect" in the field of mental disability services, i.e. once people with mental disabilities reach a certain age, there is a precipitous decline in the type and quantity of benefits or services available to them[7]. It is relatively common for the 'cliff effect' to occur at the 'older' age, i.e. at the age of one4 and above. The dilemma of lack of services is therefore more acute in the case of families of young people with mental disabilities[8].

Based on this, the study selects relatively older carers of mentally disabled young people as the target group and attempts to provide emotional support services to them using the intervention research method of group work[9]. At the same time, in a situation where epidemic

prevention and control is normalised, it is difficult to carry out offline services and innovations in format are needed to adapt to the current new situation. The study therefore experimented with an online group format[10].

2. LITERATURE REVIEW

2.1 Sources of stress for carers of adolescents with mentally disabilities

There are few studies on the stress and needs of caregivers of young people with mental disabilities, and the available literature shows that the stress levels of caregivers of young people with special needs are relatively high. According to the study, the SCL-90 and the General Quality of Life Inventory (GQOLI) were used to survey and correlate a sample of parents of mentally handicapped children in selected areas, and it was concluded that the total score and all factors were higher for parents of mentally handicapped adolescents than for the norm (Li, Xiuling and Zhao, Yang, 2014). "Caregiver load" includes two aspects: first, the negative outcomes of the caregiving experience for the family caregiver, and second, the reaction to or perception of caregiving stress (Zhang Jinyu, Lu Tangyun, Wang Junshi, Bai Jiaojiao, Gao Jian, Qian Xiaolu, 2007). From the carers' perspective, the literature shows that they have strong needs in terms of information provision, professional guidance, service assistance, financial assistance and spiritual support (Luo Yichao and Lei Jianghua, 1999).

2.2 Correlation between social support and mental health

Social support includes provision and maintenance within and outside the family, but also involves a variety of formal and informal support and assistance (Yau, H.,

Chen, K. & Ren, Y., 1998). In general, the buffering effect theory has explained the moderating effect of social support in reducing emotional exhaustion (Cohen, 1985). More recently, studies have shown that the relationship between social support and physical and psychological well-being is not a single influence relationship, but may have a complex interaction (Wang, Yanfei, 2004).

Social support is a multi-directional concept that can be specifically subdivided into instrumental support, emotional support, message support, and self-esteem support. Regarding the differences between the different dimensions of social support, there is research that demonstrates the moderating effect of the dimension of emotional support in terms of negative emotions (Zhang, Li, Lin & Chuan, and Zhang, Lin, 2014), while emotional support, such as feelings of being trusted, has also been shown to be a protective factor against caregiver load. Therefore, the provision of emotional support services can increase caregiver social support and reduce caregiver load along the dimension of informal support.

3. RESEARCH METHODOLOGY

3.1 Subject of study

After a period of preliminary interviews, the study was conducted with parents of young people with special needs who were undergoing community-based integrated rehabilitation at the M Mental Disability Family Support Centre in W. In the process of observation, the author identified and summarised several difficulties that parents of mentally handicapped children might encounter, and designed a programme of group activities based on this. A total of five group members were selected through pre-interviews with the parent groups and voluntary enrolment (see Table 1).

Table 1 - Service User Profile

No.	Name (pseudonym)	Child's Mental Disability Status	Age of the child
1	A	Moderate mental retardation	20 Years Old
2	B	High functioning autism	18 Years Old
3	C	Low functioning autism	14 Years Old
4	D	Moderate mental retardation	20 Years Old
5	E	High functioning autism	20 Years Old

3.2 Intervention studies

The design of this study adopted an observational design from the intervention study and used the PSTR scale to assess changes in the target subjects before and after the intervention. Specifically, the study relied on social support theory to design a semi-structured interview as well as an emotional support online group to deliver an action intervention to carers. Semi-structured interviews were conducted with random parents based on a syllabus to understand the basic problems, causes and needs of the carer group in the pre-study phase, and to develop a population analysis report. Based on this, the specific programme content of the emotional support groups was designed and a total of five sessions of online groups were conducted using Tencent meetings as a platform.

3.3 Research objectives

The effects of the intervention study set goals in two ways. One is the overall objective, the intervention study

aims to provide change, specifically in this study can be described as through the development of the group, the intervention of the meso support system and the provision of emotional support services, young carers with mental disabilities can have a platform to talk, share and exchange experiences, deepen the connection between group members, promote the formation of autonomy and mutual support network, relieve their physical and mental stress, and ultimately effectively and efficiently The second is a specific objective, i.e. the PSYC will be able to provide a platform for caregivers to talk and share their experiences. The second is a specific objective, i.e. a significant reduction in PSTR scale results and positive feedback and personal change for the group members.

4. INTERVENTION PROCESS

4.1 Panel content

The online group was divided into five sessions, as shown in the table below.

Table2 - Outline of activities for emotional support intervention groups

Number of group sessions	Topics	Contents
1	Breaking the ice and getting to know each other Building group contracts	Self-introduction, icebreaker games, group contracting
2	Emotional problems sharing Caregiving experience support	Sharing and discussing common emotional problems and caregiving stress in caring for the mentally challenged
3	Organising the caregiving experience Providing a source of relief	To collate the experiences of caring for children with mental disabilities that were shared at the last event and to share ways of relieving stress or solving problems
4	Understanding social support Building a network of mutual support	Introduction to social support, a review of the social support currently received and the support needed
5	Evaluate the effectiveness of the group and summarise the activities	Share changes, self-evaluation and overall gains in the group and take the PSTR scale post-test

4.2 Group process analysis

On the eve of the group, the social worker collected the basic information questionnaire and the pre-test results of the PSTR scale from the group members in the WeChat group to prepare for the follow-up assessment.

In the first session, the group was at the early stage of group development and the ice-breaking game of "Two Truths and a Fake" was conducted smoothly and in a cordial atmosphere. The group contract was shared by the social worker and was established with the agreement of the group members.

In the second session of the group, the social worker introduced a video on families with mentally handicapped children and guided the group to share problems, take turns to discuss and collate experiences in facing problems and stress on common issues. C shared the problem of her child's slow learning speed and anxiety. At the end, the group reached a consensus that they should be more patient and upbeat in the caregiving process. The group discussion was closely focused on the theme and the interaction between the group members had been largely effective in reaching mutual support.

In the third group session, the social worker and the group members reviewed the issues shared in the second activity and listed them for classification. When talking about the child's emotional control and behavioral problems, E had some emotional outbursts and would be under more psychological pressure because she was comparing herself with other understanding children in the institution. The social worker and other group members immediately reassured E and the social worker also expressed encouragement and support for her courage to share her emotions with the group.

In the fourth group session, the social worker shared the concept of social support and guided the group members to recall what kind of social support they had felt. The group members all had their own views on social support networks, including teachers in institutions, volunteers, families and the government. When B shared the support she needed, she mentioned that she would like to have support for parents of special groups in terms of emotional de-escalation and mental health, which was unanimously approved by the group members.

In the fifth group, during the separation period, the group members were more emotional due to the emotion of parting, the length of the sharing session increased and there was a tendency not to want to end the conversation and sharing, making the group sharing more loosely paced and divided. However, at the end several group members, represented by C, expressed their affirmation of the support received and again suggested the idea of a parents' support association, a self-help support organization after the group had ended.

5. INTERVENTION ASSESSMENT

5.1 Achievement of group objectives

The PSTR scale is widely used in clinical as well as social work practice and has a certain degree of reliability and validity. The scale has 50 descriptors and is scored on a 40-score assignment system. Results are rated on a scale of 43-65 as moderately stressful, below 43 as under-stressed and requiring a moderate increase in stress, and above 65 as over-stressed and requiring an appropriate decrease. A significant decrease in the numerical value of the score is assessed as an achievement of the target.

Table 3 - Status of assessment scale scores

No.	Name (pseudonym)	Pre-test scores	Post-test scores
1	A	104	58
2	B	70	57
3	C	104	91
4	D	100	75
5	E	85	60

Table 4 - Sample test of assessment scale scores

	Sample size	Average	Standard error	Standard deviation	95% Confidence interval		t	df	Sig (bilateral)
					Lower limit	Upper limit			
Pre - Post Intervention	5	24.40	6.03	13.48	7.66	41.14	4.065	4	0.016

The results of the scale showed that after the group activities, all five group members' scores decreased. The hypothesis was tested (Table 4), meaning that overall the intervention could be considered significant ($\alpha=0.05$). At the same time, three of the group members' stress levels decreased from too much stress to moderate stress, returning to normal stress levels. Although there is a possible factor of the group members having a certain tendency to answer questions during the post-test in order to meet the expectations of the social worker, in terms of the data results, the stress of caregiving for the clients was reduced through the process of group interaction.

5.2 Carers' evaluation of the effectiveness of the intervention

Based on the last group session and a group return visit within the WeChat group after the group, participants all rated the effectiveness of the group highly. The group members responded positively to the changes after the group intervention in terms of self-evaluation and the need for mutual support groups. For example, one group member affirmed that she felt supported in the group. She felt supported by the social worker who reminded everyone of the group's schedule in the WeChat group early every day, and also by the affirmation she received from the group members and the social worker during her participation, during her speech and after her speech. Another group member felt a little relaxed as she found some common problems in the communication with the parents and also learnt some good experiences from other parents.

6. CONCLUSIONS

After research and analysis, it is clear that there is a considerable amount of ongoing psychological stress among caregivers of young people with mental disabilities. The use of online groups to provide emotional support services to mothers of young people with mental disabilities is a tentative exploration of the existing service model and its adaptation to the normalisation of epidemic prevention and control. The results of the evaluation showed that despite the risks

associated with the online group and the adaptation process, the group was ultimately effective. This demonstrates that this service model has some potential for replication, and if the problems associated with the network hardware can be resolved and a strong group contract established, replication can generally be attempted. However, as an intervention study, the design of this study still has a number of weaknesses, such as the lack of a control group in the study, which lacks reference and credibility, and the need to add the Family Caregiving Stress Scale to the pre- and post-measure selection, which is something that needs to be improved in the design of the next study. At the same time, due to limited resources and lack of capacity, services are more often provided from a non-physical perspective. Considering the considerable demand for formal support from families of young people with mental health problems, there are policy gaps and resource links that need to be further developed in terms of research and practice.

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