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Practitioner Review: It's time to bridge the gap – understanding the unmet needs of consumers with attention-deficit/hyperactivity disorder – a systematic review and recommendations

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Objective: Understanding the unmet needs of healthcare consumers with attention-deficit/hyperactivity disorder (ADHD) (individuals with ADHD and their caregivers) provides critical insight into gaps in services, education and research that require focus and funding to improve outcomes. This review examines the unmet needs of ADHD consumers from a consumer perspective. **Methods:** A standardised search protocol identified peer-reviewed studies published between December 2011 and December 2021 focusing on consumer-identified needs relating to ADHD clinical care or research priorities. **Results:** 1,624 articles were screened with 23 studies that reviewed examining the needs of ADHD consumers from Europe, the U.K., Hong Kong, Iran, Australia, the U.S.A. and Canada. Consumer-identified needs related to: treatment that goes beyond medication (12 studies); improved ADHD-related education/training (17 studies); improved access to clinical services, carer support and financial assistance (14 studies); school accommodations/support (6 studies); and ongoing treatment efficacy research (1 study). **Conclusion:** ADHD consumers have substantial unmet needs in clinical, psychosocial and research contexts. Recommendations to address these needs include: improving access to and quality of multimodal care provision; incorporating recovery principles into care provision; fostering ADHD health literacy; and increasing consumer participation in research, service development and ADHD-related training/education. **Keywords:** Attention-deficit/hyperactivity disorder; consumers; needs; systematic review; recommendations.

Introduction

Attention-deficit/hyperactivity disorder (ADHD) affects 5% 7% of children and adolescents (Polanczyk, Willcutt, Salum, Kieling, & Rohde, 2014) and 2% 5% of adults (Faraone et al., 2021; Sciberras et al., 2020). ADHD can have a debilitating impact on an individual's social and emotional wellbeing, interpersonal relationships, academic and career outcomes, physical and mental health, quality of life and life expectancy (Costello & Maughan, 2015; Franke et al., 2018; Lawrence et al., 2015; Sciberras et al., 2020; Shaw et al., 2012). The impact also extends to caregivers and family (Johnston & Mash, 2001; Theule, Wiener, Tannock, & Jenkins, 2013). Improving outcomes and facilitating thriving of consumers with suspected or diagnosed ADHD and their families/caregivers (henceforth termed ADHD consumers) requires greater awareness of the unmet needs of ADHD consumers.

Overview of terminology

We use the term '*consumer*' rather than a broader term such as 'person with lived experience' to convey that individuals with mental health challenges such as ADHD have the rights to education, participating equally in their care, making informed healthcare decisions and care that supports recovery (Cohen & Ezer, 2013). We consider a consumer to be a person with ADHD or caregiver that 'makes either direct or indirect use of health services' (Gregory, 2007, p. 2).

Objective

This systematic review aims to synthesise the unmet needs identified by ADHD consumers, in order to: (1) highlight critical gaps in existing ADHD assessment and treatment approaches; and (2) inform ADHD-related clinical practice, research, and resource provision. ADHD consumers are included in the authorship team and contributed to all aspects of the study, from conception through

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to reviewing the final manuscript. We examine research published in the last 10 years to capture current needs identified by ADHD consumers. We hope that a better understanding of unmet consumer needs can lead to responses that improve outcomes for ADHD consumers.

Methods

Protocol and registration

The protocol was pre registered with PROSPERO (CRD42020201170). All search and review processes were conducted in accordance with PRISMA guidelines (Moher et al., 2009; Table S1). Of note, the current review differs from the original pre registered protocol which initially aimed to examine unmet consumer needs over a 6 year period but was subsequently expanded to cover a 10 year period to ensure a more thorough examination of recent unmet needs.

Search strategy

Medline, PsycInfo and Embase electronic databases were searched (last updated 6th December 2021). Selected search terms and database specific parameters were applied, including keywords for ‘ADHD’, ‘consumer’ and ‘information needs’ (see Table S2). No restrictions were placed relating to sample size.

Eligibility criteria

Eligible studies were peer reviewed, published between December 2011 and December 2021, available in English, focused on consumer identified needs relating to clinical care or research priorities, and focused on ADHD (or reported ADHD specific findings separately to other conditions). Studies not focused on unmet needs expressed by ADHD consumers themselves or not reporting ADHD specific results were excluded, as were conference abstracts, unpublished dissertations and existing reviews.

Study selection

Records were exported to Covidence review management software (Veritas Health Innovation, 2019). Screening involved review of titles and abstracts, followed by full texts. Forwards/backwards citation analysis of full texts identified studies not captured in the search. At least two reviewers (MB, SB, PP) completed screening. An additional reviewer (ES) adjudicated disagreements to achieve consensus.

Data extraction

Data was extracted (MB) and independently cross referenced by three reviewers (LB, SB, PP) for accuracy. Discrepancies between reviewers were discussed and resolved. A standard electronic form developed for this review was used to extract: (a) country where research was conducted; (b) study design (qualitative/quantitative/both, cross sectional); (c) methodology (survey/interview/focus group); (d) sample size (total *N*); (e) population (caregivers, young people/adults/individuals with ADHD); (f) age in years (mean/median, standard deviation, range); (g) sex (male/female, percentage); and (h) findings discussed in results section relating to consumer identified unmet needs.

Data synthesis

Key findings were synthesised by four reviewers (MB, LB, SB, PP) in three stages. As both qualitative and quantitative research is reviewed, a narrative synthesis approach was used to draw together similar findings. At each stage, two reviewers completed coding which was subsequently cross checked by a third reviewer. Using an electronic spreadsheet (see Supporting Information), codes were generated to describe key findings (e.g. findings related to challenges with getting an ADHD diagnosis were coded “difficulty obtaining diagnosis”). Where relevant, similar findings/codes were then grouped into key categories (e.g. the codes “difficulty obtaining diagnosis”, “access to services” and “provision of psychosocial treatment” were grouped into the key category “improved availability and access to clinical services”). Similar categories were then grouped into synthesised findings to represent a consumer identified need (e.g. “improved availability and access to clinical services”, “caregiver support” and “financial assistance” represented the need for “improved access to clinical services, support and financial assistance”). For some codes that were initially coded broadly, we opted to retain the same descriptor at the category and identified need level (e.g. school accommodations and support).

Risk of bias

Three reviewers (MB, SB, PP) independently assessed study quality using standardised criteria (Kmet, Lee, & Cook, 2004; see Table S3). Studies were evaluated on design, methodology, accuracy of results and conclusions made, according to the extent to which specific criteria were met (2 yes, 1 partly, 0 not addressed) and summary scores calculated. Studies meeting a conservative score of 75% or greater were included in the final review (Kmet et al., 2004).

Results

Study selection

Figure 1 details the PRISMA review process. The search generated 1,624 studies for screening, with 23 studies included. All 23 studies were of a high quality (assessment scores ranged from 75% to 100%), therefore no studies were excluded due to quality assessment criteria (Table S3). A brief comparison of findings between studies scoring above/below 90% (10 studies vs. 13 studies) revealed no notable differences between groups.

Study characteristics

Table 1 details characteristics of included studies. Twelve (52.2%) studies were conducted in a European country, including the U.K. Four studies (17.4%) took place in Asia; four (17.4%) in the USA; two (8.7%) in Australia; and one (4.3%) in Canada.

Most studies included perspectives of caregivers of individuals with ADHD (17 studies, 73.9%) and collected only qualitative data (18 studies, 78.3%).

Need: Treatment that goes beyond medication. Twelve studies (52.2%) indicated the need for care that goes beyond medication (Cheung

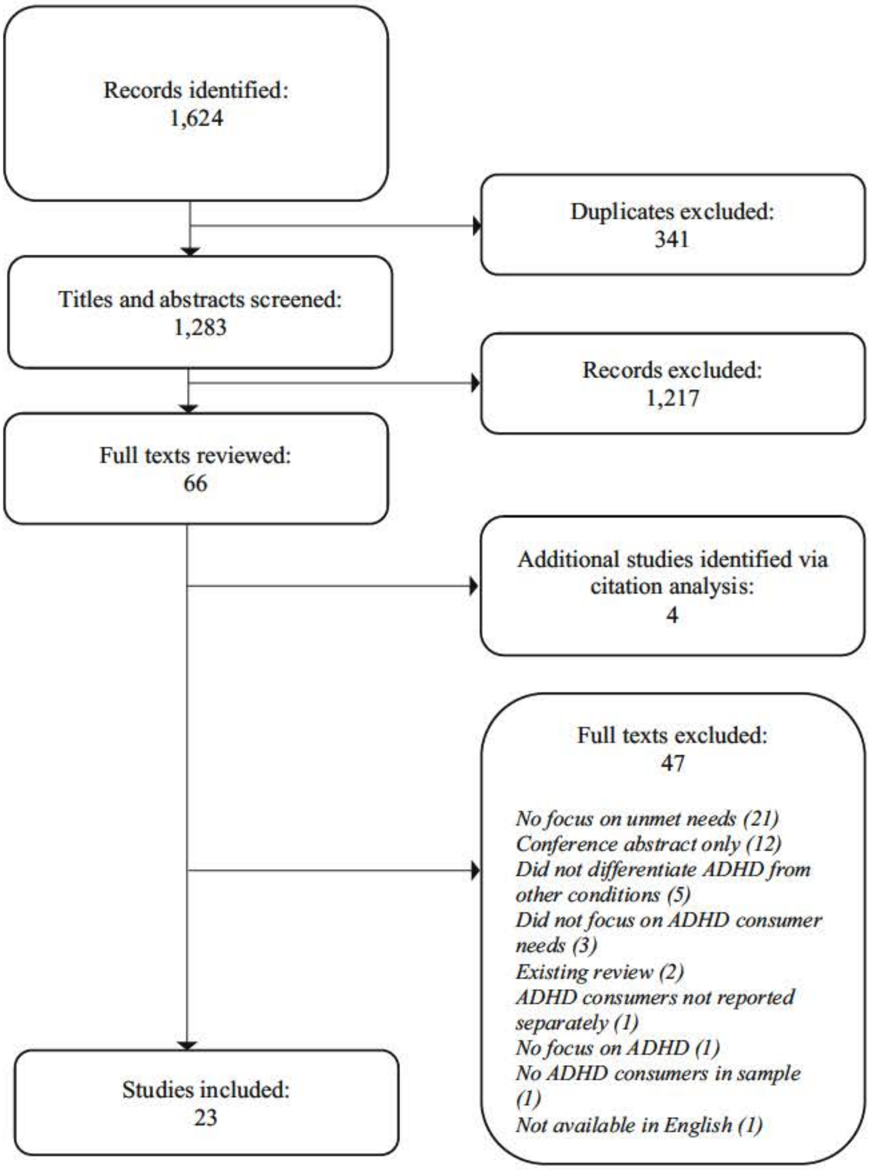

Figure 1 Adapted PRISMA review process flow chart

et al., 2015; Coletti et al., 2012; Fridman, Banaschewski, Sikirica, Quintero, & Chen, 2017; Hossainzadeh Maleki, Rasoolzadeh Tabatbaei, Mashhadi, & Moharreri, 2018; Leitch et al., 2019; McIntyre & Hennessy, 2012; Nasol, Lindly, Chavez, & Zuckerman, 2019; Reale, Frassica, Gollner, & Bonati, 2015; Sikirica et al., 2015; Simons et al., 2016; Sollie & Larsson, 2016; Vijverberg, Ferdinand, Beekman, & Van Meijel, 2020). Participants reported that medication reduces but does not eliminate ADHD symptoms (Sikirica et al., 2015; Simons et al., 2016; Sollie & Larsson, 2016) and wanted professionals to consider additional therapeutic options (Coletti et al., 2012; McIntyre & Hennessy, 2012). Young adults from Hong Kong (N = 40) reported that, while effective in the short-term, medication did not assist them to cope with challenges in adulthood (Cheung et al., 2015).

Three studies highlighted the psychological impact of ADHD (Cheung et al., 2015; Leitch et al., 2019; Sikirica et al., 2015), with 34% of European caregivers (N = 38) reporting that children experienced low self-esteem because of their ADHD (Sikirica et al., 2015). Seventy-five percent of adolescents (N = 28) reported feeling embarrassed, ashamed and annoyed about their ADHD (Sikirica et al., 2015). Australian caregivers (N = 13) reported that children expressed self-loathing, with two caregivers mentioning their child wanted to die (Leitch et al., 2019). Adolescents and young adults in Hong Kong (N = 40) suggested the need for greater investment in mental health services to meet their psychological needs (Cheung et al., 2015).

Need: improved ADHD-related education and training. Participants from 17 studies (73.9%) reported the need for ADHD education that improves health literacy for consumers, health professionals, teachers and the broader community (Ahmed, Borst, Yong, & Aslani, 2014; Cheung et al., 2015; Coletti et al., 2012; Fridman et al., 2017; Hossainzadeh

Table 1 Characteristics of reviewed studies

Reference	Country	Study methodology (all cross-sectional)	Population (*N*)	Age in years (*M* [*SD*], range)	Relevant findings
Ho et al. (2011)	Hong Kong	Interview[a]	Caregivers (12) *83.3% Female*	38.5 (NR), 35–46	Need for financial assistance and more affordable services
Coletti et al. (2012)	USA	Focus groups[a]	Caregivers (27) *78% Female*	45.3 (11.2), NR	Need for psychiatrists to consider therapies besides medication; balanced information that is comprehensive and comprehensible
McIntyre and Hennessy (2012)	Ireland	Interview[a]	Caregivers (18) *89% Female*	NR	Need for more behavioural therapy and practical advice; better access to services; alternatives to medication; improved societal attitude
Swift et al. (2013)	United Kingdom	Interview[a]	YP (10) *80% Male*	17.9 (NR), 17–18	Need for access to care provision regardless of ADHD severity; consistency of clinicians during service transition
Walker-Noack et al. (2013)	Canada	Focus groups[a]	YP (25) *60% Male*	14.3 (2.7), 10–21	Need for school accommodations; for teachers and the public to obtain accurate information about ADHD
Ahmed et al. (2014)	Australia	Focus groups[a]	Caregivers (16) *53.6% Male*	43 (median), 32–55	Poor quality of ADHD information from healthcare providers; need for concise, tailored, unbiased written information and support tools
Cheung et al. (2015)	Hong Kong	Interview[a]	Adults (40) *67.5% Male*	17.2 (NR), 16–23	Need for services to meet psychological needs; better public understanding of ADHD; education for consumers, caregivers and teachers; non-pharmacological treatment options for adults; more support from teachers in classroom
Reale et al. (2015)	Italy	Survey[a]	Caregivers (24) *Sex NR*	NR	Challenges accessing information about services; gaps in care/knowledge within services; poor service transition; need for better family and education support; affordable psychological therapy; continuity of access to pharmacological treatment
Schrevel et al. (2016)	Netherlands	Focus groups[a]	Adults (52) *53.8% Female*	43 (NR), 23–55	Need for greater social acceptance of ADHD and appreciation for differences
Sikirica et al. (2015)[c]	Europe, United Kingdom	Interview[a]	Caregivers (38) *Sex NR* YP (28) *65.8% Male*	NR Children: 11.9 (3.7), 6–17	Difficulties obtaining diagnosis; schools poorly informed/equipped to support students with ADHD; concerns about medication; need for more support

(continues)

Table 1 (continued)

Reference	Country	Study methodology (all cross-sectional)	Population (*N*)	Age in years (*M* [*SD*], range)	Relevant findings
				Adolescents: 15.3 (1.5), 13–17	and education in context of perceived stigma from others; need for financial assistance; need for information about pharmacological side-effects
Jacobson et al. (2016)	Sweden	Focus groups[a]	Caregivers, YP/Adults (7) *Sex NR*	NR	Need for research into efficacy of non-pharmacological treatment and medications
Simons et al. (2016)[d]	United Kingdom	Focus groups[a]	YP (8) *Sex NR* Adults (11) *Sex NR* Caregivers (9) *Sex NR*	NR, 12–13 NR, 18–54 NR, 25–54	Challenges with access to diagnosis, treatment and support; better support needed for medication side-effects and symptoms; need for reassurance and information
Sollie and Larsson (2016)	Norway	Survey[b]	Caregivers (214) *Sex NR*	NR	Need for school adjustments; need for care coordination at school; tailored treatment options beyond medication
Fridman et al. (2017)[c]	Europe	Survey[b]	Caregivers (3,616) *66% Female*	NR	Difficulty obtaining child diagnosis; access to behaviour therapy; insufficient information for caregivers; more help from schools
Sleath et al. (2017)	USA	Survey[b], interview[b]	YP (70) *68.6% Male*	11.9 (2.6), 7–17	Young people with ADHD had many unanswered questions about ADHD and wanted more discussion and engagement with providers
Hossainzadeh Maleki et al. (2018)	Iran	Interview[a]	Caregivers (9) *100% Male*	41.5 (NR), range NR	Need for better information from providers; non-pharmacological interventions; caregiver support
Pahlavanzadeh et al. (2018)	Iran	Interview[a]	Caregivers (27) *62.9% Female*	33.3 (NR), 24–51	Insufficient access to information about ADHD and how to support children; need for improved financial and social support
Leitch et al. (2019)	Australia	Focus groups[a]	Caregivers (13) *84.6% Female*	NR, 38–50	Need for more understanding from public, professionals and teachers; caregiver support and training; support at school
Nasol et al. (2019)	USA	Survey[b]	Caregivers (2,406) *Sex NR*	Age NR	Most common unmet treatment needs were access to medication and school-based behavioural therapy
Price et al. (2019)	United Kingdom	Interview[a]	Caregivers (28) *93% Female* YP/Adults (64) *68.8% Male*	NR NR, 14–29	Need for better information from healthcare providers; need for better information about ADHD persisting into adulthood

(continues)

Table 1 (continued)

Reference	Country	Study methodology (all cross-sectional)	Population (*N*)	Age in years (*M* [*SD*], range)	Relevant findings
Vijverberg et al. (2020)	Netherlands	Survey[b], interview[b]	YP (105) *67.6% Male*	11.8 (3), 6–17	Unmet needs relating to mental health supports; need for information on diagnosis and treatment; concern for future prospects and wanting this to be addressed in treatment
Rezel-Potts et al. (2021)	United Kingdom	Focus group[a]	Caregivers (8) *100% Female*	NR, 25–44	Training needed for GPs and school staff; integrated care with improved communication from professionals and between services; better access to mental healthcare; support for caregivers' emotional needs
Spencer et al. (2021)	USA	Interview[a]	Caregivers (41) *92.7% Female*	40.8 (7.6), NR	Need for more support; better access to services; care coordination

ADHD, attention deficit hyperactivity disorder; *M*, mean; NR, Not reported; *SD*, standard deviation; YP, Young people with ADHD.

[a] Qualitative.

[b] Quantitative.

[c] Study funded by pharmaceutical companies.

[d] Study did not aim to examine consumer needs but was included because unmet needs were identified by consumers and reported on in the article.

Maleki et al., 2018; Leitch et al., 2019; McIntyre & Hennessy, 2012; Pahlavanzadeh, Mousavi, & Maghsoudi, 2018; Price et al., 2019; Reale et al., 2015; Rezel-Potts, Kordowicz, Downs, White, & Prasad, 2021; Schrevel, Dedding, van Aken, & Broerse, 2016; Sikirica et al., 2015; Simons et al., 2016; Sleath et al., 2017; Vijverberg et al., 2020; Walker-Noack, Corkum, Elik, & Fearon, 2013).

Caregivers and adults with ADHD (Ahmed et al., 2014; Cheung et al., 2015; Hossainzadeh Maleki et al., 2018; Jacobson, Östlund, Wallgren, Österberg, & Tranæus, 2016; Pahlavanzadeh et al., 2018; Reale et al., 2015) reported needing healthcare professionals to take more time during consultations to explain ADHD and treatments. Caregivers in three studies wanted comprehensible information (Ahmed et al., 2014; Coletti et al., 2012; Rezel-Potts et al., 2021), with Australian caregivers requesting an explanation of the neurobiological origins of ADHD so they could appreciate medication efficacy and a tailored list of questions to ask healthcare providers to avoid information overload (Ahmed et al., 2014). Caregivers and young adults identified needing parenting guidelines and training to support children with ADHD (Cheung et al., 2015; Leitch et al., 2019) and needing peer support and information from others with lived experience (Ahmed et al., 2014; Simons et al., 2016). Caregivers in the U.S.A. reported wanting to work collaboratively with compassionate and caring physicians whose expertise enabled them to make informed treatment decisions (Coletti et al., 2012). While some participants in a U.K. study reported receiving sufficiently detailed information prior to transitioning from paediatric to adult services, the majority reported not being informed that ADHD is a life-long condition and wanted education and assistance with transitioning (Price et al., 2019).

Consumers reported needing practitioner education on ADHD (Ahmed et al., 2014; Price et al., 2019; Rezel-Potts et al., 2021; Sikirica et al., 2015). Australian caregivers ($N = 16$) noted that healthcare professionals lacked the time and specialised knowledge required to answer questions and recognise ADHD symptoms (Ahmed et al., 2014). Prior to their child's ADHD diagnosis, European caregivers ($N = 38$) reported being blamed by healthcare providers for their child's symptoms with child behaviour attributed to poor caregiver-child relationships or parenting (Sikirica et al., 2015). In the U.K., caregivers ($N = 28$) and individuals with ADHD ($N = 64$) recommended that general practitioners be better equipped to understand ADHD to facilitate better communication and access to appropriate services (Price et al., 2019).

Adolescents, young adults and caregivers across six studies cited a need for greater understanding of ADHD among school staff/teachers (Cheung et al., 2015; Fridman et al., 2017; Leitch et al., 2019; Rezel-Potts et al., 2021; Sikirica et al., 2015; Walker-Noack et al., 2013), including a need for appropriate guidelines/training for educators (Cheung et al., 2015). Adolescents, adults and caregivers identified the need for education to increase awareness and understanding about ADHD in the general public to reduce discrimination and stigma (Cheung et al., 2015; Leitch et al., 2019; McIntyre & Hennessy, 2012; Schrevel et al., 2016; Sikirica et al., 2015; Walker-Noack et al., 2013).

Need: Improved access to clinical services, support and financial assistance. Though some ADHD consumers in Hong Kong reported no challenges accessing health services (Cheung et al., 2015), consumers from 14 studies (60.9%) reported gaps relating to accessing appropriate clinical services, support and financial assistance (Cheung et al., 2015; Fridman et al., 2017; Ho, Chien, & Wang, 2011; Hossainzadeh Maleki et al., 2018; McIntyre & Hennessy, 2012; Nasol et al., 2019; Pahlavanzadeh et al., 2018; Reale et al., 2015; Rezel-Potts et al., 2021; Sikirica et al., 2015; Simons et al., 2016; Spencer et al., 2021; Swift et al., 2013; Vijverberg et al., 2020).

Caregivers reported challenges obtaining an ADHD diagnosis due to long waiting periods and drawn out diagnostic processes, visiting multiple doctors, problems with misdiagnosis, insufficient resources and difficulty finding professionals that would listen (McIntyre & Hennessy, 2012; Rezel-Potts et al., 2021; Sikirica et al., 2015; Simons et al., 2016). Caregivers and adolescents/young adults in several studies noted a lack of available and affordable services and long waiting times, brief and infrequent appointments, inconsistent care and frequent cancellations (Price et al., 2019; Reale et al., 2015; Simons et al., 2016; Swift et al., 2013). In a national sample of American children, caregivers most commonly reported problems accessing medication and school-based supports, particularly for families experiencing financial difficulties (Nasol et al., 2019).

Caregivers in the U.K. desired integrated care and improved access to mental healthcare for their child (Rezel-Potts et al., 2021). Caregivers from seven studies (30.4%) expressed needing financial assistance and support to address their own health and wellbeing (Fridman et al., 2017; Ho et al., 2011; Hossainzadeh Maleki et al., 2018; Pahlavanzadeh et al., 2018; Reale et al., 2015; Rezel-Potts et al., 2021; Sikirica et al., 2015).

Need: School accommodations and support. Six studies (26.1%) reported the need for increased school support, care coordination and accommodations for students with ADHD (Cheung et al., 2015; Fridman et al., 2017; Leitch et al., 2019; Sikirica et al., 2015; Sollie & Larsson, 2016; Walker-Noack et al., 2013). European caregivers ($N = 38$; Sikirica et al., 2015) and young people from Canada ($N = 25$; Walker-Noack et al., 2013) identified needing school accommodations including smaller class sizes, more time to complete tasks, less homework, more opportunities to release energy at school and one-on-one tutoring/assistance.

Need: Treatment efficacy research. One recent Swedish study (4.3%) reported the top research priorities identified by ADHD consumers focused on further establishing the efficacy of non-pharmacological treatments (e.g. family/psychological therapies, caregiver support programs, computer-aided working memory training, teacher support) and the benefits, risks and side-effects of ADHD medications (e.g. methylphenidate vs. atomoxetine, dependence risks, comorbid substance abuse; Jacobson et al., 2016).

Discussion

This systematic review found that few studies seeking insight from consumers about their needs have been published in the last 10 years, with only 23 studies identified. This number is small in the context of an estimated (as per our searches of select databases) ≥75,000 ADHD studies published in the review period. Findings highlighted that, despite advances in clinical care and the development of best practice guidelines (which incorporate input from consumers), ADHD consumers still have unmet needs.

Below, we discuss recommendations to address the unmet needs of ADHD consumers.

Recommendation: Improving access to and quality of multimodal care provision

Although seminal research studies (MTA Cooperative Group, 1999) and best practice guidelines (Canadian ADHD Resource Alliance, 2020; National Institute for Health and Care Excellence, 2018; Wolraich, Hagan, Allan, & Chan, 2019) recommend providing multimodal treatment, our findings suggest that consumers often do not have equitable access to a range of interventions. The barriers to access are challenging to address, but relevant to neurodevelopmental and mental health services more generally. Barriers to multimodal care may arise due to problems with workforce supply and distribution, the way health services are structured and the financial burden placed on consumers. For example, private practitioners (psychologists, psychiatrists, paediatricians) tend to work in isolation, requiring consumer referral to external services which may involve prohibitive wait times and costs (Mulraney et al., 2020).

To rectify this, practitioners are encouraged to work closely with other professionals (Young, Asherson, Lloyd, Absoud, & Arif, 2021) we acknowledge this is likely more easily facilitated within interdisciplinary clinics (e.g. see Coghill & Seth, 2015 for an example service model and associated resources). Greater investment from governments is also required in the form of financial assistance for consumers, funding for workforce education/training and grants to undertake research that aims to best facilitate the provision of multimodal care (Young et al., 2021). Other strategies that may improve access to multimodal service provision include using telehealth and improved ADHD training in tertiary education.

Recommendation: Incorporating recovery principles in care provision

In the mental health field, *recovery* is conceptualised as being: (a) “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles” (Anthony, 1993, p. 527); and (b) important for living a life where one feels hopeful, satisfied and able to contribute irrespective of any limitations resulting from illness or disability (Anthony, 1993; Green, 2004; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Recovery models emphasise the importance of advocacy, hope, autonomy, empowerment and the right to a life that is inclusive, meaningful and free of discrimination (Anthony, 1993; Green, 2004). Ensuring that the care provided to ADHD consumers incorporates recovery, acceptance of disability and shared management principles may help to address the identified need for care that goes beyond pharmacological treatment (Cheung et al., 2015; Leitch et al., 2019; Sikirica et al., 2015).

Despite the concept of recovery featuring broadly in mental health policies across the world (Leamy et al., 2011; Piat & Sabetti, 2009; Schrank, Bird, Rudnick, & Slade, 2012), research has scarcely examined recovery-focused care in the context of ADHD. Kronenberg, Verkerk-Tamminga, Goossens, van den Brink, and von Achterberg (2015) report a personal recovery approach in individuals with substance use disorder and co-occurring ADHD or autism, identifying four themes related to recovery: the crisis associated with diagnosis; dealing with symptoms and burden; reorganising the individual’s life; and working towards a meaningful life. More recently, research has begun to explore the concept of personal recovery in children with ADHD from the perspectives of caregivers (Edwards, Rudaizky, Toner, & Chen, 2020) and adolescents/young adults with ADHD themselves (Chen et al., 2022). More research with ADHD consumers and practitioners working in the area is required to consider what recovery-based models may look like in the context of ADHD and whether they address unmet needs.

We suggest that practitioners can help to facilitate the provision of recovery-focused care by: (a) actively developing their knowledge and awareness of recovery, acceptance of disability and shared management principles; (b) reflecting on whether their work fosters hope, optimises quality of life and considers the values, feelings, goals and strengths of ADHD consumers; and (c) considering how to incorporate these concepts into their clinical practice or research (see Table S4 for suggested resources).

Recommendation: Improving consumer and community health literacy for ADHD

Although published clinical guidelines (National Institute for Health and Care Excellence, 2018) recommend psychoeducation be provided to ADHD consumers, our findings suggest that practitioner and community health literacy about ADHD and access to quality information that promotes consumer health literacy, informed decision-making and empowered self-management, remains problematic. To address this, high-quality ADHD education/training for consumers, practitioners and teachers is required, along with education that increases community understanding of ADHD and reduces stigma (Bisset et al., 2021). However, evidence-based, best practice guidance on the content and delivery of ADHD education is currently lacking, as are psychoeducation resources that: (a) provide in-depth, consumer-supported ADHD-related information; (b) avoid judgemental language that elicits negative ingrained narratives and stereotypes; and (c) over-emphasise the challenges associated with having ADHD.

To help address this, with consumer collaboration the Australian ADHD Professionals Association (AADPA) recently developed a “Talking About ADHD” language guide which aims to encourage the use of language that fosters understanding and awareness of ADHD, aligns with recovery-focused principles and is less likely to facilitate the development of self-stigma and internalised shame (Australian ADHD Professionals Association, 2022). We suggest this guide be used to update existing psychoeducation resources and facilitate the development of future resources that are more supportive and less stigmatising of consumer experiences.

Recommendation: Increasing consumer participation

Genuine integration of consumer experience into research, service development and ADHD-related training/education may help address the consumer needs identified in this review. Use of a participatory research model, such as the collaborative framework developed by Fletcher-Watson et al. (2019) for use in autism research, could guide the integration of consumer experience into ADHD research, service development, and training/education. This framework guides researchers, practitioners and consumers to work together to identify key themes necessary for inspiring and implementing changes in practice, leading to better translation and improved outcomes for consumers (Fletcher-Watson et al., 2019). The National Mental Health Commission (2017) also provides step-by-step guidance on consumer engagement for practitioners.

Limitations

There are some limitations to this review including the exclusion of studies not published in English. As we intended to review unmet needs more broadly, the search terms used may not have captured all relevant studies. Most included studies had small samples of ADHD consumers and the majority focused on unmet needs reported by caregivers (pooled $N = 6{,}506$), with only a small, pooled sample of individuals with ADHD (pooled $N = 413$). Additionally, this review did not include consumer-based ADHD research that has not been peer-reviewed (e.g. ADHD Australia Limited, 2020; Dundee and Angus ADHD Support Group, 2018; Parents for ADHD Advocacy, 2019). Furthermore, a formal qualitative approach (e.g. reflexive thematic analysis) was not used to synthesise the results across studies.

Importantly, the recommendations presented in this paper are only based on published research, which is likely to privilege certain perspectives (e.g. European, North American and Australian perspectives are featured prominently). Meaningful comparisons between the different populations included (e.g. caregivers vs. individuals with ADHD across different age groups or ethnicities) were not feasible with the limited studies identified. Future research should examine this and the unmet needs of ADHD consumers across more diverse groups (e.g. women and girls, different ethnicities, LGBTQIA+). An updated survey of ADHD consumers should be conducted to support whether the unmet needs identified in this review are still current, particularly for populations not represented in this review. Research should seek further professional and consumer views on the recommendations discussed.

Conclusions

Peer-reviewed research has scarcely examined the unmet needs of ADHD consumers over the past 10 years. Findings suggest that ADHD consumers still have substantial needs that are yet to be addressed. These needs may be addressed by improving access to and quality of multimodal care provision, incorporating recovery principles into care provision, fostering ADHD health literacy and increasing consumer participation in research, service development and ADHD-related training/education.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Table S1. PRISMA 2009 Checklist.

Table S2. General and database-specific search terms.

Table S3. Quality Assessment.

Table S4. Suggested resources to support developing knowledge of recovery, acceptance and shared management principles.

Data S1. Data synthesis coding spreadsheet.

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Key points

- Understanding the unmet needs of ADHD consumers can provide critical insight required to address gaps and improve outcomes.
- This systematic review found that ADHD consumers have many unmet needs relating to broadly focused clinical care; ADHD-related education and training for consumers, professionals, educators and the community; access to services/supports; accommodations in schools; and ongoing research.
- The following is recommended in order to address the unmet needs of ADHD consumers: improving access to and quality of multimodal care provision; incorporating recovery principles in care provision; improving consumer and community health literacy for ADHD; and increasing consumer participation.

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