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Research Article

A Qualitative Study of Family Primary Caregivers' Perceptions of Transition Readiness in Children with Autism

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Abstract

Objective: To understand the perceptions of primary family carers of children with autism on transition readiness and to inform the development of family care interventions for children's transition readiness.

Design: Using descriptive qualitative research methods, 14 primary caregivers of children with autism were selected by purposive sampling, semi-structured in-depth interviews were conducted, and data were analyzed using content analysis to extract themes.

Results: Two themes and eight sub-themes were identified: barriers to transition readiness (lack of awareness of transition readiness, excessive parental responsibility for disease management, child illness factors, lack of resources for training and knowledge, and lack of family and social support), and facilitators of transition readiness (strong willingness of primary caregivers to prepare for transition, family and peer support, and medical and environmental support).

Conclusion: Transitional readiness is very necessary for children with autism, but there are many obstacles to carrying out the intervention due to the lack of knowledge and skills of the family's primary caregivers about transitional readiness. Medical caregivers should guide primary caregivers to participate in the transition correctly, construct a transition system, implement transition preparation, and guide primary caregivers to help children with autism transition smoothly.

Background

Autism spectrum disorders (ASD), also known as autism, is a more serious neurodevelopmental disorder, starting in early childhood, with the incidence rate of boys being five times higher than that of girls [1] Chen Si [2] reported that there are more than 10 million people with ASD and 2 million children with ASD in China, and the number of children with ASD is growing at a rate of nearly 200,000 per year. ASD varies widely among individuals, and its core features include social impairment, speech impairment, intellectual backwardness, and repetitive stereotyped behavior's

[3] which can only be partially improved by long-term rehabilitation training [4] The “Healthy China 2030” programme and the “China Children’s Development Programme (2021-2030)” both emphasize the establishment of continuous, full-cycle health services and referral services for children and adolescents [5]. Transitional readiness is a key predictor of successful transition, which refers to a purposeful and planned shift from dependent, multidisciplinary, family-led pediatric care with parental involvement in clinical decision-making to independent, specialist, patient-led, patient-initiated decision-making adult care [6]. This shift in care has positive implications for patients, families, and society. However, children often find it difficult to cope with the change in healthcare environment and paradigm due to lack of psychological preparation and habilitation [7]. The need for a transition process that begins in early adolescence to help children develop self-care, self-advocacy and decision-making skills and improve quality of life is well established [8]. During the transition process, the family primary caregiver is the primary caregiver for the transitioning child and is the primary person responsible for educational guidance, coordination, and communication of the development of the transition plan, and assessment of the entire transition process [9]. However, the current transition preparation of family primary caregivers is insufficient, which can lead to the risks of missed visits, low adherence, and disease exacerbation, and impose a heavy burden on adolescents, their families, and even society [10-13]. In this study, we used qualitative research methods to explore the knowledge of family primary caregivers about the transition readiness of children with ASD, and to provide a reference for the later development of nurses’ transition readiness training.

Study Selection

Using the purposive sampling method, in May-June 2024, the primary caregivers of autistic patients in the pediatric department of a tertiary hospital in Zhengzhou City were selected as the study subjects. Inclusion criteria: ① primary caregivers of children with autism (diagnosed and aged 10-18 years old); ② interviewees who are immediate family members of children with autism and who are long-term primary caregivers (living with the child for more than 1 year); ③ people who can express their needs normally in language; ④ voluntary participation in this study. Exclusion criteria: those with mental or verbal communication disorders. The basic information of the 14 primary caregivers of autistic children in this group is shown in Table 1.

Table 1: General information of respondents (n=14).

Interviewee	Relationship to child	Age	Educational level	Residence	Work	Marital status	Whether only child	Age of child (years)	Severity of symptoms
N1	Mother	48	College	City	part time	Married	No	13	Mild to moderate
N2	Mother	23	College	City	unemployed	Married	Yes	18	Mild
N3	Mother	40	College	City	full time	Married	No	14	serious
N4	Mother	47	Junior college	Urban	full time	Married	Yes	13	mild
N5	Mother	34	Junior college	City	part time	Married	No	14	serious
N6	Father	35	college	City	part time	Married	No	17	Mild to moderate
N7	Father	43	Junior college	City	unemployed	Married	Yes	14	serious
N8	Mother	58	Junior college	City	retirement	Married	No	12	serious
N9	Mother	30	college	Urban	unemployed	Married	Yes	10	Mild to moderate
N10	Mother	26	Junior college	Urban	unemployed	Married	Yes	15	Mild to moderate
N11	Mother	30	Junior college	City	part time	divorced	No	14	mild
N12	Mother	40	Master’s degree	City	full time	Married	Yes	13	serious
N13	Mother	36	Junior college	City	unemployed	Married	No	12	serious
N14	Mother	37	college	Urban	unemployed	divorced	No	17	Mild to moderate

Methods

Data collection method

The researcher used a descriptive qualitative research method to conduct semi-structured in-depth interviews with the interviewees in a face-to-face format. The interviewer introduced himself to the interviewees beforehand and explained the purpose of the study and the necessity of on-site recording, obtained consent, and signed an informed consent form. The outline of the interview was drawn up through reviewing the literature [14,15] and discussion in the research group, and the outline of the interview included: ① Have you ever known about transition preparation ② How do you think about transition preparation? ③What factors do you think will affect the transition preparation of children with autism to adolescents? What do you think is needed to prepare for the transition from children to adolescents? The interview was introduced with open-ended questions, and then the researcher gradually went deeper and deeper according to the answers of the research participants, narrowing down the scope of the questions and asking appropriate follow-up questions on the key information. During the interview, the researcher listened and observed the body language and emotional changes of the

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interviewees, listened attentively, and recorded the content of the interview, and tried to avoid the induction of the relevant scenarios until no new information appeared, i.e., the data were saturated, and the interview ended. Each interview time control in 30~40min.

Data collation and analysis

Interview data were created by two researchers directly with the file name by number, and all the contents of the interviewee's statement and the researcher's field observation records were inputted into a Word document and printed out, and the written data were repeatedly read, recalled the situation during the interview, analyzed the meaning of the words word-by-word, and then classified and coded by categorical reasoning. The data were analyzed using rows of categorical reasoning and coding. Data were analyzed using Colaizzi's 7-step analysis method: (1) reading all the data carefully; (2) analysing significant statements; (3) coding recurring ideas; (4) assembling the coded ideas; (5) writing a detailed, unambiguous description; (6) identifying similar ideas; and (7) going back to interviewees to seek confirmation. Interview data were collated and analyzed through a process of continuous reflection and verification by others to reconfirm the original data, compilation, and interpretation.

Ethical principles and quality control

The researcher has received in-depth study of theories related to transition preparation and training in qualitative research, which can ensure the reliability of the data collected in the study. In order to ensure the credibility of the study, this study follows the maximum difference method in selecting the interview subjects, with sufficient preparation before the interview, making detailed implementation plan; giving full consideration to the representativeness of the research subjects, establishing a trusting and friendly relationship with the main carers of the children before collecting the data; recording the interviews under the premise of informed consent, with the researcher maintaining a neutral attitude, encouraging the interviewees to fully express themselves and observing the non-verbal expression, recording the information such as tone of voice, intonation, facial expression and body language; the interview location was chosen in the pediatrics conference room, and all interviews were completed by two researchers, one for interviewing and the other for recording. The environment was kept quiet and free of interference, and the transcripts compiled after the interviews were asked to be checked by the interviewees for consistency with their wishes to enhance the credibility of the results.

Results

Theme 1: Barriers to transition readiness

Lack of awareness of transition readiness

There was a general lack of understanding of the concept of transition readiness and a lack of awareness of transition readiness amongst the child's primary carers. N1: "I'm not sure what transition readiness is, I've never heard of the concept. "N4: I think transitional preparation is giving transitional care to the child". N10: "I don't understand what I can do about transition preparation, I know very little about it. "N11: "The doctor explains to me what I should do, but I really don't understand".

Primary carers take on too much responsibility for disease management

Given the child's slight lack of daily living skills and the carer's over-indulgence, this would lead to the carer directly taking over the tasks that the child should be able to do on their own, thus affecting the child's readiness for the transition period. N1: "I think the child is too young, I'm afraid that they won't be able to do it well, I'm used to doing everything by myself". N3: "The child is not talkative and expressive, so out of instinct, one would involuntarily say and do for him, always wanting to get everything ready for him". N5: "I am usually afraid that some of my child's sudden behaviors may hurt myself or others, so I usually try to do everything for my child, so it causes my child to be very dependent on me".

Factors of the child's illness

Families of children with autism believe that social impairment, speech impairment and repetitive stereotypical behaviors of children with autism affect transition readiness. N1: "Parents say that when they communicate with their child, the child doesn't even understand, doesn't understand what is said, or doesn't listen to commands". N3: "He doesn't even socialize like people would kind of normally do, he plays with other children, he just shoves his toys and snatches other people's toys". N7: "He's so skinny these days, I don't know what's going on, the therapist said he doesn't listen in class like he did before, he just throws his toys at the teacher, he can't go to class at all". Staying up most of the night and making noisy noises, I feel so tired of looking after and correcting him".

Lack of resources for relevant knowledge training

Currently, parents mainly rely on the Internet and doctors as the two main ways to acquire disease-related knowledge. However, the authenticity of information on the Internet is difficult to distinguish, which brings great trouble to parents; on the other hand, due to the heavy pressure of their daily work, doctors often find it difficult to spare enough time to provide detailed guidance to parents.N1: "I usually brush up on Jitterbug ah, to see what people do, but I just don't know if it's useful". N6: "The therapist just gives you a talk after class to tell you how to do it at home, but we don't know the specifics, it would be nice if we could see how the therapist treats you in there". N9: "We just teach him at home, we just don't know if the process taught is the same as the therapist's". I would try to inquire about various training methods and various remedies and found a relatively reliable children's rehabilitation center after a headless process".

Lack of family and social support

Families of the children perceived multiple family and social barriers to a smooth transition to adulthood. N2: "The child's father never asked me if it was hard or tiring to treat the child outside and complained that the child was not making progress". N5: "In some cultures, autism is seen as a social burden, and they are not treated but abandoned". N3: "When raising children to socialize or communicate, some children or parents are reluctant to engage with us". N10: "My wife quits her job to stay home with my daughter for treatment, and one of us has to be on call in case something happens". N9: "The child needs long-term and special education and treatment, and the family is under great financial pressure, and we are eager to get support from the community, but we don't know if there are any relevant channels. Channels". N11: "Family members, teachers and classmates at school and people in the community can be exclusionary and judge us.

Theme 2: Facilitators of transition readiness

Strong desire for transition readiness amongst primary carers

Primary carers affirmed transition readiness and had a strong desire for the child to be able to access the educational needs of the school. N2: "If the child is well prepared, his transition to adulthood will definitely be a little bit smoother for him to recover from his own illness". N5: "I think transition preparation is definitely good for the affected person, he is able to take care of himself more, more confident and we can be a bit more relaxed". N12: "I think transition preparation is very necessary, the child can adapt to adult life faster, and we have less burden". N4: "If only we could let him play with normal children, learn more from others, not always with autistic children". N13: "At the moment, I just hope that he will be better than before, and preferably go to a normal school, I haven't thought about letting him go to a special school yet". N14: "I expect him to be able to live on his own when he grows up and he will be able to live independently when we are old"

Family and peer support

The main carers believed that family and peer support was an important part of the child's active participation in the preparation for the transition, and that family and peer support could not only enhance the child's confidence in facing the disease, but also promote the establishment of good cognitive and health habits. N3: "The child's imitation ability can be very strong, you can see that we can't even control him at home, but his sister is able to control He can follow whatever his sister does". N6: "I think the family support system has something to do with it, the child is more willing to be with the family that has been taking care of him, accompanying him, and more willing to communicate". N12: "The child is more willing to communicate with children of the same age, they should let their patients, classmates and friends communicate with them more so that they can live better like normal children".

Medical and environmental support

Medical workers pay attention to, and information technology is rich and varied, and can provide training on knowledge of transition preparation. N6: "You like Director Ma has a whole public number dedicated to it, I usually look at it when I am not doing anything, I can learn something". N8: "Therapists sometimes hold lectures and clinics; we can learn a lot by listening and looking". N11: "Sometimes the therapists also have live broadcasts on the internet, so we can listen to them at home". N7: "We often see adverts and public service activities related to children with autism, and the attention of society has increased our confidence in treatment, and we feel that we are not so lonely".

Discussion

Guiding primary carers to participate in the transition correctly

Lifelong rehabilitation for children with autism requires a lot of time, energy, and financial resources from the family's primary caregivers [16] and the primary caregiver's views on the willingness to participate in the transition preparation and the content of the intervention play an important role in improving the patient's knowledge of the disease and self-management skills. In this study, the primary caregivers fully affirmed the necessity and significance of transition preparation for their children and were willing to participate in their children's transition preparation through their own efforts and continuous learning. Therefore, healthcare professionals should attach great importance to the primary caregiver's knowledge of transition preparation and use it as an orientation to stimulate the primary caregiver's subjective initiative [17] so that he or she can guide the child and other members of the family to actively participate in the transition preparation. Early preparation strategies are adopted, using the accompanying visit as an opportunity for the child to observe doctor-patient communication styles and skills, and gradually transferring to the child the task of taking control of his or her condition and the concept of lifelong health care. At the same time, we provide psychological support to the child in a way that is appropriate to the child's development and psychological state and help the chronically ill child to realize the importance of taking responsibility for his or her health in the transition to illness.

Carrying out primary caregiver skills instruction to improve children's readiness for transition

The skill level of primary caregivers directly affects children's transition readiness, which is an important factor in promoting children's independent return and social integration [18-19]. In this study, there were still general deficiencies in the knowledge and management skills of carers, and it was common that parents were overprotective of their adolescent patients and assumed full responsibility for their disease management, while the children were less involved in disease management and lacked knowledge and skills for self-management. Studies have shown that the degree of parental involvement in disease management is negatively correlated with the transition readiness of adolescent chronic disease patients, and the more disease management responsibility parents assume, the worse the patients' transition readiness [20,21]. In this study, primary caregivers were eager to learn relevant knowledge and caregiving skills; however, parental involvement in the patient's disease management did not fully represent the effective role of family support. Caregiver or family characteristics, such as family management and family caregiving skills, can have an impact on adolescent transition readiness or quality of life [22]. Transition messages to the child's primary caregiver should be initiated in early adolescence to increase the awareness of transition readiness and self-management of the child and family. Transition preparation should be based on evidence through family meetings [23] peer-to-peer exchanges, online media, community clinics and other multi-channel methods, to understand the possible physiological and disease changes that may occur during the transition period of the child, transition needs at different points in time, and to develop personalized transition interventions, including knowledge of the disease, consultation with specialists, participation in decision-making, medication management, access to information, and the assumption of the responsibility for self-care [24,25] competencies to achieve better transition outcomes [25,26].

Explore the transition preparation model to build a transition system for children with autism

The establishment of a transition preparation service system for children with autism is an important factor in facilitating the regression of the disease and improving the quality of life of the children, as well as returning to and integrating into society independently with a good psychological state. Due to the special communication and intellectual characteristics of children with autism, studies have shown that primary caregivers are generally under great psychological and physical pressure in caring for children with autism, [27] and a comprehensive transition preparation service system is particularly important. There are fewer studies on transition preparation for autism at home and abroad. In a study of smooth transition preparation for adolescents with chronic illness, a foreign research team conducted a comprehensive transition programme, [28] including the development of a transition preparation assessment tool, a disease education manual, and a website for adolescents, their parents, healthcare professionals, and researchers to learn. In addition, the U.S. Department of Maternal and Child Health, in collaboration with the American Alliance for Adolescent Health Promotion (AAAHP), developed the Got Transition tool, [29] which consists of six core components: developing a transition policy, tracking transition progress, assessing readiness for transition, planning for adult care, transitioning to adult care, and integrating into adult practice, providing transition services for clinical practice. provides a framework for transition services in clinical practice. Overseas studies have pointed out that the establishment of transition teams or dedicated transition clinics that include pediatricians, adult physicians, nurses, and other multi-disciplinary experts can help to improve patients' level of transition readiness and facilitate a smooth transition [30,31]. Relevant researchers and healthcare professionals can form a multidisciplinary team, combined with China's national conditions and drawing on the content of foreign transition projects, to establish a transition preparation service system suitable for the families of children with autism in China, medical institutions and special education to accelerate the development of professional qualifications, popularize the knowledge of ASD disorders, and enhance the degree of social inclusiveness, to promote the return of children with autism and their integration into society.

Conclusion

This study explored the experience of transition preparation of primary caregivers of children with autism and summarized four themes: the existence of a lack of awareness of transition preparation among primary caregivers of families, the affirmation of the necessity of transition preparation, the existence of factors hindering the preparation of children for transition, and the promotion of factors that promote the preparation of children for transition. Managers should pay attention to providing the conditions for implementation of the intervention, actively carrying out skills guidance for primary caregivers, building a service system for transition preparation of children with autism, and constructing feasible intervention plans based on the influencing factors, so as to create good conditions for the implementation of the intervention for the primary caregivers of children with autism. Further research is needed from the perspectives of children and healthcare professionals to comprehensively explain the readiness of children with autism for transition.

Contributors

Yangyang Qin and Shu Liu were responsible for the topic selection, literature search, draf of the paper and data analysis. Danshi Hao participated in literature screening, literature quality evaluation, and made the fnal revision of the paper. All authors conducted the search of literature, reviewed the articles, helped with data synthesis and interpretation, and played a major role in writing the manuscript. All authors agree to publish.

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Conflict of Interest

No conflict of interest.

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