

Voices from the parents: Exploring the unmet important family needs of parents of preschoolers with autism spectrum disorder in community setting using the family needs questionnaire – Hong Kong Chinese translated version

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Abstract

This study aims to systemically investigate the unmet family needs of parents of preschoolers with Autism Spectrum Disorder. The 54-item Family Need Questionnaire (FNQ) was translated and validated to enable quantitative analysis of the importance of diverse family needs and their status of being addressed or not. A total of 112 parents of ASD children were recruited in the autism centre. Most of the children were newly diagnosed and the families were new to the various services for their children and the families. The results suggested that the children-centred needs outweighed the parent-centred ones in terms of need importance. Furthermore, it is alarming to reveal that over three-fourth of the parents reported that 15 out of shortlisted 22 important family needs were under the “unmet” categories, suggesting huge service gaps that require immediate attention from policy makers and service providers. Themes of the most important unmet needs highlighted the priority in addressing the needs for information, continuity of service, communication, access to care, and social inclusion. The clinical and practical implications in treatment design and service planning was further discussed.

Keywords: autism spectrum disorders, family needs, preschoolers

Autism Spectrum Disorders (ASDs) are lifelong, complex neurodevelopmental disorders characterized by core deficits in three domains: social interaction, communication and stereotypic or repetitive behaviours (Newschaffer, Croen, Daniels, Giarelli,

Grether, Levy, et al., 2007; Lai, Lombardo, & Baron-Cohen, 2014). Centers for Disease Control and Preventions (2014) estimated that 1 in 68 children are suffering from ASD recently. The prevalence of ASD is estimated to be around 6 per 1000, however, is varying

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between countries. A recent Hong Kong study reported that an estimated incidence of ASD is 5.95 per 10,000, while the prevalence was 16.1 per 10 000 for children less than 15 years old (Wong & Hui, 2008).

It is known that the prevalence of ASD is on the upward trend. People, especially children, suffering from ASD and their family urge holistic, multi-disciplinary and early intervention services. Formal services and programs are vital for the successful adaptation of the families. The existing service hardly catches up with increasing demands. A systematic assessment on their service needs could aid service planning, while service providers should monitor parents' perceived needs, examine how well their needs are addressed by the designed service and respond to the needs identified in order to promote healthy adaptation (Donovan, 1988).

Needs assessments by capturing the perceived unmet need was no new to the field (Magi & Allander, 1981), and is regarded as a paradigm shift from agency-centred approach to family-centred one for children with developmental disabilities including ASD (Sperry, Whaley, Shaw & Brame, 1999). There is shared interest between service planners for which family-centred services are built on assumption that tailored supports towards family needs is crucial, while policy makers require information about the needs of the service users as a whole (Cassidy, McConkey, Truesdale-Kennedy & Slevin, 2008). Hence, assessing the unmet needs from the parents' perspective provide an excellent interacting point for both to highlight modality of service to be implemented for the former, and areas of the service system which need to be modified or strengthened for the latter.

Study by Leung and colleagues (2010) were noted to be one of the first kinds in Hong Kong to identify the service needs of families with children with developmental disabilities apart from service satisfaction. It set as a good example on how utilizing systematic investigate could inform policy making. The Service Needs Questionnaire (SNQ) well covered the personal and family stress in one part, and the need for various services in the other among the 29 items of the scale, and showed good psychometric properties. However, it was emphasizing more on the learning and behavioural difficulties aspects. Secondly, it was targeting students with special educational needs, and may not address the uniqueness of children with ASD in terms of their communicative and social difficulties adequately. Hence, echoing the report by Department of Health (Leung, Leung & Chan, 2005), the present study aimed to investigate systematically the family needs of parents of ASD preschoolers using the well validated Family Needs Questionnaire.

Methods

Participants

Data were collected from 112 consecutive children age 1.6 to 5.8 years-old, who were diagnosed to have Autism Spectrum Disorder (ASD) by either developmental pediatricians or clinical psychologists in the Department of Health's Child Assessment Centres (CACs) of the Government. Children with parents who have severe mental illness were excluded from the study. The research is approved by the Kowloon West Cluster Research Ethics Committee of the Hospital Authority as part of a bigger study on the stress and needs of parents with ASD children.

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Table 1 provided the demographic information of the participants and their families. The gender ratio for the ASD preschoolers were 5.22:1 (male: female). The mean age was 3.4 ($SD = .9$) with range from 1.6 to 5.8. The principle diagnoses given by the CACs were mainly Autism (42.9%) or autistic symptoms (53.6%). A minority was given Asperger's Disorder (3.6%). In terms of the family background, the fathers were slightly elder than the mothers, with mean ages of 39.9 and 36.0 respectively. Most of the children did not have siblings (73.8%). Most families had monthly incomes (77.3%) while 18.6% of the families were on Comprehensive Social Security Assistance (CSSA) by the Government. The range of the family incomes were distributed diversely from below \$10,000 (19.7%), between \$10,000 and <\$20,000 (30.4%), between \$20,000 and <\$30,000 (19.6%), to more than \$30,000 (19.6%).

Materials

For the current study, the survey consisted of (i) the translated Family Needs Questionnaire (Siklos & Kerns, 2006) and (ii) several additional scales and questions developed by the research team to understand the characteristics of the child and the family.

Family Needs Questionnaire – Hong Kong Chinese version

The Family Needs Questionnaire was adopted by Siklos and Kerns (2006) to evaluate the family needs of parents of children with ASD or Down syndrome. Originally, it was developed to depict the needs of family members of various samples of patients with traumatic brain injury (Kreutzer, Serio & Berquist, 1994; Waaland, Burns & Cockrell, 1993). The overlapping impairments, namely, intellectual impairment, disruptive

behaviours and social impairments, were shared with children with ASD. In addition, both TBI and ASD were lifelong conditions, and parents reported comparable themes such as feelings of helplessness and stress, the need for information, for professional and community support, and for involvement with care (Sperry et al., 1999; Ellis, Luiselli, Amirault, Byrne, O'Malley-Cannon, Taras et al., 2002; Cassidy et al., 2008). Brown and colleagues (2011, 2012) has studied school-age children with ASD and found it applicable to such populations. Only responses endorsed as important or very important are used when describing unmet needs (= partly met or unmet). Partly met needs are included in the unmet category, given that if a need is not fully met, more can be carried out to ameliorate it (Kreutzer et al., 1994; Brown et al., 2012).

The FNQ (54-item version; Siklos et al., 2006) was first translated into Hong Kong Chinese by an independent bilingual translator. The instructions, the items and the ratings were then given to another independent person with educational psychology background and have proficient bilingual ability for back-translation. Based on the feedback from an expert panel composing occupational therapist, physiotherapist, speech therapist, social workers, and rehabilitation workers, the first version was modified accordingly. Final adjustment was made after field-testing with parents of ASD children at the authors' autism centre. The Cronbach's Alpha of the translated scale was 0.95, suggesting good internal reliability (Cronbach's Alpha = .90 in Siklos et al., 2006). Due to the limitation of the setting, no re-test reliability was calculated as the ASD children were likely to receive intervention from the centres or elsewhere, for which would affect the ratings in terms of service needs. The summation of the raw scores of FNQ was correlated with the Autism Parenting Stress Index (Silva & Schalock, 2011). Pearson correlation was 0.42 with $p = .018$, suggestive of acceptable convergent validity.

Table 1
Demographic data (N = 112)

<i>Age</i>	
Mean (SD)	3.4 (0.9)
Range	1.6-5.8
<i>Gender</i>	
Male	94
Female	18
M:F	5.22:1
<i>Principle Diagnosis</i>	
Autism	42.9%
Autistic symptoms	53.6%
Asperger's Disorder	3.6%
<i>Age of Father</i>	
Mean (SD)	39.9 (6.7)
<i>Age of Mother</i>	
Mean (SD)	36.0 (5.0)
<i>Number of Siblings</i>	
0	79 (73.8%)
1	22 (20.6%)
2	6 (5.6%)
<i>Family's Economic Status</i>	
Employed	75 (77.3%)
On CSSA	18 (18.6%)
Others	4 (4.1%)
<i>Family Income</i>	
Less than \$5,000	3 (2.7%)
\$5,000 to <\$10,000	19 (17.0%)
\$10,000 to <\$20,000	34 (30.4%)
\$20,000 to <\$30,000	22 (19.6%)
More than \$30,000	22 (19.6%)
Others	12 (10.8%)

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It is aimed that the translated version to be as adherent to the original while it could be easily understood by the Chinese-speaking parents. It should be noted that, however, that there may be cultural difference in the use of Chinese in different regions of Asia, namely, Mainland China, Taiwan, or other Southeast Asia countries.

Procedures

The data was collected from ASD children receiving services for church-sponsored, early intervention programs in Kingdom A – Development Centre for Persons with Autism since October 2011. Each child was seen by a clinical psychologist (T.C.C.) for confirming the autism diagnosis received in previous diagnostic evaluation and performing a thorough psychological assessment workup before s/he receives any intervention, as part of an outcome research project intending to evaluate the effectiveness of the parent-mediated early intervention program. At the same time, parents would be asked to fill in a battery of psychometric measures, including the Family Needs Questionnaire (FNQ), and other demographic information.

Analyses

The analyses were primarily descriptive. It was aimed to provide a broad picture for the family needs so as to provide recommendations to service providers in planning corresponding programmes to meet the service gaps. Hence, percentages were used to estimate the proportions of the importance and unmet needs. Cronbach's alpha was used to determine the internal consistency of the translated Family Needs Questionnaire and Pearson's correlational analysis was performed to determine the convergent validity. SPSS version 21 was used to subserve those analyses.

Ethical Consideration

No foreseeable harm would be done on the participants and parents. The parents were orally briefed about the purpose of the study with a written description and consent form. Their participation would not affect their service use in the centre at which the data were collected. Contact of investigators was left to participants in case of any undesirable consequence after completing the questionnaire.

Results

The rated importance on different family needs

The range of the % rated as important was diverse, from almost all parents rating "I need to be actively involved in my child's treatments and therapies." (98.2%), to the other extreme "I need to take week-long vacations by myself each year." (10.7%), suggesting that the questionnaire was able to discriminate the relative importance of different family needs in the targeted participants. It should be noted that for most of the parents, their children were newly diagnosed recently. Most often they knew hardly anything about autism few months before. A total of 22 (out of 54) items had the rated importance higher than 80%, meaning that over four-fifth of the parents regard these needs were of vital importance.

Despite the shortlisting has made the family needs more concise, the 22 family needs could still be overwhelming if not distracting to service planners. It may require policy changes or enormous budgets to address all those needs. Meanwhile, further analysis by looking into the unmet needs would be more focused and practical. By drawing a line at 75%, 15 family needs remained on

the list of the unmet important family needs (Bolded, Table 2). It should be aware that the percentages were counted on those needs that were rated as importance in the first place. Exclusively these needs were child-centred and most of them were directly related to interventions to the child. Others were apparently related to the parents, nevertheless, they were needs on equipping the parents to handle and coped with the ASD conditions.

Themes shared by the important unmet family needs

Referencing to the frequently reported needs as summarized by Brown and colleagues (2010), the bolded items could be grouped into few categories, namely, need for information (items 2, 17, 18, 19), continuity and coordination of services (items 7, 10, 34), communication with the family (items 1, 8, 28), and access to care (items 3, 9, 13), and lastly social inclusion for the child (items 6, 20).

The need for information was diversified including the knowledge about the characteristics of autism pathology and daily behavioural manifestations, the understanding of the treatment progress, and skills on parenting and managing difficult behaviours. The need for the continuity and coordination of services included regular service for schooldays and summertime, and consistent behavioural therapy. The coordination among professionals to agree on the best treatment plan was highly needed as well. Communication with the family means involving the parents in the treatment, and to respect and count their opinions and understand their needs in planning the interventions. Access to care refers to availability of service in crisis and on regular basis. When in doubt professional advice would be available. The need for social inclusion was also unanswered according to the survey results. Finding friends and having social activities that suit their children are no easy for the parents.

Discussion

Parents of ASD children had differentiable needs that could be surveyed and stratified. However, most of the time either the resources were limited that only preliminary and short-term service could be provided by public sectors, usually also implicated long waiting time (could be up to over 12 months), or high intensity service is open to those who are able to pay from own pockets. There was local report that majority family spends nearly five thousand Hong Kong Dollars for private individual treatment and about half spends additional two thousand five hundred Dollars for group service (Heep Hong Society, 2013). It is thus unsurprising that parents are struggling on what services to do with their ASD children. The family needs, especially the psychosocial needs of the parents, are usually less prioritized if not scarified. Policy makers, and service planners in particular, could be benefited from talking with their first time service users to understand the unmet needs. The present study revealed that of those important family needs (22 out of 54), more than three-fourth of parents found that 15 of those 22 important needs were unmet.

Among those unmet important family needs, the child-centred needs (e.g., “I need to be actively involved in my child’s treatments and therapies.”; rated important: 98.2%) outweighed the parent-centred ones (“I need to have time to spend alone with my partner.”; rated important: 47.3%). On one hand, it could be understandable as parents were likely to be still adjusting their life priority after knowing the diagnosis. On the other hand, the scarcity of service limited their options in addressing their own needs as discussed above. In reference to the study suggesting that parents with lower stress could indeed associated with better intervention outcomes of the ASD children (Osborne, McHugh, Saunders, & Reed, 2008), service model or treatment modality should never keep parents out from

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Table 2
Family Needs Questionnaire items ranked by % reported as important and % reported as unmet ($N = 112$)

	% Rated important ¹	% Rated unmet ²
3. I need services continuously rather than only in times of crisis.	98.2	78.6
2. I need to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child.	97.3	81.3
1. I need to be actively involved in my child's treatments and therapies.	95.5	75.9
9. I need to have a professional to turn to for advice or services when my child needs help.	93.8	77.7
7. I need to have different professionals agree on the best way to help my child.	93.8	78.6
18. I need to have information regarding my child's therapeutic or educational progress.	92.9	76.8
6. I need for my child to have friends of his/her own.	92.9	78.6
20. I need to have my child to have social activities other than with his/her own parents and siblings.	91.1	75.0
21. I need to have consistent speech therapy for my child.	91.1	73.2
38. I need to have my questions answered honestly.	89.3	68.8
13. I need to work with professionals who have expertise with children who have the same disorder as my child.	88.4	77.7
17. I need to be shown what to do when my child is acting unusually or is displaying difficult behaviours.	88.4	80.4
10. I need to have consistent behavioural therapy for my child.	86.6	77.7
8. I need to be shown that my opinions are used in planning my child's treatment, therapies, or education.	84.8	82.1
34. I need to have my child's therapies continue throughout the summer months and school breaks.	84.8	75.0
14. I need to have consistent occupational therapy for my child.	84.8	72.3
50. I need to have my spouse and me agree on decisions regarding our child.	83.0	57.1
19. I need to have help in deciding how much to let my child do by himself/herself.	82.1	78.6

Table 2 (Continued)
 Family Needs Questionnaire items ranked by % reported as important and
 % reported as unmet ($N = 112$)

	% Rated important ¹	% Rated unmet ²
28. I need for the professionals working with my child to understand the needs of my child and my family.	80.4	78.6
43. I need financial support (e.g. from government) in order to provide my child with his/her therapies, treatments, and care.	79.5	70.5
37. I need help in remaining hopeful about my child's future.	79.5	77.7
15. I need to be told why my child acts in ways that are different, difficult, or unusual.	79.5	75.0
32. I need to have my child's teachers understand his/her problems.	78.6	60.7
48. I need my child to have a teacher's aide with him/her at school who has knowledge about, or expertise with, working with children with the same disorder as my child.	78.6	75.9
12. I need weekend and after-school activities for my developmentally delayed child.	77.7	65.2
27. I need to be told if I am making good decisions about my child.	77.7	73.2
49. I need to have the professionals working with my child to speak to me in terms I can understand.	75.9	63.4
42. I need to be shown respect by the professionals working with my child.	74.1	49.9
11. I need to have help from other family members in taking care of my child.	74.1	60.7
4. I need to have consistent physical therapy for my child.	74.1	72.3
29. I need for my child's friends to feel comfortable around my child.	72.3	75.9
36. I need help dealing with my fears about my child's future.	70.5	81.3
41. I need information about special programs and services available to my child and my family.	65.2	74.1
35. I need to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviours.	64.3	72.3
47. I need my child's school to set up a specialized education plan for my child.	63.4	78.6
30. I need to have other family members understand my child's problems.	60.7	64.3

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Table 2 (Continued)

Family Needs Questionnaire items ranked by % reported as important and % reported as unmet ($N = 112$)

	% Rated important ¹	% Rated unmet ²
24. I need to get enough rest or sleep.	60.7	58.9
39. I need to be encouraged to ask for help.	59.8	64.3
25. I need to get a break from my responsibilities.	58.9	74.1
45. I need the children in my child's classroom to understand that my child cannot help his/her unusual behaviours and difficulties.	58.0	71.4
33. I need to discuss feelings about my child with a parent who has a child with the same disorder.	56.3	76.8
51. I need my child's doctor and dentist to have expertise working with children with the same disorder as my child.	52.7	69.6
31. I need to have my child's after-school friends understand his/her problems.	50.0	69.6
5. I need for professionals to be discrete when talking about my child while he/she is in the room.	50.0	64.3
46. I need to have time to spend alone with my partner.	48.2	66.1
23. I need to have counselling for myself and my spouse/partner.	47.3	65.2
16. I need to have time to spend alone with my other children.	42.9	43.8
26. I need to spend time with my friends.	39.3	67.9
44. I need respite care for my child.	36.6	52.7
22. I need to have help with housework.	35.7	45.5
54. I need to take week-long vacations by myself each year.	26.8	60.7
40. I need to have counselling for my other children.	18.8	45.5
53. I need to take 3-week long family vacations each year.	14.3	60.7
52. I need to go out for dinner with my family three times each week.	10.7	52.7

Note.¹Important = rated as *important* or *very important*. ²Unmet = rated as *partly met* or *unmet*. Only those rated first as *important* are included in this score. Bolded items were those % rated important exceeding 80% and % rated unmet exceeding 75% (15 items in total)

the treatment planning. Informed by this conceptualization, the Early Parent-mediated Intervention for Parents with Autism children (EPICA) of Kingdom A encourages heavily on parent's involvement in the orientation training. Prior to the group, they would be invited to attend information talks and workshops, and psychoeducational support group would be suggested after. Preliminary results were encouraging that the parenting stress was reduced after the program and three months follow-up, which usually is aligned with the improvement shown in the ASD children.

To respond to the need for information, psychoeducation should be emphasized as much as, if not more, direct intervention to ASD children. The understanding of ASD characteristics, general and specific parenting skills, and connecting ASD children with reachable social worlds are essential to parents to cope with the parenthood according to the present study. It also provides the basis for parent empowerment. From "I need to be told...(item 13)", "I need to be shown... (item 17)", "I need to have information...(item 18)", unmet needs consisted of more informative nature of psychoeducation. Information indeed could psychologically reduce uncertainty and thus anxiety and panic. The benefit could be substantiated by assisting parents to make informed decision in choosing approaches and modalities of treatment, which in turn could benefit the children therapeutically. However, effective psychoeducation should not stop as perceiving parents as passive recipients of information and "sage" expert advices.

The need for continuity and coordination of services are huge challenges to service providers. In Hong Kong the conventional practice is to provide time-limited short-term follow up by most public sectors, namely, the child assessment centres, or the child and adolescent psychiatric units in hospitals. While the clinical settings usually could only provide fixed sessions of treatment, educational setting is relatively more sustaining. Nevertheless,

summertime and school breaks as indicated from the survey (item 34), could be a potential disastrous period for the family. For coordination among different disciplines, namely, the speech therapists, occupational therapists, psychologists, and special teachers, there is inadequate platform to discuss and coordinate their interventions. Even within the same discipline the case is not any way easier.

Need for access to care on regular basis has been supplemented by the initiative such as the Community Care Fund (CCF) since 2011 on a pilot basis. It did provide an unprecedented opportunity to the low-income family to access to professional service regularly (until the child has been allocated to remedial preschool service such as early education and training centre, integrated child care centre, or special child care centre). However, few centres recognized to provide such service would have psychologists or behavioural experts in providing advice to parents in handling crises. Most centres on the list provided individual or group treatments emphasizing educational and remedial aspects. Family crises could be solely counted on other unspecialized social work service such as those in Integrated Family Service Centres provided or subvented by the Social Welfare Department. It is thus highly recommended the CCF scheme could cover the contribution of social worker in addition to the existing list of psychologists, different therapists and special teachers.

Finally, getting suitable social activities to the ASD children could be a nightmare to their parents. It is a common misconception that children with ASD do not have social needs given their compromised social skills. To address those needs, parents could enroll their children into typical pre-schooler classes just like most parents do. However, the endings would not be too unfamiliar to them that either the teachers would repeatedly warn them for the children's "misbehaviours", or the ASD children would simply be alienated by other children in the group. The integration does not

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only take patience, but often requires a skilled group leader to be knowledgeable in managing children with special needs.

The study was limited by the quantitative data derived from the set Family Needs Questionnaire. Although it is regarded as more comprehensive and specific to ASD conditions than other counterparts available in Chinese (e.g., Service Needs Questionnaire; Leung et al., 2010), it fell short of qualitative information about the family needs and related dilemma of the parents who are undergoing the transition into a very special form of parenthood (cf. Brown et al., 2012). Conducting focus groups could provide a more in-depth analysis of those themes revealed in the present study. Apart from the data nature, the lack of monitoring of the change hinder the investigation of the potential dynamic longitudinal changes of the unmet family needs when the ASD children grow from toddlers to preschoolers. In the design of the study, the length of the FNQ (54 items) were the major consideration in not implementing in follow-up measures. Instead, other psychological dimensions, namely, the parenting stress (Autism Parenting Stress Index; Silva et al., 2011) and family impact (Impact on Family Scale; Williams et al., 2006), were studied and shall be reported elsewhere.

Conclusion

The present study was the one of the first attempt in Hong Kong to systematically investigate the family needs of parents of ASD preschoolers, in which most of them were newly diagnosed and the families were undergoing gigantic changes. Many important needs were reported to be unmet, which depict how desperate were those parents, and the service gaps that service planners could initiate to address. The themes derived from the shortlisted important family needs, namely, the needs for information, continuity of service, communication with family by professionals, access to care, and social inclusion, could facilitate modifying existing services or

conceptualizing new services. These themes are applicable to service orientation, content, and evaluation (3167 words).

Acknowledgements

Gratitude is due to the participating parents who devoted their time and effort in completing the long list of questionnaires before they receive any service from the centre. Thanks to the hard work of Kingdom A's colleagues Tessa Chan for most data entry, Esther Koo for coordinating the administration of the study, and student intern Lynn Chan for editing the dataset. Also thanks to independent translators Yat Lee for translating the questionnaire and Allison Luk for the back-translation. The mentorship from Dr Raymond Chan, the former senior clinical psychologist of Kwai Chung Hospital, for the development of the centre as a whole and the conceptualization of the study was high appreciated. Finally, special thanks to the former Division Head S.L. Chan for her unconditional and continual support for the clinical research work under her leadership.

摘要

來自家長的聲音：探索患有自閉症譜系障礙之學前兒童的家庭需要

本研究旨在有系統地探討患有自閉症之學前兒童父母的一些未滿足的家庭需求。為確保能量化分析家庭需要之重要性，以及其需要有否被滿足，研究運用經翻譯及驗證，含有54個項目的家庭需要問卷（FNQ）。研究於自閉症中心招募了112患有自閉症兒童之家長，當中大部分家長的孩子為初診斷、並初次接觸對其子女或家庭所需要的各種服務。研究結果顯示在以兒童為中心的需求的重要性比父母為中心的需求為高。此外，令人震驚的是，超過四分之三的家長表示，22項被家長評為重要的需求當中，有15項是在“未滿足”的類別，此等龐

大的服務與需求差距必須為政策制定者和服務提供者所正視。另外，就最重要及未被滿足的需求進行進一步分析後，強調應滿足資訊、服務延續、與家長溝通、日常及緊急聯絡服務、以及孩子融合社群的需要。本研究亦進一步討論研究結果對於臨牀及實際上設計治療及計劃服務所帶來的影響。

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