

Information needs and services for autism in China: is there any gap between them?

Information
needs and
services

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Abstract

Purpose – This study aims to explore the gap between information needs and services for autism in China.

Design/methodology/approach – The gap is revealed by investigating the status quo of autism information needs and services. The authors extracted categories and subcategories of information needs through content analysis of academic documents and then supplemented the subcategories through text mining of an online forum. Meanwhile, categories and subcategories of information services were extracted through content analysis of autism websites. Finally, the authors matched the two to explore the gap and designed a quantitative index to measure it.

Findings – A total of eight and ten categories of information needs and services are extracted, respectively. In total, six categories of information needs can be partly matched, but nearly half of the subcategories failed. Huge gaps in economic support, sociality and policy mechanisms categories are observed through the quantitative index and medium gaps in social resource services and employment categories while almost no gaps in psychological/emotional counseling, rehabilitation skills training and professional knowledge/information categories.

Originality/value – This study takes a deep insight into the gap between autism information needs and services in China, providing evidences and suggestions for information providers to improve their services. Academic documents and online forum data are adopted to avoid the impact of stigmatization, which provides a multi-source data analysis approach for the information needs of special groups.

Keywords Autism, Information need, Information service, Information gap, China, Multi-source data

Paper type Research paper

1. Introduction

Autism spectrum disorder (ASD), hereinafter referred to as “autism”, is a congenital brain disorder that usually occurs in early childhood. In a broad sense, presented by the American Psychiatric Association, autism includes autistic disorder, Asperger syndrome, childhood disintegrative disorder and pervasive developmental disorder. Whether it is Asperger



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syndrome (on the high-functioning end of the spectrum) or autism disorder with more severe symptoms, children with autism often have problems with pretend play, social interactions, verbal and nonverbal communication (Neil, 2018) and repetitive behaviors (Miles, 2011). According to the reports in 2017, there were at least ten million people with autism in China, among which two million were children (Institute, 2017). Unfortunately, China Disabled Persons' Development Statistical Bulletin 2019 (Federation, 2020) revealed that there were only 2,238 rehabilitation service institutions for autistics and nearly half of which were privately founded by parents of autistics, hence the lack of quantity, quality and authority of service. Therefore, as a supplement, the Internet has become a common information source for people trouble by autism (in this study, specifically refers to families of autistics).

In reality, the disorder brings stigma, misconceptions and social discrimination on autistic children and their caregivers. The concept of "Face" and shame-socialized intensifies the problem (Liao *et al.*, 2019), preventing caregivers from talking about autism in real life. This phenomenon is common in many vulnerable people, such as young first-time mothers and HIV/AIDS patients, whose information needs are often unclear, unobvious and even sensitive (Ruthven *et al.*, 2018; Zukoski *et al.*, 2011). Thus, health information services for these vulnerable groups are of great social significance and challenge, as well as an important and valuable research question in consumer health informatics (CHI) from the research perspective of special groups. This research focusing on autism information needs and services, which refer to the information needs and services for or related to autism, would provide new insights for a better understanding of these vulnerable people and would improve the research of CHI.

There have been some studies on autism information needs and services. Liu and Zou made an overview of the needs of and social support for autistic children's parents in China and classified them into five categories (Liu and Zou, 2015). Nevertheless, researchers ignored the information needs of autism-related users posted on the Internet in China and have not developed comprehensive and well-structured information needs categories for autism. On the other side of information services, the review by Sun *et al.* of healthcare service and education provision of autism in China pointed out an underdeveloped system of service provision for autism domestically (Sun *et al.*, 2013). Similarly, there is no sufficient research on online autism information services in China. Usually, studies on autism information only highlighted either needs or services, seldom giving attention to both sides.

In fact, information needs and services are interconnected. Research on information needs conduces to improve knowledge services by matching user needs with increasing information resources (Ma *et al.*, 2017). Knowing what information consumers need will assist with the presentation of healthcare information (Clarke *et al.*, 2016). Therefore, this paper mainly focuses on the integrated consideration of autism information needs and services for further advance in highlighting the gap between the two ends. This paper not only improves the theory of CHI by offering new ideas to study the information needs and services of such special groups but also provides references for information service providers to improve their services.

2. Literature review

2.1 Autism information needs

Information needs, which are thought to arise from basic human needs that have cognitive, physiological and psychological/emotional qualities (Wilson, 1981), provide an initial impetus to information seeking and keep the information-seeking process as a driver (Savolainen, 2017). Similar to information needs in general, health information needs, that information needs within the context related to health, incorporate physiological, cognitive and affective elements that drive people to seek information about disease prevention, detection and

treatment or information that will provide aid in dealing with the disease emotionally (Wilson, 1991). Some scholars believe that from the perspective of patient needs, it is more valuable to define health information needs in a broader context. In other words, to some extent, patient needs such as financial needs, support needs and legal needs should be taken into consideration (Chi *et al.*, 2020). Recent studies on health information behaviors (e.g. health information seeking) (Oh *et al.*, 2016) and health information literacy (Enwald *et al.*, 2015), which pay more attention to vulnerable groups (e.g. older people, people with depression) (Enwald *et al.*, 2017; Tana *et al.*, 2020), contribute to in-depth research on health information needs.

Autism information needs are considered to be a particular type of health information needs. Related studies focused on the specific information needs of autistics' families, including knowledge of disease, rehabilitation or information about special programs and services (Martinović and Stričević). Some scholars identified the topics of autism information needs in their studies, but the categories of each paper differ a lot. The topics included but not limited to professional information, rehabilitation, social security, psychological support (Liu and Zou, 2015), medicine and health, therapy, school and education, employment and higher education, social and recreational activities, government agencies and financial assistance (Gibson *et al.*, 2017). Unfortunately, the above information topics were characterized at a general level only. While scrutinizing the specific content of information needs, other scholars tend to focus on certain topics such as psychological needs (Zhao *et al.*, 2017), special educational needs (Su *et al.*, 2014; Van Herwegen *et al.*, 2018) and sexual education needs (Mackin *et al.*, 2016). All of the above shows that there is still a lack of comprehensive, systematic and structured categories of autism information needs.

Research methods on health information needs include interviews, surveys and alternatives (e.g. manual or automatic text analysis of user-generated content (UGC) (Pian *et al.*, 2020) or document analysis). When it comes to autism information needs, most studies employed interviews or surveys. Some researchers interviewed parents or educators of autistics (Hoppe, 2005; Dieleman *et al.*, 2018; Li *et al.*, 2016) or conducted focus groups (Rabba *et al.*, 2019). These face-to-face methods are conducive to accumulate more context information and detailed descriptions, but have the disadvantages of small sample size and strong subjectivity of authors. Other scholars used a survey-based methodology to get a bigger size of statistics, making the quantification of information needs possible (Papageorgiou and Kalyva, 2010; Van Herwegen *et al.*, 2018; Huang *et al.*, 2009; Gu and Liu, 2016; Guo *et al.*, 2014). Also, some scholars combined interviews and surveys (Green, 2007; Lin *et al.*, 2007; Su *et al.*, 2014; Gibson *et al.*, 2017).

Besides, some scholars used alternatives methods through relevant academic documents (Liu and Zou, 2015) or UGC on the Internet (Beykikhoshk *et al.*, 2015; Shi and Xu, 2015). On the one hand, content analysis of academic documents could be used to make an overview of previous research by determining and quantifying the category of autism information needs from the research results (Liu and Zou, 2015). On the other hand, the lack of information leads parents of autistics to consult, share and exchange information online (e.g. online forum) (Chávez and Sabelli, 2020; Lin and Chang, 2018). For these special groups, the online environment allows them to more freely ask for sensitive information (Ruthven *et al.*, 2018), and the online UGC has become fresh and effective research data for the study on health information needs (Hasler *et al.*, 2014; Ji *et al.*, 2017). In previous studies, the content analysis (e.g. open-coding analysis) (Shi and Xu, 2015; Abel *et al.*, 2019; Roffeei *et al.*, 2015; Boursier *et al.*, 2019) and data mining method (Beykikhoshk *et al.*, 2015) have been used on autism-related UGC. But seldom aimed at studying the information needs. Merely two articles retrieved from paper databases employed China's autism-related UGC as research data (Jin, 2016; Shi and Xu, 2015), indicating that domestic UGC has yet to receive due scholarly attention for studying autism information needs.

2.2 Autism information services

The growing consumer health information needs inject great impetus to the development of health information services, among which health information website is an important form. The health information websites with a large amount of disease-related information have become an important source for patients and their families to meet their health information needs. These websites can be generally divided into two types: the comprehensive one including various diseases and the specific one for a certain disease. Previous studies explored the content (Steiner *et al.*, 2019; Vivion *et al.*, 2020), quality and readability (Sowtera *et al.*, 2016; Udayanga *et al.*, 2020; Whitten *et al.*, 2013), and structural characteristics (Rains and Karmikel, 2009) of health information websites by qualitative or quantitative analysis methods.

For autism, previous studies demonstrated that 86% of parents of autistic children had used websites as sources of information (Mackintosh *et al.*, 2005), and national organization websites (14.35%) and other websites (9.34%) are the top two preferred Internet sources for autistics' parents (Gibson *et al.*, 2017). These parents are looking for information from different sources, expecting to have a more centralized channel to meet their information needs (Martinović and Stričević). It can be said that the websites play important roles in the integration and provision of autism information service. There are many websites of the National Autism Associations globally, such as the Autism Society of America (<http://www.autism-society.org>), Autism Society Canada (<https://autismcanada.org/>) and National Autistic Society (United Kingdom) (<https://www.autism.org.uk/>). Stephenson *et al.* examined the quality of the information in terms of educational and therapy interventions on these official websites by coding (Stephenson *et al.*, 2012). The quality of information in autism-relevant websites was also evaluated by using the DISCERN tool (an instrument for judging the quality of consumer health information on treatment choices) (Grant *et al.*, 2015) or content analysis (Reichow *et al.*, 2012). Some other scholars focused on the content of the websites by extracting the tabs of the Autism Society of America (Thomas, 2017) and analyzing eight websites of autism organizations through conventional content analysis (Leatherland and Chown, 2015).

However, there is no official website of autism information service in China yet. Even the official website of the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR, <https://www.cappdr.org/>) does not pay enough attention to autism. Yu and Xu made a simple comparison of Chinese and American autism network services during constructing the knowledge base of autism Q&A, suggesting that autism websites in China though rich in content were scarce and lack of authority (Yu and Xu, 2015). Besides, few studies have focused on the autism websites in China. Therefore, it is of great significance to study what information is available and what is still in need of Chinese autism websites.

The review of prior research indicated that although many studies have been conducted to examine autism information needs, these investigations have not identified a comprehensive and sufficiently specific set of categories depicting needs of this type. Previous studies also ignored the focus on UGC (needs expressed by users on the forum). On the other hand, few studies have focused on Chinese autism websites, which makes it difficult to understand what autism information is available and what is still to be needed. Besides, prior studies tended to focus on one of autism information needs or services. Such a fragmented perspective restricts our understanding of their relationships. Only by clarifying the gap between the information needs and services, we can make more reasonable suggestions for information service providers so that they can provide something that the autistics and their families really need. Thus, to explore the gap between information needs and services for autism in China, the research questions in this paper are

RQ1. What are the users' autism information needs in China?

RQ2. What information services do China's online autism information services provide?

Based on RQ1 and RQ2, RQ3 is raised: Is there any gap between autism information needs and services in China? If so, where are the gaps?

3. Methods

This study employed multi-source data and multiple methods to answer three research questions (Table 1).

3.1 Autism information needs from academic documents and online forum

First, categories and subcategories of information needs were extracted from relevant academic documents through content analysis. Chinese documents were taken from China National Knowledge Infrastructure (CNKI) and English ones were from Web of Science. Because autistics' parents are the main users of autism information, "user" was defined as "autistics' parents" here to exclude irrelevant content for accurate and targeted search results. The first search query was "autism". The second search queries "parent(s) need(s)" and "family need(s)" were searched within the results of the first query. Synonyms for "need(s)" including demand(s) and requirement(s) were also searched to make sure the all-inclusion of relevant documents. In the search results, we only retained the documents whose research object or scope is about China. Finally, we got 32 Chinese documents and three English documents whose publish date are from December 2007 to May 2019. Although there have been some studies on autism information needs in the world, little attention has been given to China, so the number of documents able to be taken as references for the research was relatively small.

The content analysis was independently conducted by two coders. First, we located the information needs described in the document, often in results or discussion parts. And then, the categories were extracted from headings concluded by each document, and the subcategories subordinate to the above category were extracted from the text following this heading. An example of the analysis process is given in Figure 1. The intercoder reliability calculated by the Holsti formula (Holsti, 1969) was 0.87. Regarding the typology of health information needs (Rutten *et al.*, 2005), two coders negotiated the discrepancies and reached a consensus. Finally, the categories were quantified rather than the subcategories since the former one was more inductive. The statistical process could be explained as whenever the subcategory was mentioned, the frequency for the category would be increased by certain times accordingly.

Second, text mining on forum posts submitted by users (most of them are family members of autistics) was conducted to supplement the subcategories of autism information needs. The Elim Autism Forum (<http://new.elimautism.org/>) was selected as the data source, which had the most posts about autism in China. Posts of four main modules in Elim Autism Forum ranked by hits from November 2001 to May 2019 were crawled by Scrapy framework in Python. After cleaning irrelevant posts, 1053 posts were finally adopted. A keyword list can accurately describe information needs which are often multifaceted, and each aspect can be

Research question	Research data	Research methods
RQ1 (Information needs)	Relevant academic documents Online forum posts	Content analysis Text mining
RQ2 (Information services)	Autism information websites	Content analysis
RQ3 (The gap between information needs and services)	Results of RQ1 and RQ2	Content analysis

Table 1.
Research data and
methods in this study

described by many keywords (Ma *et al.*, 2017). Thus, a keyword list was chosen as a representation of information needs on the forum. Word segmentation of posts was done by jieba (a tool for Chinese word segmentation) in Python, adding a custom dictionary and a stop word dictionary from the network. The term frequency-inverse document frequency (TF-IDF) algorithm was used to select keywords to represent the main content of the posts. Then a cword matrix of TF-IDF Top250 keywords was constructed, and hierarchical clustering analysis was conducted by SPSS based on it. According to the clustering result, we cut the dendrogram at the desired level and named the topic of each cluster by manual interpretation of keywords in it.

Finally, the above two classification results were manually combined into one table according to their characteristics. This manual combination work was conducted by two coders and the intercoder reliability calculated by the Holsti formula (Holsti, 1969) was 0.864. After sufficient negotiation, two coders reached a consensus of the final matching result. To measure the need intensity, a quantitative index was designed, which considers the document frequency and the keyword count of the need categories (Formula sees 4.1.3).

3.2 Autism information services from autism websites

The websites were selected from the searching results on Baidu (<https://www.baidu.com/>) (Surman and Bath, 2013; Steiner *et al.*, 2019), whose penetration rate among search engine users reached 90.9% (CNNIC, 2019). The query “autism website” was used to search autism information websites in China. URLs to be selected were from the first three pages (30 links). Excluding comprehensive health information sites, news pages, forums, advertisements and rehabilitation agency portals, six websites were finally adopted: a. China Autism Network (<http://www.cautism.com/>), b. China Autism Support Network (<http://www.guduzheng.net/>), c. Autism China (<https://www.autismcn.com/>), d. 99 Autism (<http://www.99zbz.com/>), e. Autism Network (<http://www.guduzheng.com.cn/>), f. Home of Autism (<http://zibizheng.com/>). These websites are dedicated to providing information and services related to autism. Although this is not a complete collection of websites, it covers the websites most frequently used by users. Data were collected before November 2019.

The website navigation is the organization and disclosure of network information resources (Gao and Yang, 2002). In this study, the categories of information services were extracted from the website navigation bar and subcategories from its subordinate ones. Due to the diversity of websites and the lack of a unified knowledge structure, there were some differences between the navigations of each website. After the integration of different expressions of the categories sharing the same meaning, the categories were allocated following the frequency principle: if a category can always be found in the first category of navigation on websites, naturally it should be classified as the first category; otherwise, it should be recognized as subcategory belonging to its upper-level category where it appeared

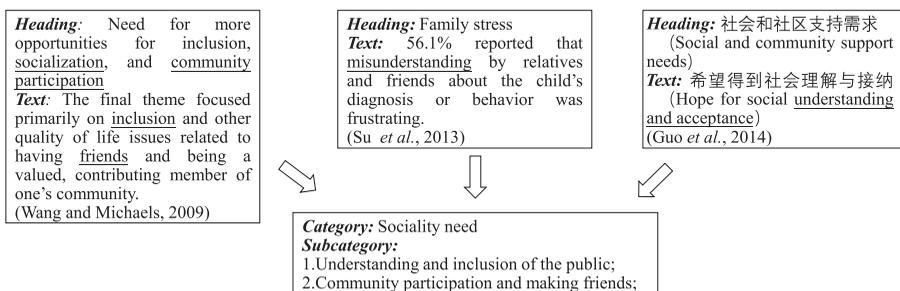


Figure 1.
An example of content analysis of academic documents

the most frequently. Besides, some categories irrelevant to this study were removed, such as “Online examination” and “Contact us”. This process was also performed by two coders. The intercoder reliability calculated by the Holsti formula (Holsti, 1969) was 0.892, and discrepancies were resolved through discussion. Finally, we calculated the frequency of each subcategory.

3.3 Compare to reveal the gap

We used content analysis to compare information needs with information services in an all-round way to determine whether there was a gap and where the gaps were. For each subcategory of information needs, it would be matched to the service category or subcategory that satisfied the needs. This process was also performed by two coders and the intercoder reliability calculated by the Holsti formula was 0.873. Finally, a quantitative index was designed to measure the matching degree (Formula sees 4.3).

4. Results

4.1 Autism information needs

4.1.1 Information needs from documents. Through content analysis, eight categories and 26 subcategories of autism information needs were extracted from academic documents. The categories and their frequency are shown in Figure 2. The subcategories will be presented later (Table 4 in 4.1.3). As shown in Figure 2, the information needs are diversified, covering a wide range but unevenly distributed. In fact, users are not only concerned with the autism disorder itself, such as the professional knowledge and rehabilitation skills, but also some emotional and economic problems, which caused by autism that affect their daily life and family relationships.

4.1.2 Information needs from online forum. TF-IDF Top10 of keywords from Elim Autism Forum were shown in Table 2. In total, ten clusters of 250 keywords are shown in Figure 3 with the keyword count. A hand of keywords were adjusted in terms of their clusters according to the consumer health knowledge map related to autism put forward by Jin (2016). An example of the “Professional institutions/personnel” cluster is given in Table 3. As the same results of information needs from documents, that from the forum are distributed unevenly too.

On the forum, users prefer to describe phenomena or events in their lives rather than express their needs directly. For example, users tend to describe the child’s abnormal behavior (such as stereotypical behavior, screaming, etc.) rather than directly pose the question that what the symptoms of autism are, which is what they want to know. The habit of describing something stops the word “symptom” from being posted on the forum. As a

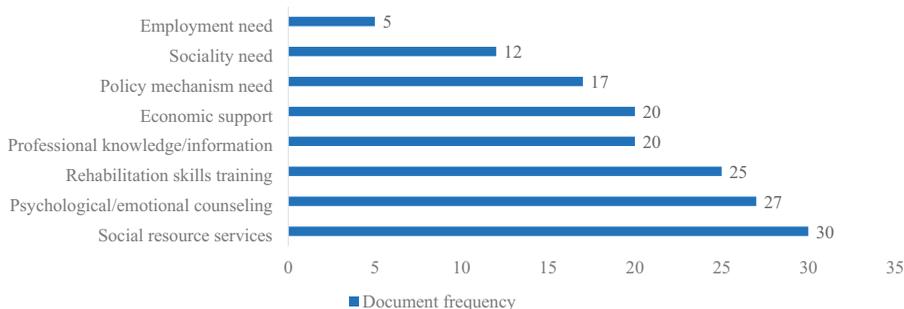


Figure 2. Information needs categories from the academic documents

result, in the process of naming the keywords clusters, we were supposed to infer the implicit needs hidden behind the user’s oral presentation. This inference is also one of the bases for combining the two results of information needs into one table.

4.1.3 *Comprehensive information needs.* Based on the two results from academic documents and forum posts, comprehensive autism information needs categories were summarized in Table 4. From Figures 2 and 3, we can find that the categories from documents and the forum were not all one-to-one correspondence. In the process of combination and supplement, the social results of the forum were integrated into the rigorous results of the documents because the interpretability of machine clustering is not as strong as the manual classification applied in documents. Two coders assigned each keyword to a corresponding subcategory in Table 4 according to its literal meaning and potential needs by inference from the original posts. The subcategories were supplemented if some keywords cannot be categorized into the existing subcategory. Take the keywords in Table 3 for example, keywords “center, special education, institutions, services” correspond to subcategory “Medical and rehabilitation education institutions”, keywords “professional, consult, Zou Xiaobing, experts, lectures” correspond to subcategory “Professional consultation” and

Table 2.
TF-IDF Top10
keywords

Keywords	TF-IDF	Keywords	TF-IDF
Behavior	0.01663	Game	0.00728
Training	0.01367	Instruction	0.00689
Teacher	0.01164	Language	0.00688
Ability	0.00878	Learning	0.00643
Emotion	0.00815	Method	0.00639

Figure 3.
Keywords clusters
from the forum

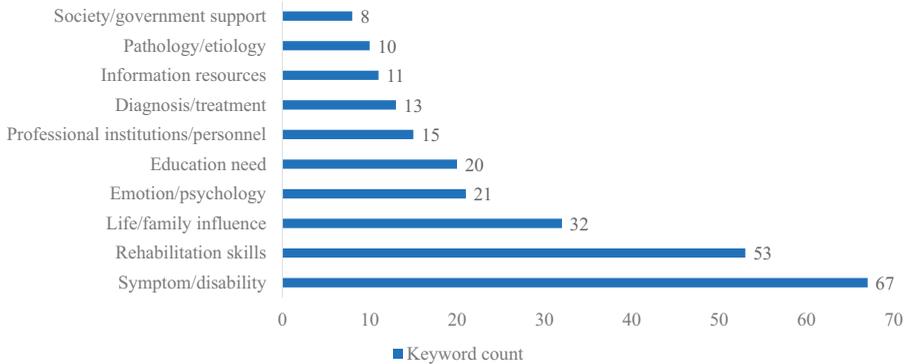


Table 3.
An example of
keywords cluster

Category	Keywords	Keyword count
Professional institutions/ personnel	Guide, lecture, center, lead, early education, experts, special education, professional, consult, training, institution, Zou Xiaobing*, services, special teacher, personal training	15

Note(s): *Zou Xiaobing is a famous expert on autism in China

Category	Subcategory	Representative keywords (*Keyword source)	Document frequency	Keyword Count	Need intensity
Social resource services	School and integrated educational environment Medical and rehabilitation education institutions Professional consultation Care placement	Accompany reading, school, kindergarten, teacher, learning, lessons (4) Center, special education, institutions, services, early education (7) Professional, Zou Xiaobing, experts (7) Grow up, self-care, future (3)	30	40	0.51
Psychological/emotional counseling	Relieve negative emotions Families communication Psychological counseling Family reconciliation	Anxiety, fear, breakdown, worry (5) Communicate, forum, comfort, discussion, emotion, sharing, confidence (3, 5, 8) Psychological, help(5) Second child, divorce, family, the aged (3)	27	30	0.45
Rehabilitation skills training	Professional guidance Rehabilitation methods	Special teacher, guide, lectures, training (7) Remind, nursery rhymes, rewards, corrections, game, toy, sensory integration, interventions, tabletop, punishments (2)	25	58	0.47
Professional knowledge/information	Diagnosis of autism Treatment of autism News information *Symptom and disability *Relevant life information *Cause and pathogenesis	High-functioning, hospital, examination(9) Music, early intervention, RDI(9) Articles, computers, newspapers, information, knowledge, television, research (4,8) Stereotyped, scream, self-talk, behavior, imitation, language, ability, instruction (1) Renting house (3) Mind, genes, Asperger, environment (6)	20	100	0.49
Economic support	Government and education subsidy Charity donations Property trusts	Government (10) Public welfare (10) —	20	2	0.29

(continued)

Table 4.
The comprehensive categories of autism information needs

Category	Subcategory	Representative keywords (*Keyword source)	Document frequency	Keyword Count	Need intensity
Policy mechanism need	Respite care policy	—	17	2	0.25
	Social security system and relevant legislation	Disabled person(10)			
Sociality need	*Immigration policy	America(10)			
	Understanding and inclusion of the public	Society, culture, stranger, community (3,10)	12	17	0.21
Employment need	Community participation and making friends	Sociality, socialize, daily life, playmate, peers(3)			
	Employment care Vocational education	Work (3) —	5	1	0.07

Note(s): *Keywords cluster: 1. Symptoms/disability. 2. Rehabilitation skills. 3. Life/family influence. 4. Education need. 5. Emotion/psychology. 6. Pathology/etiology. 7. Professional institutions/personnel. 8. Information resources. 9. Diagnosis/treatment. 10. Society/government support. * The subcategories in bold with * are newly supplemented contents from forum keywords

Table 4.

keywords “training, personal training, special teacher, guide, lead” correspond to subcategory “Professional guidance”.

In Table 4, the categories are all from academic documents. The subcategories that list the contents of each category mostly derive from documents, while the bold with * are newly supplemented contents from forum keywords. With their cluster source noting in the parentheses, representative keywords derived from the forum are partly displayed to show what words people would use to express their needs online. Some subcategories have no keywords noted with “—”, suggesting that users hardly express these kinds of needs on online forum. The frequency of documents, the keyword count and the need intensity of each category are listed behind. To measure the need intensity (NI), we designed a quantitative index as Formula (1):

$$\text{Need Intensity}(NI_i) = \alpha * \frac{F_i}{N_d} + (1 - \alpha) * \frac{N_i}{N_k} \quad (1)$$

Where F_i is the document frequency of the i -th category in Table 4, and N_d is the sum of document sample. N_i is the keyword count of the i -th category, and N_k is the sum of keywords. The parameter α decides the weight of document frequency and number of forum keywords, whose value can be determined by the graph method. In Figure 4, we try the value of α of 0.4, 0.5 and 0.6, suggesting that α only influences the rankings of the first four need categories. Since the keywords from the forum are more scattered and less rigorous than the subcategories from documents, the weight for the document frequency should not be smaller than that for the number of forum keywords, 0.4 should be excluded. When α is equal to 0.6, the NI of professional knowledge/information, rehabilitation skills training and psychological/emotional counseling are with little difference. So here $\alpha = 0.5$ is appropriate to measure the NI.

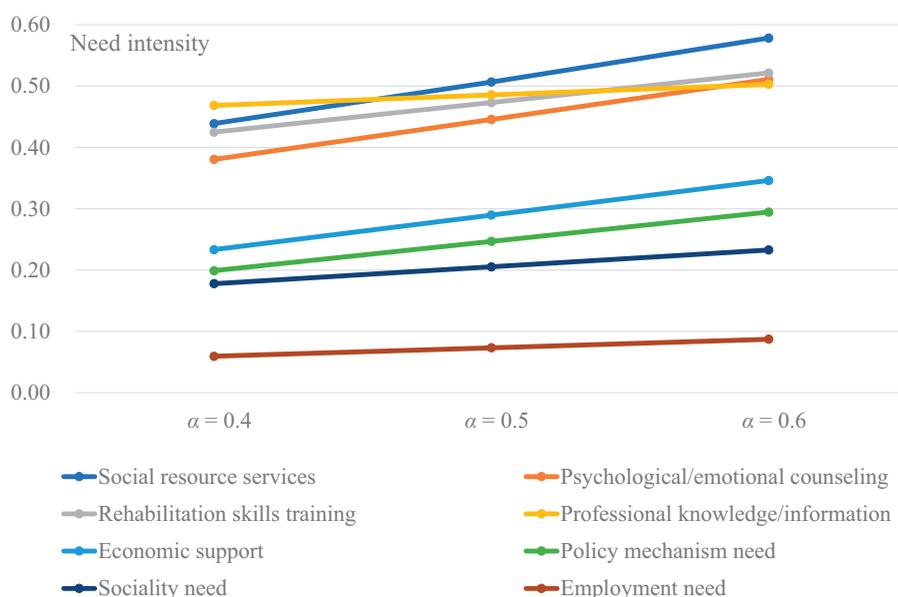


Figure 4. Need intensity of different value of α

4.2 Autism information services

Table 5 shows the content analysis result of the six autism information websites from the following dimensions: category, subcategory and sites frequency of subcategory. Autism information services on websites cover a wide range of information with uneven distribution. The majority of the websites provide basic knowledge and news about autism, such as autism symptoms, diagnosis, rehabilitation and other information concerned by parents. The services are concentrated on “Autism rehabilitation” and “Treatment method”, and there are more than ten subcategories under these two categories. But are these services enough? It is necessary to compare and match the information needs with services to make the final judgment that whether there is any gap between them and where the gaps are.

4.3 The gap between information needs and services

The comparison and matching of Table 4 and Table 5 by content analysis can discover the gap between the information needs and services. Each need subcategory in Table 4 is matched to the service category or subcategory in Table 5 whose content can meet this need. For example, in need category “Social resource services”, the subcategory “Medical and rehabilitation education institutions” can be matched to the service category “Experts and institutions”. “Professional consultation” can be matched to “Autism experts”, “Online consultation” and “Training seminars”. But the two need subcategories “School and integrated educational environment” and “Care placement” cannot be matched to any service category or subcategory. One need can be matched by many service categories or subcategories, and vice versa, so the need and service categories are many-to-many correspondence. In some cases, some need subcategories are failing to find their matching pair in the service categories or subcategories, suggesting that there are gaps between them. In order to measure the gap, a quantitative index-matching degree is defined as Formula (2):

Category	Subcategory	Site frequency	Subcategory	Site frequency
News information	Media attention	5	Research progress	3
	Policy and regulation	5	School and employment	1
	Training seminars	4	Home of volunteers	1
Understanding autism	Symptoms and manifestations	6	Treatment of autism	5
	What is autism	5	Prevention of autism	3
	Causes of autism	5		
Diagnosis of autism	Distinguish and identify	3	Clinical diagnosis	2
	Diagnostic hospitals	2	Psychological tests	1
Autism rehabilitation	Language training	6	Gross motor	2
	Social interaction	6	Fine motor	2
	Self-care	6	Family training	2
	Cognitive training	5	Skill training	2
	Emotional behavior	5	Nutrition	1
	Aging curing	3	Physical fitness	1
	Sensory integration training (SIT)	5	Floor time	3
	TEACCH Structured Teaching	5	Picture Exchange Communication System (PECS)	3
Treatment method	Applied Behavior Analysis (ABA)	5	Drug therapy	3
	Play and Culture Intervention (PCI)	5	Animal therapy	1
	Inclusive education	4	Music therapy	1
	Auditory Integration Training (AIT)	4	Chinese traditional treatment	1
	Relationship Development Intervention (RDI)	4	Natural training	1
	National autism institute	4	Autism teacher	1
	Autism experts	4		
	Mind course	4	Parenting essay	2
Parent world	Psychological counseling	2	Father and mother	1
	Autism movie	4	Autism TV	2
	Media broadcast	3	Autism documentary	1
Video highlights	Expert lecture video	3	Charity video	1
	Training teaching	3		
	Rain Man Story	3	Autism lesson plan	2
Abstracts and stories	Abstract browse	3	Academic papers	2
	Autism celebrities	2	Expert articles	1
	Autism books	2		
Other services	Online consultation	3	Teacher training	1
	Trust Evaluation Center	1		

Table 5.
The categories of autism information services on websites

$$\text{Matching degree}_i = \frac{MNS_i}{TNS_i} * 100\% \quad (2)$$

Where MNS_i is the number of already matched need subcategories in the i -th category, and TNS_i is the sum of need subcategories in the i -th category in Table 4. The matching degree represents how many subcategories of each need category have been satisfied by the available services. Table 6 shows the gap between autism information needs and services.

Need category	Need intensity*	Matching degree*	Which need subcategory is not matched
Social resource services	0.51, Medium	0.5, Partly	Schools and integrated educational environment Care placement
Psychological/ emotional counseling	0.45, Medium	1.0, Mostly	—
Rehabilitation skills training	0.47, Medium	1.0, Mostly	—
Professional knowledge/ information	0.49, Medium	0.83, Mostly	Relevant life information (e.g. renting a house)
Economic support	0.29, Weak	0, Seldom	Government and education subsidy Charity donations Property trusts
Policy mechanism need	0.25, Weak	0.33, Seldom	Breathing services Immigration policy
Sociality need	0.21, Weak	0, Seldom	Understanding and inclusion of the public Community participation and making friends
Employment need	0.07, Weak	0.5, Partly	Vocational education

Note(s): * The threshold division of need intensity (Table 4) and matching degree: Weak/Seldom: 0.0–0.35. Medium/Partly: 0.36–0.67. Strong/Mostly: 0.68–1.0. (Taylor, 1990)

Table 6.
The gap between autism-related information needs and services

The qualitative description of need intensity and matching degree refers to the threshold division of correlation coefficient (Taylor, 1990). For each need category, the mismatched subcategories are listed in the last column, which figure out where the gaps are and can be seen as the striving direction for information providers.

5. Discussion

5.1 Findings

In this paper, we find the gap between autism information needs and services and get some extra findings during the investigation of the needs and services.

For RQ1 (what are the users' autism information needs in China?), there are eight categories, and 26 subcategories of autism information needs are extracted from academic documents and online forum, making up for the previous research' blank. Before, Gibson *et al.* divided the autism information needs into six categories by open coding as follows: medicine and health, therapy, school and education, employment and higher education, social and recreational activities and government agencies/financial assistance (Gibson *et al.*, 2017). Except for the above six categories, some important information needs that have been overlooked are discovered in our study, such as the need for psychological/emotional counseling. Moreover, the information needs are subdivided into subcategories in more detail. In addition, there was an unexpected discovery that there is no information need for sexual education in China seemingly while that is considered necessary and important by parents of autistics in the United States (Mackin *et al.*, 2016). One possible explanation is that amid traditional Chinese culture, users' attitude toward sex and its relevant knowledge is comparatively conservative.

Moreover, some differences exist in the ranking of information needs from two data sources. In academic documents, social resource services are concerned most, and psychological and emotional counseling and rehabilitation skills training rank 2nd and 3rd, respectively. While on the forum, symptoms and disability are mentioned most,

rehabilitation skills and life/family influence rank 2nd and 3rd, respectively. It can be concluded parents as subjects of interviews or surveys are more likely to ask for social help in education, medicine and psychology. In contrast, users on the forum focus more on people with autism and care much about the information of symptoms and rehabilitation by sharing their experience. Moreover, these two data sources are complementary. Some information needs categories only appeared in one source. For example, "Symptoms and ability" only appeared on the forum while "Respite care policy" only appeared in documents. The possible explanation is that the users on the forum usually describe symptoms and share the experience, which they are unwilling to share in real life, resulting in many keywords in "Symptoms and ability". Network users may rarely consider certain formal or indirect needs (such as respite care policy and property trusts). The low value of TF-IDF also may hinder the discovery of these indirect needs.

For RQ2 (what information services do China's online autism information services provide?), website information services with ten categories and 65 subcategories are extracted, and the results reveal that the majority of the autism websites in China have not been structured reasonably with rigorous knowledge organization. The classification of the service categories is sometimes overlapped or confusing for the users. For example, some websites regard "Autism rehabilitation" and "Treatment method" as two classes, but others combine them into one or divide them into several classes. In fact, there is no authoritative statement to tell their differences or connections, hence no clear boundaries between them. A similar situation occurs in some other categories. For the settlement of casual classification, it is necessary to construct an authoritative autism knowledge structure or to establish a national official autism information website like Autism Society of America.

For RQ3 (whether there is any gap between autism information needs and services in China?), the answer is yes. We find that the gap exists obviously, and there still some important information needs fail to be matched by autism website services. The matching degrees show that the information needs for economic support, sociality and policy mechanisms are hardly matched. Before, Xiong *et al.* found that parents of children with autism had the heaviest financial burden but did not receive as much economic assistance as families of physical disabled and mental disabled children (Xiong *et al.*, 2011). Acquiring economic assistance needs parents of autistics to get the disability certification but they did not want to do so (Xiong *et al.*, 2011), which suggests a need for an assistance mechanism for autism distinguish from other disabilities. Many studies showed that parents live under great social pressure, and they struggle to accept their children as autistics (Billstedt *et al.*, 2011; Constantini, 2014), requiring an inclusive society without discrimination. Besides, the information needs for social resource services and employment are only partly satisfied while that for psychological/emotional counseling, rehabilitation skills training and professional knowledge/information mostly. These mismatched information needs can be divided into two kinds: one is that it cannot be satisfied unilaterally by providing information services through the network, such as the need for schools and integrated education environment, care placement, education subsidy and policy mechanism, which call for the joint efforts of all walks of life to create a more inclusive and autism friendly society. Another one is the need that information service providers have not yet considered, such as sociality needs, charity donations, vocational education, relevant life information and so on. These needs can be satisfied gradually by the improvement of providers. In addition, the matching degree is only the symbol of the matching coverage of information needs. Though the matching degree equal to one, it does not mean that there is no need to better the provider's services. For example, the need for "Family reconciliation" is satisfied by only one service subcategory "Father and mother", far away from being enough. More services for families are still needed. In the same way, the matching degree equal to zero does not mean that they are not satisfied at all because they may be satisfied by other means. For example, "Community participation

and making friends” of “Sociality need” can be satisfied through other platforms such as dating websites.

5.2 Implications

This study has both theoretical and practical implications. Theoretically, this study improves the research of CHI. First, the comprehensive and structured categories of autism information needs could help other research on autism-related information behaviors to understand their information needs, filling the research gap of CHIN in the field of autism. Second, the results confirm that employing multi-source data helps to discover the information needs of such special groups plagued by stigma from an overall perspective. Online data could be adopted to find their potential information needs when they suffer stigma or other difficulties. Lastly, previous studies ignored the online information needs and services in China, and we make up for this research vacancy by adopting online data and combining information needs and services in one research.

In practical, this study provides evidence for information service providers to enhance their services. First, the exhaustive autism information needs show to society what they really need and call for attention and inclusion. Second, the categories of autism information needs could be used as a reference for the navigation design of websites. Third, for those information needs ignored by the information providers above, five suggestions are proposed, offering reliable bases and references for the high-quality development of information services, and for the whole society to create an autism-friendly environment: (1) Pay attention to family relationships. Provide more counseling services about family and marriage, such as divorce, second child and others. Healthy and harmonious family relationships are more conducive to the development of autistic children. (2) Popularize autism knowledge for a more inclusive society for autistics. Understanding by society and eliminating stigma would be friendly for autistics and their caregivers. (3) Open channels of donations. Some people find no platform through which their financial aid can be distributed to where it needs though they are willing to do so. Official autism organizations can establish the foundation through the Internet with a strict supervision mechanism. (4) Add life information sections such as renting houses, employment and making friends. An integrated information platform can help autistics to seek information in daily life. (5) Provide online vocational education resources. Pennefather’s research has proved that online training within small groups of parents may be a feasible, efficient service delivery method (Pennefather *et al.*, 2018).

6. Conclusion

With a high incidence of autism, autism information needs are more and more diverse and urging, and relevant information services are also developing constantly. This study used qualitative and limited quantitative methods with multi-source data to explore the gap between autism information needs and services. On the one hand, comprehensive autism information needs with eight categories and 26 subcategories are extracted, among which the need for “Social resource services” is strongest, as well as website information services with ten categories and 65 subcategories, among which “Autism rehabilitation” and “Treatment method” occupied over 12 subcategories, respectively. On the other hand, results show obvious gaps between autism information needs and services: information needs for policy mechanism, economic support and sociality are seldom matched, still in need of extra attention, and that for social resource services and employment are partly matched, while that for psychological/emotional counseling, professional knowledge/information and rehabilitation skills training have been already mostly satisfied by autism information

websites. In total, five specific suggestions for information providers are given after analysis. Thus, this study improves the research of CHI and provides evidence for information providers to improve their services of great theoretical and practical implications.

7. Limitations and future work

This study also has some limitations. First, the number of academic documents taken as references for the content analysis was relatively small because little attention has been given to China though there have been some studies on autism information needs in the world. Second, due to the inadequate professional thesaurus of autism, the text preprocessing of forum posts was subjective to some degree. Furthermore, the keywords selection of TF-IDF Top250 may ignore some other needs expressed not that frequently. Third, we only chose representative websites as the research data of information services, ignoring (electronic) library, mobile application and other service forms since the impracticability of covering all kinds of platforms. Finally, our study focused on parents/families of autistics and did not give enough attention to the autistics themselves who have the ability to seeking information on their own.

In the future, subsequent research can expand the data set of information needs from other forums or Q&A communities. Other research methods and algorithms can be tried to explore the topic of information needs, such as topic model Latent Dirichlet Allocation (LDA). Besides, the content of each topic of information needs can be researched from a fine-grained perspective in future studies. Furthermore, the information needs and behaviors of the persons with high-functioning autism could be paid more attention to. In addition, scholars can investigate different forms of autism information services and discover the differences between them. With deep insights, it can provide evidence for service providers who are in the pursuit of better services.

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