

## 创新团队成果专栏

## 孤独症谱系障碍RUBI-PT方案的改编及适应性调查

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**[摘要]** **目的**·探究“行为干预研究单位孤独症网络家长培训”[the Research Units in Behavioral Intervention (RUBI) Autism Network Parent Training, RUBI-PT] 方案的中国本土化改编并对其适应性进行调查。**方法**·按照文化改编的4个步骤对RUBI-PT方案进行改编, 包括信息收集、初步改编设计、初步改编测试、进一步调整。信息收集阶段邀请了6位儿科专家和2位心理治疗师进行6次焦点小组访谈, 并根据专家意见从语言、治疗形式、治疗设置等方面对RUBI-PT方案进行初步改编; 初步改编测试阶段招募了16位孤独症谱系障碍 (autism spectrum disorder, ASD) 患儿的家长, 分2批参加线上RUBI-PT, 结束后收集项目反馈问卷并行适应性调查分析, 最后根据测试结果进行方案的进一步调整。**结果**·RUBI-PT的初步改编方案由个体培训调整为团体培训, 包含8次核心技能课程, 采用线上会议形式实施。初步测试结果显示, 家长对于上课进度、上课过程、课后作业完成情况、作业点评情况的满意度分别为90%、80%、100%和100%; 课程难度方面, 第7次课(功能性沟通训练)和第8次课(教授技能)的难度最大。依据上述调查结果和专家小组意见完成进一步调整, 最终形成本土化RUBI-PT的改编方案。**结论**·经过改编和适应性调查, 形成了适用于中国ASD儿童家庭的家长行为训练策略即RUBI-PT。

**[关键词]** 孤独症谱系障碍; 家长行为训练; 行为干预研究单位孤独症网络家长培训; 文化改编; 适应性调查

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## Adaptation and adaptability survey of the RUBI-PT program for autism spectrum disorders

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**[Abstract]** **Objective**·To explore the adaptation and adaptability of RUBI-PT (the Research Units in Behavioral Intervention Autism Network Parent Training) program in China. **Methods**·According to the four steps of cultural adaptation, the RUBI-PT program was adapted, including information collection, preliminary adaptation design, preliminary adaptation test and further adjustment. In the information collection phase, six pediatricians and two psychotherapists were invited to conduct six focus group interviews, and according to the expert opinions, the RUBI-PT program was preliminarily adapted from the aspects of language, treatment format and treatment setting. In the preliminary adaptation test phase, 16 parents of autism spectrum disorder (ASD) children were recruited and divided into two batches to participate in the online RUBI-PT. After the treatment, the project feedback questionnaires were collected, and the adaptability was investigated and analyzed. Finally, the scheme was further adjusted according to the test results. **Results**·The preliminary adaptation program of RUBI-PT was adjusted from individual training to group training, including eight core skills sessions, which were implemented in the form of online meetings. The preliminary test results showed that parents' satisfaction with lesson progress, lesson process, completion of homework and comments to homework were 90%, 80%, 100% and 100%, respectively; in terms of the course difficulty, parents reported that the 7th session (functional communication training) and the 8th session (teaching skills) were the most difficult. Based on the above survey results and the opinions of the expert group, further adjustments were completed, and an adaptation program for localized RUBI-PT was ultimately formed. **Conclusion**·After adaptation and adaptability investigation, the RUBI-PT, which is suitable for Chinese families with ASD children to conduct behavioral parent training, has been formed.

**[Key words]** autism spectrum disorder (ASD); behavioral parent training (BPT); the Research Units in Behavioral Intervention Autism Network Parent Training (RUBI-PT); cultural adaptation; adaptive survey

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孤独症谱系障碍 (autism spectrum disorder, ASD) 是一类以社会交互及交流困难、行为模式局限和重复为核心特征的神经发育性疾病<sup>[1]</sup>。与神经发育正常及患有其他神经发育障碍的个体相比, ASD 儿童及成人更有可能表现出具有挑战性的行为<sup>[2]</sup>, 包括攻击他人、发脾气、不服从、自我伤害等破坏性行为。有研究<sup>[3]</sup>表明, 在 ASD 青少年中有超过一半的患者会对他人表现出攻击性。HOSSAIN 等<sup>[4]</sup>的伞状系统综述总结发现, ASD 儿童和青少年共病破坏性、冲动控制和行为障碍的患病率从 12% 到 48% 不等; 该类人群的破坏性行为与更多的精神药物使用、更多的内化和外化症状以及更严重的功能障碍相关<sup>[5]</sup>, 不利于疾病康复; 同时, ASD 儿童和青少年的破坏性行为还会影响他人, 表现出的问题行为、肢体和语言攻击等会增加父母的压力和痛苦<sup>[6-7]</sup>, 也会导致专业干预人员的职业倦怠增加、情绪稳定性下降<sup>[8]</sup>。因此, 在孤独症治疗的实践中, 临床工作者需要重视对于破坏性行为的干预。

家长行为训练 (behavioral parent training, BPT) 是一种向家长传授有效技能, 以帮助他们管理孩子需求的干预措施。BPT 强调父母作为改变者的角色, 能够显著提升父母的自我效能感、减少其养育压力<sup>[9-10]</sup>, 以实现有效减少 ASD 儿童的破坏性行为<sup>[11]</sup>。其中, 行为干预研究单位孤独症网络家长培训 [the Research Units in Behavioral Intervention (RUBI) Autism Network Parent Training, RUBI-PT] 是第一个经过严格的随机对照研究验证的、专门针对 ASD 儿童父母的 BPT 计划, 由儿科精神药理学研究单位 (the Research Units on Pediatric Psychopharmacology, RUPP) 研发, 其目的是培训父母的技能以减少儿童行为问题。RUBI-PT 以应用行为分析和功能性分析为理论基础, 教给父母一系列行为策略。作为一种高度结构化的干预措施, RUBI-PT 具有培训难度低、治疗保真度高、便于临床推广等优势。开发团队对该培训的可行性和有效性进行系列研究<sup>[9, 12-13]</sup>, 结果显示家长们对 RUBI-PT 的接受度和完成度较高, 参与 RUBI-PT 的父母比只获得心理教育的父母报告了更大的自我效能感以及更少的压力。IADAROLA 等<sup>[14]</sup>的研究也获得了同样的结论。同时, 临床随机对照研究证据提示 RUBI-PT 在减少 ASD 儿童的破坏性行为方面是有效的<sup>[9, 13]</sup>, 也可显著改善儿童的适应性功能、进餐行为和睡眠习惯等<sup>[15-16]</sup>。

尽管 BPT 在美国等发达国家已是较为成熟的干预方式, 如可以帮助护理人员减少 ASD 儿童的破坏性行为<sup>[11]</sup>, 但在我国开展 BPT 干预研究尚属于新兴领域, 且在引入有循证证据支持的干预方案时需要考虑文化差异的影响<sup>[17]</sup>。基于此, 本研究引入 RUBI-PT 方案进行团体形式的改编, 形成结构化培训手册, 以期为中国 ASD 儿童的家长提供针对破坏性行为管理的培训方案。

## 1 对象与方法

### 1.1 对 RUBI-PT 方案的改编过程

本研究采用 BARRERA 等<sup>[18]</sup>提出的文化改编 (culture adaptation) 方法对 RUBI-PT 方案进行本土化改编。改编过程涉及 4 个步骤, 依次为信息收集、初步改编设计、初步改编测试、进一步调整。上述改编步骤虽较简单, 但包含了完善的文化改编模型的基本要素<sup>[19]</sup>, 因此较适用于行为干预方案的本土化改编。

**1.1.1 信息收集** 信息收集阶段的主要工作是通过资料整理、质性或量化分析找出原始循证干预方案的积极和消极因素, 并开展焦点小组活动以讨论改编后的文化適切性。本研究邀请了 8 位专家 (6 位为三甲甲等医院儿科行为学专家, 2 位为心理治疗师) 组成专家讨论小组, 共进行 6 次焦点小组访谈, 即经过文献回顾来探讨 RUBI-PT 的循证证据以及改编可行性。而后, 收集针对 RUBI-PT 方案的改编建议。

**1.1.2 初步改编设计** 根据前一阶段收集的改编建议, 本研究团队对 RUBI-PT 方案进行初步改编设计。

**1.1.3 初步改编测试** 为了对初步改编后的 RUBI-PT 方案进行测试, 本研究团队于 2020 年 7—9 月在上海交通大学医学院附属新华医院发育行为儿童保健科门诊招募 16 位确诊 ASD 的患儿家长 (分为 2 组、每组 8 人), 参加为期 8 周的线上 RUBI-PT, 对实施过程的重点及难点、改编方案的适用性及可行性以及家长的满意度、意见和建议等进行调查。家长的纳入标准: ① 年龄 20~50 岁, 且其患儿年龄 2~14 岁。② 患儿的主要照料者。③ 具备参与线上课程或填写问卷的电子设备。

培训开始前, 本研究团队向患儿家长发放人口学信息问卷并进行分析。该问卷涉及 ASD 患儿的年龄、性别、是否为独生子、主要照料者, 家长本人及其配偶的年龄、受教育程度、每日和孩子互动时长、家庭年收入等。8 周培训结束后, 由家长匿名填写项目反

馈问卷。该问卷从上课进度、上课过程、课后作业完成情况、作业点评情况、课程难度、意见反馈等6个方面对初步改编的RUBI-PT方案的满意度和难度进行信息收集,并为本土化RUBI-PT的进一步修改提供基础。项目反馈问卷采用单选、多选及填空题相结合的方式,通过对选择题的各选项人数和百分比进行计算来量化家长的反馈情况。

**1.1.4 进一步调整** 根据初步改编测试的反馈结果,重新与专家小组进行讨论,以形成具有可行性和文化适应性的RUBI-PT改编方案。

## 1.2 统计学方法

使用SPSS 21.0软件对初步改编测试中收集的人口学信息和项目反馈数据进行分析。定量资料用 $\bar{x}\pm s$ 表示,定性资料用频数(百分率)表示。

## 2 结果

### 2.1 RUBI-PT的初步改编方案

经焦点小组访谈后,专家提出了以下针对RUBI-PT方案的改编建议:①调整语言,完善治疗方案相关材料的翻译与修订。②调整治疗形式,由个体治疗变化为团体治疗。③调整治疗时长,在缩减治疗时长与保障家长学习效果之间取得平衡。④建议配套本土化视频。另外,专家还建议需选择合适的线上平台对RUBI-PT进行实施,以打破空间限制,扩大服务范围,便于后续推广。

根据上述建议,本研究团队对RUBI-PT方案进行了初步改编设计:①由2位心理治疗师对原英文手

册内容进行翻译和校订,并结合文化表达习惯进行适当调整,形成中文版手册。②依据手册内容,同时考虑到团体治疗形式的特点,本研究团队调整了课程结构和内容,即将原RUBI-PT方案包含的11节核心课程调整为8节。其中,原方案中的“强化策略”模块分为两节课,第2节课的内容是“发现孩子的优点”以及通过儿童主导的游戏教授游戏和社交技能,考虑到团体中家长与孩子的游戏互动质量存在较大差异,使得家长对此内容的学习需求可能不一致,因此删去了该部分而仅保留第1节强化策略课程(包含强化的概念和应用要点),以满足家长的行为管理需求;原方案中的“教授技能”模块也分为2次进行教授,由于该两节课的内容具有强相关性,因此将其合并为1节;原方案核心课程的最后一节是“泛化和维持”,由于该内容需根据个性化需求制定泛化和维持策略,在团体治疗中缺乏可行性,故而删去。③按每周1次、每次90 min设置培训课程的频率和时长,整个培训周期可缩短至8周。④原方案的英语视频中呈现的问题行为类型、家长的应对方式在中国家庭中同样存在,即文化差异较小,继而考虑可沿用原版视频,由心理治疗师提供翻译,以帮助家长理解。另外,本研究对多个线上平台进行测试后发现,腾讯会议的功能较完善,可共享屏幕、演示课件、播放视频、在线视频对话、录制会议等,能够满足多人同时在线授课,且操作简单、运行流畅,故而选择该平台作为媒介进行团体授课。

经过改编后,初步改编的RUBI-PT方案相较于原方案的主要差异见表1。

表1 初步改编的RUBI-PT方案与原方案的差异

Tab 1 Differences between the preliminary adaptation of the RUBI-PT program and the original version

Adaptation content	Original version	Preliminary adapted version
Language	English	Chinese
Treatment format	Individual therapy	Group therapy
Treatment setting	11 sessions*:	8 sessions:
	① Behavioral principles	① Course introduction and behavioral principles
	② Prevention strategies	② Prevention strategies
	③ Daily schedules	③ Daily schedules
	④ Reinforcement 1	④ Reinforcement
	⑤ Reinforcement 2	⑤ Planned ignoring
	⑥ Planned ignoring	⑥ Compliance training
	⑦ Compliance training	⑦ Functional communication training
	⑧ Functional communication training	⑧ Teaching skills
	⑨ Teaching skills 1	
	⑩ Teaching skills 2	
	⑪ Generalization and maintenance	

**Note:** \* The 11 sessions are all the core sessions in the original RUBI-PT program, and the developers also designed 7 elective sessions, as well as several telephone follow-ups and home visits. The adaptations in this study were for the core sessions only.

## 2.2 参与线上RUBI-PT的患儿家长的人口学信息统计

我们对16位参与线上RUBI-PT的ASD患儿家长的人口学信息进行统计后发现, ASD患儿的平均年龄为(3.94±1.53)岁, 男性占比81.25%; 家长中, 母亲的平均年龄为(35.53±4.22)岁、父亲的平均年龄为(34.69±4.50)岁。其他具体信息见表2。

表2 ASD患儿家长的人口学信息(n=16)

Tab 2 Demographic information of parents of children with ASD (n=16)

Item	Demographic information
<b>ASD child</b>	
Age/year	3.94 ± 1.53
Gender/n(%)	
Male	13 (81.25)
Female	3 (18.75)
Only child or not/n(%)	
Yes	7 (43.75)
No	9 (56.25)
Primary caregiver/n(%)	
Mother	9 (56.25)
Father	2 (12.50)
Both mother and father	4 (25.00)
Grandmother	1 (6.25)
<b>Parent</b>	
Age of mother/year	35.53 ± 4.22
Age of father/year	34.69 ± 4.50
Daily interaction time with the child/n(%)	
30 min-1 h	3 (18.75)
1-2 h	7 (43.75)
More than 2 h	6 (37.50)
Mother's education level/n(%)	
Bachelor's degree and above	6 (37.50)
Associate's degree	5 (31.25)
High school and below	5 (31.25)
Father's education level/n(%)	
Bachelor's degree and above	7 (43.75)
Associate's degree	2 (12.50)
High school and below	7 (43.75)
Total household income last year/n(%)	
Below RMB 100 000 yuan	4 (25.00)
RMB 100 000-200 000 yuan	5 (31.25)
Above RMB 200 000 yuan	7 (43.75)

## 2.3 初步改编测试, 家长反馈情况

本研究共收集到了10位家长的问卷反馈。有关上课进度、上课过程、课后作业完成情况、作业点评情况这4个方面的反馈结果(表3)显示: ①上课进度, 有90%的家长认为整体进度节奏把握得当。②上课过程, 有80%的家长认为课程准备充分、讲解清晰、目标明确。③课后作业完成情况, 100%的家长表示可以轻松完成, 能够帮助自己更好地学习干预技巧。④作业点评情况, 100%的家长获得了及时的点评, 其困惑也得到了解答。以上结果均表示, 家长对于改编后的线上团体RUBI-PT的满意度较高。

问卷中, 课程难度方面采用多选题的形式, 对RUBI-PT中家长最容易、最难掌握的课程情况进行了解。结果(表4)显示, 8次课程中家长认为第6次课程合规性训练(10人/100%)、第2次课程预防策略(8人/80%)、第3次课程每日时间表(8人/80%)最容易掌握, 而第8次课程教授技能(8人/80%)和第7次课程功能性沟通训练(6人/60%)最难掌握。

同时, 问卷中的意见反馈条目收集情况如下: 后续参与进一步训练课程的意向方面, 有7位家长表示愿意参与; 开放性意见反馈方面, 1位家长提出“希望课程能继续帮助更多人”, 另1位家长建议“课程内容可以更丰富、多举例子以加深印象, 课程结束后可以做一下全部课程的回顾”。

## 2.4 RUBI-PT初步改编方案的进一步调整

针对前述反馈的较难掌握的2次课程, 结合家长意见, 经专家小组进一步讨论后决定课程基本大纲仍保持不变, 可通过以下方式降低家长的学习难度、提高学习效果: ①增加与课程内容相关的案例讨论、互动环节, 以提高家长的参与度。②在最后1次课程的末尾, 增加对全课程的回顾总结环节。③由于采用线上团体干预形式, 为最大程度地提供支持, 在家长参与RUBI-PT期间, 治疗师会在微信群中收集家长的问题、给予解答, 并对家庭作业进行点评, 以确保家长将学到的行为管理方法正确应用于生活中; 同时, 8周的培训结束后, 治疗师会鼓励家长定期提交家庭作业记录单, 继续为其提供专业指导。最终, 改编完成的RUBI-PT内容见表5。

表3 上课进度、上课过程、课后作业完成情况、作业点评情况的问卷结果统计( $n=10$ )Tab 3 Statistics of questionnaire results on lesson progress, lesson process, completion of homework and comments to homework ( $n=10$ )

Evaluation dimension	Option (single choice)	n (%)
Lesson progress	1. The lesson progress is well grasped. Learners can follow the rhythm of the therapist to complete learning	9 (90)
	2. The lesson progress is a little fast. Learning is a little difficult for learners	1 (10)
	3. The lesson progress is slow and could be appropriately accelerated	0 (0)
	4. The progress of some lessons is a bit fast or slow	0 (0)
Lesson process	1. Well-prepared lessons with clear presentations and objectives	8 (80)
	2. Rich examples, assisting in understanding intervention techniques	1 (10)
	3. High level of participation and full interaction	1 (10)
	4. Few examples, difficult to understand	0 (0)
	5. Few interactions, not much participation	0 (0)
Completion of homework	1. Easy to complete, helping learners to learn intervention skills better	10 (100)
	2. Difficult to complete, difficult to achieve the expected goals	0 (0)
Comments to homework	1. The comments are timely and helpful in answering questions and solving problems	10 (100)
	2. The comments are timely, but the comments do not help solving the problems that arise in the assignment	0 (0)
	3. The comments are not timely enough, but the contents of the comments help answering questions and solving problems	0 (0)
	4. The comments are not timely enough, but sloppy and perfunctory, and do not help solving problems that arise in the assignment	0 (0)

表4 总体课程难易程度评价

Tab 4 Evaluation of overall course difficulty level

Lesson	Difficulty/n(%)	
	The easiest lesson	The hardest lesson
Course introduction and behavioral principles	7 (70)	1 (10)
Prevention strategies	8 (80)	1 (10)
Daily schedules	8 (80)	2 (20)
Reinforcement	6 (60)	3 (30)
Planned ignoring	7 (70)	2 (20)
Compliance training	10 (100)	1 (10)
Functional communication training	4 (40)	6 (60)
Teaching skills	3 (30)	8 (80)

表5 改编后的 RUBI-PT

Tab 5 RUB-PT after adaptation

Session	Theme	Main content
1	课程介绍和行为原则 (Course introduction and behavioral principles)	介绍总体治疗目标、行为功能的概念、行为的前因后果 (Introducing overall treatment goals, the concept of behavioral function, the causes and consequences of behavior)
2	预防策略 (Prevention strategies)	讨论行为问题的前因并制定预防策略 (Discussing antecedents to behavior problems and developing preventive strategies)
3	每日时间表 (Daily schedules)	制定每日时间表,使用视觉时间表以减少行为问题 (Developing a daily schedule, and using visual schedules to reduce behavioral problems)
4	强化 (Reinforcement)	引入强化物的概念,以促进合规性、增加期望行为,并教授新的行为 (Introducing the concept of reinforcer to promote compliance, strengthen desired behaviors, and teach new behaviors)
5	计划忽视 (Planned ignoring)	探索系统性地使用消退(通过有计划的忽视)来减少行为问题 [Exploring systematic use of extinction ( <i>via</i> planned ignoring) to reduce behavioral problems]
6	合规性训练 (Compliance training)	分析不服从指令的原因、教授指令训练的步骤和要点,促进孩子的合规性 (Analyzing the causes of noncompliant behaviors, and teaching the steps and key points of command training to enhance children's compliance)

Continued Tab

Session	Theme	Main content
7	功能性沟通训练 (Functional communication training)	通过系统性强化策略,教授替代性沟通技能,以取代问题行为 (Through systematic reinforcement, teaching alternative communicative skills to replace problematic behaviors)
8	教授技能 (Teaching skills)	使用任务分析和链式教学法,以促进新的适应性技能。在教授技能的同时,教授各种提示程序 (Using task analysis and chaining to promote new adaptive skills. Teaching various prompting procedures as well as skills)

### 3 讨论

本研究遵循信息收集、初步改编设计、初步改编测试、进一步调整这一文化改编过程,针对RUBI-PT方案进行本土化改编。测试阶段中,家长对上课进度、上课过程、课后作业完成情况、作业点评情况等均较满意,表明该改编方案在中国ASD家庭中具有较高的可行性和适应性;且在此初步方案基础上,本课题组结合反馈意见进行调整并形成了最终的RUBI-PT方案。

有研究报道称,ASD儿童的问题行为如不能被恰当处理将会严重影响其康复训练的开展,因此专家建议应将问题行为(不合适行为)的处理纳入培训核心要点<sup>[20]</sup>,从而以科学手段帮助家长学会行为管理技能。目前,我国在孤独症干预领域尚缺少有效的干预指南和指导手册,而借鉴并修订国外有循证证据的干预方案对于解决这一问题更便捷、有效的<sup>[21]</sup>。因此,本研究引入了国外有循证依据支持的ASD儿童破坏性行为干预方案并加以文化适应性改编,以期为国内孤独症儿童的行为干预提供科学指导。

尽管众多研究表明BPT是减少儿童破坏性行为的循证方法之一,但许多家庭在获得BPT方面会面临诸多障碍,如家庭所在地区BPT的可及性、交通和日程安排方面等。本研究考虑到疫情的影响,以及扩大培训项目受益范围、减少地域资源制约等因素,项目实施时使用了网络形式,即通过远程实施RUBI-PT从而扩大了ASD干预的地域可及性。与本研究一致,国外相关研究也为RUBI-PT远程开展的有效性提供了证据支持。MARTIN等<sup>[22]</sup>以14位孤独症儿童家长为对象,对远程实施RUBI-PT的可行性进行试验;结果发现医师可通过远程医疗实施干预方案,且家长对培训内容、远程服务形式的评价均较高。同时,该研究还发现远程开展RUBI-PT能有效减少孤独症儿童的破坏性行为、提高他们的适应能

力,还能减轻父母的压力、提高父母的育儿能力。

另外,本研究对RUBI-PT进行了团体形式的改编,能够覆盖到更多群体。个体治疗服务的获得往往需要更长时间的等待,因此在团体环境中进行BPT可最大限度地提高治疗的可用性、可及性,并最终提高ASD患儿家长的参与度<sup>[23]</sup>。与个体形式相比,团体形式的家长培训更易被纳入社区诊所,在减少儿童问题行为的疗效方面并不逊色,且需要的时间更少、成本更低<sup>[24]</sup>。目前,在ASD临床干预实践中,团体BPT主要聚焦于改善ASD患儿的核心症状方面,很少关注如何减少其破坏性行为<sup>[11]</sup>。BEARSS等<sup>[9]</sup>研究显示,RUBI-PT作为一个高度结构化的、有临床脚本和指导的家长培训项目,是一种适合群体使用的循证治疗方案。BURRELL等<sup>[25]</sup>在原方案的基础上形成了团体RUBI-PT方案,并对18名伴有破坏性行为的ASD儿童进行了团体RUBI-PT的可行性试验;结果发现家长对于团体形式的RUBI-PT满意度较高,且在疗效方面患儿的破坏性行为有了明显改善。这与本研究结果相一致,即团体形式的RUBI-PT项目是可行的。

然而,本研究的改编过程中也存在一定的局限性。首先,改编后的RUBI-PT只包含了原项目的核心课程内容,当家长的困难涉及喂养、睡眠、如厕训练等特定行为主题时,因团体形式、课程时长等限制可能难以提供详尽的解答。因此,未来将考虑对补充主题的课程内容也进行适当改编,为有需要的家长提供针对性支持。其次,本研究在改编过程中采取的方法为量化研究方法,缺少质性分析,难以对文化差异、养育环境产生的影响进行深入探讨。与国外相比,中国ASD患儿家长对于行为管理策略的需求、困难点存在差异,如传统中国家庭中祖父母参与养育情况多,更易出现教养方式不一致、家庭冲突等。未来在进行方案的进一步优化时,可开展家长访谈、质性分析等,以采集更多家长的需求和反馈资料,更好

地满足本土化需求。

本研究的初步调查结果显示, 家长对改编后的RUBI-PT方案的课程内容、进度安排、技能教学等方面满意度较高, 可通过视频示教、案例讨论、家庭作业练习等方式掌握行为管理技巧。继而提示, 此方案对于中国ASD家庭的接受度较高, 并具备较好的可行性。为保障项目的治疗一致性以及可推广性, RUBI-PT需由具备专业资质、能够熟练掌握并应用行为分析原理、了解ASD儿童发育行为特点的治疗师实施。后续, 本研究团队将继续完善中文版RUBI-PT手册, 为治疗师提供培训过程中可用的临床脚本, 并开展相关人员的培训及资格认证, 以提高该方案在实施过程中的保真度; 同时, 我们还将对该方案的其他潜在疗效因子进行深入摸索, 对治疗过程中治疗师与家长的互动模式以及家长的参与程度、作业完成度等进行记录、分析, 为如何提高干预效果提供启示。

#### 利益冲突声明/Conflict of Interests

所有作者声明不存在利益冲突。

All authors disclose no relevant conflict of interests.

#### 伦理批准和知情同意/Ethics Approval and Patient Consent

本研究涉及的所有改编调查均已通过上海交通大学医学院附属新华医院伦理委员会审核批准(审批号: XHEC-C-2019-076)。所有参与的家长被告知研究流程后均同意参加, 并已签署知情同意书。All adapted investigations involved in this study were reviewed and approved by Ethics Committee of Xinhua Hospital, Shanghai Jiao Tong University School of Medicine (Approval No. XHEC-C-2019-076). All participating parents were agreed to participate after being informed of the study process and have signed informed consent forms.

#### 作者贡献/Authors' Contributions

吕娜负责数据的整理分析和文章的撰写, 杨涵舒负责文章的撰写与修改, 任芳负责问卷资料的采集和初步分析, 章玲丽、李斐、徐明玉负责文章的修改和校订。所有作者均阅读并同意了最终稿件的提交。

LÜ Na was responsible for data organization, analysis and article writing. YANG Hanshu was responsible for writing and revising article. REN Fang was responsible for the collection and preliminary analysis of questionnaire data. ZHANG Lingli, LI Fei and XU Mingyu were responsible for revising and proofreading the article. All the authors have read the last version of paper and consented for submission.

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## 学术快讯

### 上海交通大学基础医学院、上海市免疫学研究所邹强团队等揭示乳酸介导 CTLA-4 的 RNA 剪接以维持 Treg 细胞免疫抑制功能的机制

2024年2月27日,上海交通大学基础医学院、上海市免疫学研究所邹强研究团队等在 *Immunity* 杂志在线发表了题为 *Lactate modulates RNA splicing to promote CTLA-4 expression in tumor-infiltrating regulatory T cells* 的研究论文。该研究发现代谢产物乳酸通过促进肿瘤浸润 Treg 细胞中 CTLA-4 的 RNA 剪接及其表达从而维持 Treg 细胞免疫抑制功能的作用机制,阐述了乳酸-Foxp3-USP39-CTLA-4 信号轴介导肿瘤浸润 Treg 细胞高表达 CTLA-4 的分子机制,为肿瘤免疫治疗提供了新方向。



# 环境与儿童健康

孤独症谱系障碍(RUBI-PP)方案的改编及适用性调查

教育部重点  
上海市重点

MOE-Shanghai Key Laboratory of Children's Environmental



## 特约创新团队介绍

### 创新团队名称

儿童发育及障碍机制解析

### 团队主要成员

李斐(主任医师/博士) 徐楠杰(研究员/博士)

仇子龙(研究员/博士) 黄菊(研究员/博士)

朱永川(研究员/博士) 方伟群(研究员/博士)

王广海(副研究员/博士) 洪小琦(助理研究员/博士)

章玲丽(住院医师/博士)

### 团队负责人介绍

#### 李斐 Li Fei

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李斐 (1976—), 上海交通大学医学院附属新华医院/新华儿童医院副院长, 发育行为儿童保健科行政主任, 教育部-上海市儿童环境与健康重点实验室主任。2004年博士毕业于重庆医科大学儿科医学院。2004—2009年先后于上海交通大学医学院、美国波士顿及佐治亚医科大学接受发育行为儿科学及认知神经生物学两轮博士后训练。现任中华医学会儿科分会发育行为学组副组长、国际孤独症研究学会 Senior Mentor、国际神经精神药理学临床新药创新研发委员会会员。

李斐教授长期致力于儿童孤独症等神经发育障碍疾病的三级防控和临床工作, 针对其壁垒开展转化驱动性研究。建立上海孤独症儿童早期发展队列, 相关成果受到 *Nature* 杂志专访及高度评价。先后获得6项国家自然科学基金支持, 包括杰出青年基金、优秀青年基金、重点项目、中国-加拿大政府间国际合作重点项目等。近年来以第一/通信(含共同)作者于 *Nature Communication*、*American Journal of Psychiatry*、*Molecular Psychiatry* 等学术期刊发表论文60余篇。获“全国青年岗位能手”、上海领军人才、上海市优秀学术带头人、上海市“曙光学者”、上海市“浦江学者”等荣誉。

Li Fei (1976—), vice president of Xinhua Children's Hospital/Xinhua Hospital, Shanghai Jiao Tong University School of Medicine, director of Department of Developmental and Behavioral Pediatric & Child Primary Care, and director of MOE-Shanghai Key Laboratory of Children's Environmental Health. Dr. Li received her Ph.D from Chongqing Medical University in 2004. From 2004 to 2009, she completed two postdoctoral trainings in Developmental Behavioral Pediatrics and Cognitive Neurobiology, respectively, at Shanghai Jiao Tong University School of Medicine, Boston University Medical Campus and Georgia Regents University. She is also vice chair of Developmental and Behavioral Pediatric Youth Committee of Chinese Medical Society, Senior Mentor of International Society for Autism Research (INSAR), and a member of Clinical New Drug Innovation and Development Committee of the International College for Neuropharmacology (CINP).

She has rich experience in clinical practice, as well as in the three-level prevention and treatment of autism spectrum disorder (ASD) and other neurodevelopmental disorders. Meanwhile targeting at the clinical barriers of these neurodevelopmental disorders, she has carried out translation-driven scientific research with multidisciplinary approaches. She has established the Shanghai Autism Early Developmental Cohort, and the works based on it have been interviewed and highly commented by the *Nature* Spotlight - Precision Medicine in China. She has received six National Natural Science Foundation of China, including Distinguished Young Scholar, Excellent Young Scholar, Key Project and Key Projects of China-Canada International Cooperation. In recent years, she has published up to 60 papers as the first/corresponding author on the high-profile journals, such as *Nature Communication*, *American Journal of Psychiatry* and *Molecular Psychiatry*. In addition, she was awarded as "National Youth Post Expert", Shanghai Leading Talent, Shanghai Outstanding Academic Leader, Shanghai "Dawn Scholar", Shanghai "Pujiang Scholar", and so on.



## 主要研究方向

李斐教授研究组围绕社交行为及相关疾病（孤独症）这一国际脑科学重大前沿科学问题，聚焦“社交行为的环路基础和疾病机制”总体研究方向，致力于解析社交行为这一脑高级认知功能的工作原理，整合啮齿类、非人灵长类动物和疾病人群的跨物种研究平台，开发具有特色的精准干预方案，解决孤独症面临的诊疗困境。近2年来，团队发表SCI论文40余篇，其中中国科学院1区论文15篇；新增承担国家级及上海市级项目16项；团队成员作为主要参与者获教育部科学研究优秀成果奖、上海市自然科学奖一等奖、上海市科技进步奖一等奖各1项。

Dr. Li's research group focuses on the international cutting-edge scientific issue of social behavior and related diseases such as ASD, aiming to understand the circuit basis on social behaviors and pathological mechanism of social disorders, across human population, non-human primates and rodent models, and develops unique and precise intervention programs to address the diagnostic and treatment challenges for ASD. During the last two years, the group has published more than 40 SCI-indexed papers, 15 in Journal Citation Report (JCR) Q1 journals, and received 16 new National or Shanghai municipal fundings. And the team members, as the main contributors, have won the Excellent Scientific Research Achievement Award awarded by Ministry of Education, the First Prize of Shanghai Natural Science Award, and the First Prize of Shanghai Science and Technology Progress Award.

## 近2年代表性成果

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- 2) WANG J C, YU J H, WANG M D, et al. Discovery and validation of novel genes in a large Chinese autism spectrum disorder cohort[J]. Biol Psychiatry, 2023, 94(10): 792–803.
- 3) MA B, SHAN X, YU J, et al. Social deficits *via* dysregulated Rac1-dependent excitability control of prefrontal cortical neurons and increased GABA/glutamate ratios[J]. Cell Rep, 2022, 41(9): 111722.
- 4) HE H, YU Y F, LIEW Z, et al. Association of maternal autoimmune diseases with risk of mental disorders in offspring in Denmark[J]. JAMA Netw Open, 2022, 5(4): e227503.
- 5) SUN J J, YUAN Y, WU X H, et al. Excitatory SST neurons in the medial paralemniscal nucleus control repetitive self-grooming and encode reward[J]. Neuron, 2022, 110(20): 3356–3373.e8.
- 6) HE L N, CHEN S, YANG Q, et al. EphB2-dependent prefrontal cortex activation promotes long-range social approach and partner responsiveness[J]. Proc Natl Acad Sci USA, 2023, 120(9): e2219952120.
- 7) DAI Y, LIU Y Q, ZHANG L L, et al. Shanghai autism early development: an integrative Chinese ASD cohort[J]. Neurosci Bull, 2022, 38(12): 1603–1607.