

Parental Perspectives on their Children's Transition from Child to Adult Mental Health Services: A Narrative Systematic Review

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Systematic Review

Keywords: Young persons, Transition, Transfer, Parents, CAHMS, Mental Health, Mental health, Narrative Review

Posted Date: June 18th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-9896269/v1>

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Additional Declarations: No competing interests reported.

Abstract

Background

The transition to adult healthcare implies challenges for young persons with a mental health condition, which makes them reliant on their parents. This narrative review examines parents' perceptions and evaluations of the transition process as well as parents' and young persons' perceptions on the parental role during this period.

Methods

This review followed PRISMA guidelines and included empirical qualitative and quantitative studies. Six databases were systematically searched at two timepoints (12.06.24 & 12.01.26), with screening conducted in two stages (i.e., titles/abstracts and full-texts). Findings were synthesised using thematic analysis for qualitative data and descriptive analysis for quantitative data.

Results

From screened 6,631 records, 23 studies were included. Parents generally reported negative experiences of transition, highlighting needs for involvement, information, and support, alongside emotional stress and concerns about continuity and quality of AMHS care. Parents were consistently described as key partners, providing practical and emotional support while facilitating increasing autonomy. The parental role was characterised by sustained responsibility, advocacy, and difficulties reducing involvement due to service gaps.

Conclusion

The findings indicate substantial shortcomings in the transition process and highlight the need for improvements at individual, institutional, and policy levels. Transition models should adopt a family-oriented approach that recognizes parents as important partners and provides coordinated support until the transition process is completed. Future research should examine parental perspectives in greater depth and actively involve parents in the development and evaluation of transition services, highlighting a structural mismatch between youth-centred transition models and the ongoing reliance on parental support in practice.

Introduction

Parents are often central figures in their children's lives, providing care, guidance, and support throughout childhood (2–5). When children reach the age of 18 years and enter adulthood, parental roles often begin to change (2, 4–7). As young people seek greater independence and assume more responsibility for their own lives, parents are required to adapt to new forms of involvement (2, 4–7). This transition can be especially complex for families of young people with chronic mental health conditions, where parents frequently carry substantial responsibility for managing symptoms, coordinating care, and supporting treatment adherence (6–8). The shift from child and adolescent (CAMHS) to adult (AMHS) mental health services often coincides with these developmental changes, creating additional challenges for both young people and their parents (6, 7). In the present paper, we examine parents' perspectives on their child's transition from child to adult health care and the evolving nature of their roles during this period.

The transition from adolescence to early adulthood is marked by growth, newfound independence but also challenges and pivotal events like first romantic relationships, graduation, as well as significant biological and psychosocial changes (9). For young people with a chronic health condition, this poses additional hurdles (10). If young patients require ongoing treatment, they typically transfer from CAMHS to AMHS around the age of 18 years. Numerous young persons feel confused, overwhelmed, and unprepared during this process (6, 11, 12), which can result in failed transitions, treatment non-adherence, or even death (8, 13–16).

Since the transition process involves various barriers and challenges, young persons' parents[1] play a pivotal role in supporting young patients during the medical transition. They often advocate for their children and help bridge gaps in care (3, 5). Healthcare providers recognize the crucial role parents play during the medical transition and emphasize the need for parents' satisfaction with the process and their ability to support their child's growing independence (3). Nonetheless, transitional care is primarily aimed at the young patients and neglect parents (17, 18). At the same time, this youth-centred orientation contrasts with the realities of care, where parents often remain essential for coordinating treatment and supporting treatment adherence.

Parents themselves report mixed feelings on their changing role and evolving relationships with young persons and health providers during the transition process: On one hand they welcome their child's increasing autonomy (4). On the other hand, they experience

stress, anxiety, and exhaustion due to reduced involvement in treatment, the differences in the CAHMS and AHMS, and inadequate transition preparation for both their children and themselves (4, 6, 7, 19–21).

Hill et al. (7) reviewed the literature on parental and professional perspectives on CAHMS and ways to improve the transition to AHMS. They found that families faced various obstacles during the transition, especially concerning preparation and communication with mental health services (7). In the current narrative review, we expand upon the findings from Hill et al. (7) by a) including research after 2018 (i.e., eight years later), b) focusing on the roles that parents assume during the transition process, and c) examining young patients’ perspectives on parental roles in the transition process.

To address this, we formulated the following research questions:

RQ1: What do parents of children with a mental health condition need so that they perceive their child and themselves as ready for the transition?

RQ2: How do parents of children with a mental health condition evaluate the transition process of their children from CAMHS to AMHS?

RQ3: How do a) parents of and b) children with a mental health condition perceive the parental role in the transition process?

Methods

A systematic literature review was conducted following the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines (22) and was preregistered with the international prospective register of systematic reviews (PROSPERO, ID: CRD42024559592; (1)).

Search strategy

The first systematic search was carried out on the 12th June 2024 and a second, refresher search was conducted on the 12th January 2026. The search string consisted of keywords on the medical transition, parents as a sample, and mental health. The search was conducted in the following databases: APA PsycNet, EBSCOhost (APA PsycArticles, APA PsycINFO, CINAHL Complete, Psychology and Behavioral Science Collection, PSYINDEX), Embase, PubMed, PubPsych (ERIC, ISOC-Psicologia, MEDLINE, Narcis, Pascal, PsychData, PSYINDEX), and Web of Science (see supplementary file 1 for the full search strategy).

Inclusion and exclusion criteria

For the current review we included empirical studies from peer-reviewed journals in English or German language, without restrictions on the publication period or research methodology (i.e., both quantitative and qualitative research was included). Included publications focused on at least one of three outcome variables: the *evaluation of the transition process* by parents, the *perception of the parental role* by parents or parents and young persons, or the *transition readiness* of either child or parent from the parental perspective. Study samples consisted of either only parents, whose children had been diagnosed with a mental health condition according to ICD-10 (23), or of both parents and their children. Studies reporting on families of children with somatic illnesses were included if there were comorbidities with a mental health condition and the transition process primarily took place in mental health care (see Table 1 for detailed inclusion and exclusion criteria).

[Table 1 about here]

Study selection and data extraction

After exporting and pooling the search results from the databases and the removal of duplicates, one author (Original search: MK; Refresher search: VK, AS) screened titles and abstracts regarding the inclusion criteria of the review. Afterwards, full texts were procured and, if accessible, each full text was screened by at least two reviewers (original search: MK, CK, JG; refresher search: VK, AS). Any discrepancies in the screening process were resolved by consulting another researcher (original search: LA, TI; refresher search: LA).

The following information relating to the transition within mental health services was extracted from the included publications: Parents' evaluation of the transition process, parental perception of the parental role in (transition) treatment and of the general parental role (in transition), the young person's perspective on the role of their parents, and parental needs in preparation of the young person's transition and transition readiness. Furthermore, information about the authors, publication year, study design, sample characteristics, young person's diagnosis, and transition status at the time of the study were extracted.

Data synthesis and quality appraisal

Qualitative and quantitative data were analyzed separately. For the qualitative studies a narrative data synthesis was conducted using thematic analysis (24). Analysis and coding of the text units were carried out by two authors (SB, RS) at two separate instances. Meaningful content was coded inductively and/or deductively into a structured category system to enable systematic analysis. For the quantitative data, descriptive analyses were conducted (i.e., *M/SD*, *n/%*). For mixed-method studies, the qualitative and quantitative aspects were analyzed separately.

To assess the quality and risk of bias of the included studies, the checklists of the Critical Appraisal Skills Programme (CASP; 25,26) were used. The assessment yielded an overall rating for each study on a scale of one to three (1 = high quality, 2 = acceptable quality, 3 = low quality). No studies were excluded from this review based on the quality rating, as the aim was to summarize all available findings on the topic regardless of methodological quality. For mixed-method studies, both the qualitative and quantitative CASP checklists were applied in the quality assessment.

Results

Study selection

From a total of 9,439 search results in the first systematic database search, 4,108 duplicates were removed (see Fig. 1 for the PRISMA flowchart). Of the remaining 5,331 publications, 5,183 were excluded during the title and abstract screening. In the second screening, 144 full texts were reviewed, of which 22 matched the eligibility criteria and were included in the review. The refresher search yielded 2,030 search results, of which 730 were removed as duplicates. In the first screening, 1,300 titles and abstracts were screened and 1,281 records were excluded for not meeting the eligibility criteria. In the second screening 16 full texts were reviewed and one study was identified as suitable for inclusion. In sum, 23 publications were included in the current review.

[Figure 1 about here]

Study Characteristics

Among the 23 included studies, three were mixed-methods studies, yet the relevant data for this review was exclusively found in the qualitative components (27–29); thus, they were classified as qualitative studies. Overall, 20 qualitative and three quantitative studies with prospective longitudinal research designs were reviewed (see Table 2).

Table 2
Study Characteristics

Reference	Study design	Country	Sample	Young persons' diagnoses	Transition state	Overarching project	Quality assessment
Andershed et al. (2017)	Qualitative; narrative interviews	Sweden	3 fathers, 7 mothers (age: $M = 50$); 9 employed, 1 retired, 1 without statement, 6 with basic school leaving certificate, 3 with university degree	SCZ, depr., anx., unknown to 3 parents	Post		Acceptable
Appleton et al. (2021)	Qualitative; narrative interviews	UK	15 parents; 7 boys, 8 girls (age: $M = 19.42$)	AD, anx., SD co-occurring with aff. dis./Anx., ASD, ADHD, other	unsuccessful transition/transition without aftertreatment	MILE-STONE sample pool	Acceptable
Appleton et al. (2022)	Qualitative; narrative interviews	UK	15 parents; 7 boys, 9 girls (age: $M = 19.31$)	AD, anx., ASD co-occurring with AD/Anx., ASD, ADHD, other	unsuccessful transition/transition without aftertreatment		Acceptable
Boonstra et al. (2024)	Qualitative; semi-structured interviews	UK, Ireland, Netherlands, Croatia	3 parents	Depr., anx., PTSD, BPD, ED, self-injury, SUD, ADHD	Post or unsuccessful transition	MILE-STONE sample pool	Low
Cheak-Zamora & Teti (2015)	Qualitative; focus groups	USA	2 male and 17 female parents	ASD	Post		Acceptable
Cleverley et al. (2022)	Mixed-method; Delphi study	Canada	17 parents; 12 employed	Anx., AD, PD	Post		Acceptable
Eklund et al. (2016)	Quantitative; prospective cohort study	UK	91 parents	ADHD	Pre, ongoing, post		Acceptable
Gerritsen et al. (2022)	Quantitative; prospective cohort study	Belgium, Ireland, Croatia, France, Germany, Italy, UK, Netherlands	651 parents	Depr., anx., ADHD, ASD, ED, trauma, PD, OCD, SCZ, behavioral disorders, somatic disorders, BD	Pre, ongoing, post	MILE-STONE sample pool	Acceptable
Gerritsen et al. (2024)	Quantitative; prospective cohort study	Belgium, Ireland, Croatia,	457 patients,	Depr., anx., ADHD, ASD, ED, trauma, PD,	Pre, ongoing, post	MILE-STONE	Acceptable
Note. ADHD = attention deficit hyperactivity disorder; Aff. dis. = affective disorders; Anx. = anxiety disorder; ASD = autism spectrum disorder; BPD = borderline personality disorder; BD = bipolar disorder; Depr. = depression; ED = eating disorders; MHS = mental health services; OCD = obsessive-compulsive disorder; PD = personality disorder; PTSD = posttraumatic stress disorder; SCZ = schizophrenia;							
SUD = substance use disorder; UK = United Kingdom.							

Reference	Study design	Country	Sample	Young persons' diagnoses	Transition state	Overarching project	Quality assessment
		France, Germany, Italy, UK, Netherlands	383 parents	OCD, SCZ, behavioral disorders, somatic disorders, BD		sample pool	
Gerten & Hensley (2014)	Mixed-method; online survey with qualitative and quantitative questions	USA	19 mothers (age: 35–70)	Depr., anx., ED, SUD, ADHD, OCD, SCZ, BD	Post		Acceptable
Graaf et al., 2024	Qualitative; focus groups	USA	36 parents				Acceptable
Hovish et al. (2012)	Qualitative; semi-structured interviews	UK	6 parents; 6 boys, 5 girls	Paranoid SCZ, depr., ED, OCD, anx., BD, schizoaffective disorder, psychotic disorder, AD, Asperger	Post	TRACK project	Low
Janssens et al. (2020)	Mixed-method; semi-structured interviews	UK	27 mothers, 3 fathers; 44 boys, 20 girls (age: 14–29)	ADHD	Pre, post, reentry in MHS (without transition)	TRACK project	High
Lindgren et al. (2016)	Qualitative; interviews	Sweden	8 mothers, 2 fathers		Post		Low
Livanou et al. (2021)	Qualitative; semi-structured interviews	UK	5 parents	BD, SCZ, PD, ASD, learning disorders	Pre, post; pre transition parents surveys	TRACK project	Acceptable
Livanou et al. (2024)	Qualitative; group setting	UK	2 mothers	Behavioral disorders, trauma, neurologic developmental disorders, self-injury	Pre, ongoing, post; post transition parent surveys		Acceptable
Lockertsen et al. (2021)	Qualitative; semi-structured interviews	Norway	9 mothers, 3 fathers	Anorexia nervosa	Post		Low
McNamara et al. (2017)	Qualitative;	Ireland	5 parents	SCZ, OCD, Anx., SUD, ADHD, Depr.,	Ongoing, post	TRACK project	Low
Note. ADHD = attention deficit hyperactivity disorder; Aff. dis. = affective disorders; Anx. = anxiety disorder; ASD = autism spectrum disorder; BPD = borderline personality disorder; BD = bipolar disorder; Depr. = depression; ED = eating disorders; MHS = mental health services; OCD = obsessive-compulsive disorder; PD = personality disorder; PTSD = posttraumatic stress disorder; SCZ = schizophrenia; SUD = substance use disorder; UK = United Kingdom.							

Reference	Study design	Country	Sample	Young persons' diagnoses	Transition state	Overarching project	Quality assessment
	semi-structured interviews			BD, BPD, Asperger			
Price et al. (2019)	Qualitative; semi-structured interviews	UK	27 mothers, 3 fathers; 44 boys, 20 girls (age: 14–29)	ADHD	Pre, ongoing, reentry in MHS (without transition)	CATCH-uS project	Low
Scanferla et al. (2023)	Qualitative; semi-structured interviews	France	4 mothers, 2 fathers (age: 30 to > 60); 12 girls (age: $M = 22.5$)	Anorexia nervosa, Bulimia nervosa	Post		Acceptable
Singh et al. (2010)	Mixed-methods; questionnaire and semi-structured interviews	UK	6 parents; 11 patients	AD, anx., neurologic developmental disorders, persisting mental disorders, SUD, ED, behavioral disorders, PD	Post	TRACK project	Low
Swift et al. (2013)	Qualitative; semi-structured interviews	UK	At least 7 parents; 8 boys, 2 girls (age: 17–18)	ADHD	Pre, ongoing, post	TRAMS project	Acceptable
Wales et al. (2021)	Qualitative; semi-structured interviews	UK	5 mothers, 1 father; 5 girls	ED	Ongoing, post		Low
Note. ADHD = attention deficit hyperactivity disorder; Aff. dis. = affective disorders; Anx. = anxiety disorder; ASD = autism spectrum disorder; BPD = borderline personality disorder; BD = bipolar disorder; Depr. = depression; ED = eating disorders; MHS = mental health services; OCD = obsessive-compulsive disorder; PD = personality disorder; PTSD = posttraumatic stress disorder; SCZ = schizophrenia;							
SUD = substance use disorder; UK = United Kingdom.							

[Table 2 about here]

The studies were published between 2010 and 2024 and were conducted in Europe and North America. Regarding the study samples, 13 studies included only parents, while in the remaining nine studies both parents and young persons sampled. The diagnoses of the young patients included anxiety, attention deficit hyperactivity disorder, autism, disorders due to psychoactive substance use, schizophrenia, or post-traumatic stress-, mood-, personality-, eating-, or obsessive-compulsive disorders.

The studies took place before (16), during (30), or after the transfer had taken place (20, 27, 28, 31–38). Other study designs included surveys at multiple points during the transition process (29, 39–44) or focused on uncompleted transitions (Appleton et al., 2021, 2022). One publication did not report the transition status at the time of the survey (46).

Quality assessment

One study was of high quality (29), while 15 studies were of acceptable quality (8, 16, 27, 28, 30, 31, 33, 36, 37, 39–41, 43, 45, 46), and seven studies were deemed to be of low quality (20, 32, 34, 35, 38, 42, 44) (see Table 2 and Supplementary File 2 for details).

Findings of the quantitative synthesis

As only three quantitative studies were included (39–41), their results are summarized briefly in this section without division into sub-topics.

In one study, the same number of parents (37.9%) were either very or not satisfied with the transition (41). Appropriateness of end of care (i.e., transition readiness, -information, and -preparation, confidence in the AMHS team, and contentment with the received care and involvement) as well as preparation for end of care (e.g., readiness for care to end, being informed appropriately and in due time that care would end) were correlated positively with transition satisfaction (41).

Most parents felt unprepared for their changing role and responsibilities (39, 41), with two thirds reportedly desiring more support, especially regarding transition planning and information (39).

The majority of parents in another study (68.7%) felt that their child needed further treatment before transitioning: While a minority (19.6%) of young patients successfully transitioned within 24 months, 40.6% had not received any mental health treatment by the end of the study (40). Whether they had completed the transfer or remained in CAMHS was significantly positively associated with their parents' desire for treatment continuity (40).

Findings of the qualitative studies

Needs during and evaluation of the transition process

Parents' evaluations of the transition process were grouped into five themes: *parental desire for participation and involvement, information about and support during the transition process, emotional stress, evaluations of AMHS*, as well as *cooperation between CAMHS and AMHS*. Where available, themes were divided into parents' and young persons' needs from the parental perspective (see Table 3).

Table 3
Themes Derived from the Qualitative Data Synthesis (N = 20)

Themes	References	Total n (%)	Positive n (%)	Negative n (%)
Needs during and evaluation of the transition process	Andershed et al., 2017; Appleton et al., 2021, 2022; Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Clevery et al., 2022; Gerten & Hensley, 2014; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; McNamara et al., 2017; Price et al., 2019; Scanferla et al., 2023; Singh et al., 2010; Swift et al., 2013; Wales et al., 2021	20 (100.0)		
Parental desire for participation and involvement	Andershed et al., 2017; Appleton et al., 2021; Cheak-Zamora & Teti, 2015; Clevery et al., 2022; Gerten & Hensley, 2014; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Lockertsen et al., 2021; McNamara et al., 2017; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	14 (70.0)		
Parents' needs and evaluation of the transition (parents' perspective)	Andershed et al., 2017; Appleton et al., 2021; Cheak-Zamora & Teti, 2015; Clevery et al., 2022; Gerten & Hensley, 2014; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Lockertsen et al., 2021; McNamara et al., 2017; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	14 (70.0)	10 (50.0)	10 (50.0)
Child's needs and evaluation of the transition (parents' perspective)	-	0 (0.0)		
Information about and support during the transition process	Andershed et al., 2017; Appleton et al., 2022; Cheak-Zamora & Teti, 2015; Clevery et al., 2022; Gerten & Hensley, 2014; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; Price et al., 2019; Scanferla et al., 2023; Singh et al., 2010; Swift et al., 2013; Wales et al., 2021	15 (75.0)		
Parents' needs and evaluation of the transition (parents' perspective)	Andershed et al., 2017; Appleton et al., 2022; Gerten & Hensley, 2014; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; Price et al., 2019; Scanferla et al., 2023; Singh et al., 2010; Swift et al., 2013	12 (60.0)	2 (10.0)	11 (55.0)
Child's needs and evaluation of the transition (parents' perspective)	Appleton et al., 2021; Clevery et al., 2022; Gerten & Hensley, 2014; Janssens et al., 2020; Livanou et al., 2021, 2024; Lockertsen et al., 2021; Price et al., 2019; Wales et al., 2021	9 (45.0)	1 (5.0)	8 (40.0)
Emotional stress	Andershed et al., 2017; Appleton et al., 2021, 2022; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; McNamara et al., 2017; Scanferla et al., 2023; Singh et al., 2010; Wales et al., 2021	15 (75.0)		
Parents' needs and evaluation of the transition (parents' perspective)	Andershed et al., 2017; Appleton et al., 2021, 2022; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Hovish et al., 2012; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; McNamara et al., 2017; Singh et al., 2010; Wales et al., 2021	13 (65.0)	0 (0.0)	13 (65.0)
Child's needs and evaluation of the transition (parents' perspective)	Janssens et al., 2020; Livanou et al., 2024; Lockertsen et al., 2021	3 (15.0)	0 (0.0)	3 (15.0)
Evaluations of AMHS	Andershed et al., 2017; Appleton et al., 2021, 2022; Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; Price et al., 2019; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	17 (85.0)		
Parents' needs and evaluation of the	Appleton et al., 2021; Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Hovish et al., 2012; Lindgren et al., 2016; Lockertsen et al.,	10 (50.0)	4 (20.0)	8 (40.0)
Notes. Positive = positively evaluated aspects, negative = negatively evaluated aspects; Percentages refer to the total number of included studies.				

Themes	References	Total n (%)	Positive n (%)	Negative n (%)
transition (parents' perspective)	2021; Price et al., 2019; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021			
Child's needs and evaluation of the transition (parents' perspective)	Andershed et al., 2017; Appleton et al., 2021, 2022; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	13 (65.0)	1 (5.0)	12 (60.0)
Cooperation between CAMHS and AMHS	Andershed et al., 2017; Appleton et al., 2021, 2022; Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Cleverley et al., 2022; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021, 2024; Lockertsen et al., 2021; McNamara et al., 2017; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	17 (85.0)		
Parents' needs and evaluation of the transition (parents' perspective)	Andershed et al., 2017; Appleton et al., 2021; Graaf et al., 2024; Livanou et al., 2024; Scanferla et al., 2023	5 (25.0)	0 (0.0)	5 (25.0)
Child's needs and evaluation of the transition (parents' perspective)	Andershed et al., 2017; Appleton et al., 2021, 2022; Cheak-Zamora & Teti, 2015; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Livanou et al., 2024; Lockertsen et al., 2021; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	12 (60.0)	1 (5.0)	10 (50.0)
Perception of the parents' role in the transition process	Andershed et al., 2017; Appleton et al., 2021; Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Cleverley et al., 2022; Gerten & Hensley, 2014; Graaf et al., 2024; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021; Lockertsen et al., 2021; McNamara et al., 2017; Price et al., 2019; Scanferla et al., 2023; Singh et al., 2010; Swift et al., 2013; Wales et al., 2021	18 (90.0)		
Existing parental participation and involvement in treatment and transition	Andershed et al., 2017; Boonstra et al., 2024; Cleverley et al., 2022; Janssens et al., 2020; Lindgren et al., 2016	5 (25.0)		
Parents' perspective	Andershed et al., 2017; Boonstra et al., 2024; Cleverley et al., 2022; Janssens et al., 2020; Lindgren et al., 2016	5 (25.0)		
Young persons' perspective	-	0 (0.0)		
Stress due to role change	Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Lockertsen et al., 2021; McNamara et al., 2017; Wales et al., 2021	9 (45.0)		
Parents' perspective	Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Lockertsen et al., 2021; McNamara et al., 2017; Wales et al., 2021	9 (45.0)		
Young persons' perspective	-	0 (0.0)		
Granting (more) autonomy	Andershed et al., 2017; Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021; Lockertsen et al., 2021; McNamara et al., 2017; Scanferla et al., 2023; Singh et al., 2010; Wales et al., 2021	13 (65.0)		
Parents' perspective	Andershed et al., 2017; Gerten & Hensley, 2014; Hovish et al., 2012; Janssens et al., 2020; Lindgren et al., 2016; Lockertsen et al., 2021; Singh et al., 2010; Wales et al., 2021	8 (40.0)		

Notes. Positive = positively evaluated aspects, negative = negatively evaluated aspects; Percentages refer to the total number of included studies.

Themes	References	Total n (%)	Positive n (%)	Negative n (%)
Young persons' perspective	Boonstra et al., 2024; Cheak-Zamora & Teti, 2015; Hovish et al., 2012; Livanou et al., 2021; McNamara et al., 2017; Scanferla et al., 2023; Singh et al., 2010; Wales et al., 2021	8 (40.0)		
Continued practical and emotional responsibility	Andershed et al., 2017; Appleton et al., 2021; Cheak-Zamora & Teti, 2015; Gerten & Hensley, 2014; Graaf et al., 2024; Janssens et al., 2020; Lindgren et al., 2016; Livanou et al., 2021; Lockertsen et al., 2021; McNamara et al., 2017; Price et al., 2019; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	14 (70.0)		
Parents' perspective	Andershed et al., 2017; Appleton et al., 2021; Cheak-Zamora & Teti, 2015; Janssens et al., 2020; Lindgren et al., 2016; Lockertsen et al., 2021; Price et al., 2019; Scanferla et al., 2023; Swift et al., 2013; Wales et al., 2021	10 (50.0)		
Young persons' perspective	Appleton et al., 2021; Cheak-Zamora & Teti, 2015; Janssens et al., 2020; Livanou et al., 2021; McNamara et al., 2017; Price et al., 2019; Scanferla et al., 2023; Swift et al., 2013	8 (40.0)		
Notes. Positive = positively evaluated aspects, negative = negatively evaluated aspects; Percentages refer to the total number of included studies.				

Negative feelings were reported across themes as a common consequence of families' unmet needs and were therefore not limited to the theme *emotional stress* alone. In particular, insufficient information and poor communication were identified as important contributors to negative emotions across multiple aspects of the transition process (16, 20, 35, 36, 42).

Parental desire for participation and involvement were reported in 14 papers (70%) and was only reported as a need for the parents. They reported that they valued respectful and cooperative relations with healthcare providers and an active participation in their child's treatment (31, 43, 46). However, they perceived their involvement hindered by legal provisions (e.g., confidentiality once their child turned 18 years) (31) and providers lacking empathy for them as caregivers (28).

Information about and support during the transition process was addressed in 15 publications (75%). Parents criticized that the help provided was often insufficient and professionals failed to adhere to prior agreements (16, 35).

[Table 3 about here]

Parents' needs and evaluation of the transition (parents' perspective). In most publications ($n = 12$, 55%), parents desired more comprehensive information on the transition process (16, 29), relevant healthcare services (36), and their child's condition (20). They reported gathering additional information by themselves and drawing on informal sources (16, 20). Further, they sought greater emotional (28) and organizational (38) support. Although in two papers (10%), parents rated the support they received during the transition as adequate (20, 28).

Child's needs and evaluation of the transition (parents' perspective). In eight (40%) papers, parents described their children's support needs during and information about the transition as unmet. To them, young persons lacked access to qualified contact persons (20), appropriate communication channels (44), or assistance to manage their mental health themselves (29). Some parents stated that young persons were not prepared for the treatment in CAMHS to end (33).

Emotional stress. In 15 publications (75%) parents spoke about their own or their families' emotions in the context of the transition and stress was described in all studies.

Parents' needs and evaluation of the transition (parents' perspective). In 13 papers (65%) parents attributed their negative emotions (e.g., anxiety; Appleton et al., 2021), exclusion (34), powerlessness (37), & uncertainty (33, 44) to their unfulfilled needs during the transition process. Despite parents' own struggles and young people's fluctuating treatment adherence during the transition, parents continued to feel responsible for supporting their children throughout the process (20). Many found it difficult to fulfil further social or job-related obligations and sometimes developed mental health issues themselves (20). Given their perception of not being able to integrate their worries and opinions in their child's treatment, they felt left alone (34, 38). Furthermore, reactions from healthcare professionals made them feel guilty, insecure (28, 31), and judged for their attempts to advocate for their child's needs (Appleton et al., 2021; Lindgren et al., 2016).

Child's needs and evaluation of the transition (parents' perspective). Parents in three publications (15%) related aspects of the transition to emotional stress and health deterioration of the young patients (20). They perceived the loss of trusted contacts in CAHMS (36), expectations of AMHS as overly medication-focused, and other simultaneously occurring major life changes (29) as stressors.

Evaluation of AMHS. In 17 publications (85%), parents discussed differences between CAHMS and AMHS. The latter was perceived as less accessible, due to a colder, more regulated atmosphere (37), and information being less available (43), resulting in discontinuation of treatment (8, 44).

Parents' needs and evaluation of the transition (parents' perspective). Parents in four publications (20%) were satisfied with the AMHS, whereas 10 papers (50%) reported negative experiences. They positively highlighted understanding, supportive providers (35), and low-threshold access (32) in AMHS. Others were sceptical of AMHS based on reports of poor quality (16, 44). For some, negative experiences with AMHS resulted in resignation and the decision to care for the young person's themselves or pay for private treatment (8, 35).

Child's needs and evaluation of the transition (parents' perspective). In 13 papers (65%) parents rated the AMHS mostly negatively, whereas one study (5%) mentioned one satisfied parent (31). Parents found AMHS unsuitable for their children's developmental (30) or illness-related (33) requirements; for example, by demanding high independence from young patients (28). Some criticized treatment discontinuation after referrals to poorly informed general practitioners (8, 45). Prolonged waiting times reportedly led to symptom deteriorations for some young persons (35) and parents recommended better preparation for young persons in transition, including the development of coping strategies (29).

Cooperation between CAMHS and AMHS was addressed by parents in 17 publications (85%). Services were often perceived as disconnected (31, 42), leaving many parents confused about the transition (45) and experiencing it as a sudden change (29).

Parents' needs and evaluation of the transition (parents' perspective). In five publications (25%) parents described negative experiences related to service cooperation, emphasizing the needs for a gradual organized process (36), a familiar, joint contact person (37), and consistent individualized care (46).

Child's needs and evaluation of the transition (parents' perspective). In 12 studies (60%) parents generally evaluated the service cooperation for their children negatively, while in one paper (5%) they reported young persons to be well prepared (8). However, parents in 10 publications (50%) emphasized cooperation deficits, like the communication between services (37). They criticized the cut-off age at 18 years, as they saw it as an inflexible threshold for the end of treatment in CAMHS (29, 34) and desired a person-centred transition depended on the young patient's skills and level of maturity (20, 44).

Perception of the parents' role in the transition process

The perceived role that parents play during the transition process was addressed in 18 studies (90%), with findings grouped into four themes: *Existing parental participation and involvement in the treatment and transition (parental perspective)*, *stress due to role change (parental perspective)*, *granting (more) autonomy (parental perspective and young persons' perspective)*, and *continued practical and emotional responsibility (parental perspective and young persons' perspective)* (see Table 3).

Negative emotions were reported in relation to the parental role during their child's transition, particularly concerns about their child's increased autonomy in AMHS (20, 30) as well as in parents experiencing stress about their ongoing responsibilities (31, 35).

Existing parental participation and involvement in treatment and transition (parent's perspective) was seen in five publications (25%). Parents felt especially satisfied when invited to take part in discussions about and planning the transition process (31, 32). However, some stated, they also had to advocate for their child's access to health services (29).

Stress due to role change (parent's perspective) was reported in nine publications (45%), as the transition process for them was connected to less involvement in the treatment processes (42), less family support (35), and less information due to different legal regulations in AMHS (33). Some parents felt uncertain about their housing situation following the role change (20).

Granting (more) autonomy – i.e., the development of the young persons' autonomy during the transition – was addressed in 13 studies (65%).

Parents' perspective. Eight papers (40%) reported parents' views on their children's autonomy following the transition. Compared to CAMHS, most parents were reportedly less involved in AMHS (38), which was well received by some (44) and stressful for others (34). Further, some experienced it as a "tightrope act" to support the young persons while letting them take responsibility for their own life ((35), p. 100). Parents said, they would find it easier to reduce their support if they were still provided with information about their child's treatment (44).

Young persons' perspective. Eight publications (40%) reported young persons' views on the involvement of their parents in the transition process, which ranged from valuing increased discretion and independence (38, 42) to requiring continued parental support due to insufficient knowledge (44). Some young patients wanted flexibility to involve their parents in their care when needed (30, 37).

Continued practical and emotional responsibility during the transition process was reported in 14 studies (70%).

Parent's perspective. Ten publications (50%) emphasized parents' extensive responsibilities during and after their child's transition. This included managing appointments (43) and daily routines (31), explaining healthcare information to their child (29), researching healthcare facilities (20), or teaching self-management skills (16). They also reported that they assumed medical tasks (33), even compensating for inadequate professional care and limited emotional support during mental health crises (8). Parents felt taken for granted by healthcare services (31) and overwhelmed by their caring responsibilities alongside their everyday obligations (35).

Young persons' perspective. In eight studies (40%) young persons described their parents' role during the transition process, valuing active parental involvement in coping with everyday challenges, supporting their mental well-being, and navigating the transition itself (30, 37, 42). They particularly highlighted parents' support with administrative procedures and accessing health care (29, 37).

Discussion

This narrative review synthesized research on parents' perspectives on the transition from CAMHS to AMHS. Overall, the findings indicate substantial shortcomings in transitional care, with parents reporting predominantly negative experiences for both them and their children (16, 20, 35, 36, 42). Parents more often emphasized a lack of information, discontinuity of care, and their continued involvement (16, 20), whereas young people appeared to value informed decision-making, flexible independence, and access to trusted support when needed (20). At the same time, parents emerged as important partners who frequently compensated for service gaps while supporting their child's developing autonomy. These findings suggest that effective transition planning should balance family involvement with the young person's increasing independence. However, this balance is rarely clearly operationalized in research or clinical practice. While many transition programmes are explicitly designed to be youth-centred and aim to foster autonomy (17, 18), our findings suggest that they remain difficult to implement without continued parental involvement. Parents frequently play a key role in coordinating care, supporting treatment adherence, and influencing service use (8, 16, 20, 27–35, 37, 38, 42–44, 46), indicating that transition processes are, in practice, not solely youth-driven. This points to a structural mismatch between the conceptual focus of transition programmes and the realities of care, risking interventions that promote independence in theory while relying on unacknowledged parental involvement in practice.

Needs and the evaluation of the CAMHS-AMHS transition from the parent's perspective

To address two of the research questions, we analysed parents' needs during the transition and their assessments of the transfer from CAMHS to AMHS. Parents reported overwhelmingly negative experiences in most studies (13 qualitative studies, 3 quantitative studies), while even eight of the nine positive reports (8 qualitative, 1 quantitative study) were coupled with criticism. Aligned with earlier reviews emphasizing the systemic problems in transitional care (2, 4, 7, 21), this indicates that the transition remains inadequate and challenging for parents, regardless of their children's medical condition.

Consequently, parents frequently expressed negative emotions such as anxiety, worries, stress, and feelings of exclusion (8, 28, 31, 33, 34, 38, 42, 44, 45). This emotional burden for parents is mirrored in transition research across various health conditions (2, 4, 7, 21, 47) and warrants attention, as parents' positive attitudes are associated with successful transition outcomes (3). Indeed, we found that parents called for improved transition preparation and education (16, 20, 28–31, 35, 37, 39, 41, 43) and more support for families, as they often received the transition as abrupt end of care (8, 16, 20, 29, 33, 44).

Furthermore, parents criticized a cultural and structural disconnect between CAMHS and AMHS, including AMHS-infrastructures not meeting young adults' needs (8, 20, 28–31, 35–37, 43, 45), poor communication between services (31, 37, 42, 45), and treatment interruptions (8, 20, 29, 37, 40, 43, 45). The review by Hill et al. (7) also emphasized the collaboration between CAMHS and AMHS; thus parental reports in the current review suggest only limited progress has been made almost a decade later. In our view potential approaches on multiple levels include young person-focused transition clinics, special training for healthcare providers, and more flexible age limits adapting to the individual stage of development. Despite consistent criticism on transition preparation across reviews on different conditions (2, 4, 6, 7, 19, 21, 47), specific challenges and actionable solutions have yet to be examined. The prevalence of negative evaluations suggests systemic deficits and thus calls for a comprehensive revision of the transition process in cooperation with all key stakeholders. Therefore, prioritizing the lack of communication, service collaboration and continuity of care might support families through the challenging transition process and enhance acceptance.

Although both parents and young people evaluated the CAMHS to AMHS transition predominantly negatively, their criticisms emphasized partly different needs. Parents more frequently highlighted the need for information - seeking additional information independently when formal communication was insufficient – (16, 29, 36, 48) and active involvement in decision-making (31, 43, 46). In contrast, young people appeared to place greater value on relational continuity – i.e., access to a trusted and familiar professional – (48) and support that strengthened their self-management capacities (29).

Role of Parents in the CAMHS-AMHS transition

In our analysis of perspectives on the parental role in transition many parents thought they paved the way for their children to undergo treatment in AMHS, especially by compensating lacking professional support and fostering self-management skills (8, 29, 31, 43, 44, 48).

Parents set high expectations for themselves by labelling themselves as experts or advocates (8, 28, 29, 31, 33, 35, 37), while at the same time reporting dramatic implications for their own life (48). Those extensive responsibilities and willingness to make sacrifices can also be found in parents of children with a somatic, chronic health condition (21).

Parents frequently reported stress associated with changing roles (8, 33, 34, 37, 44), while parents rarely reported that young persons' acknowledged the personal toll the transition placed on parents; suggesting that substantial parental labour may remain largely invisible within the transition process. Furthermore, when describing transition-related tasks and responsibilities, parents reported a broader range of practical, emotional, and coordinative duties than young people themselves (16, 29–31, 37, 42, 43, 48).

Consistent with previous findings (6, 7), only few parents agreed to reduce their involvement in AMHS in favour of greater autonomy for their child (44, 49). Similarly, parents' perceptions of their involvement in somatic care varied individually (2, 4, 5, 21). However, as in mental healthcare, parents more often found it difficult to hand over responsibilities (5, 19, 21).

Finally, the young persons with a mental health condition highly appreciated the help from their parents (8, 16, 29, 30, 37, 42, 43), which emphasizes parents as key contributors to successful transitions. However, young persons were partially more ambivalent, as some valued their newly gained independence, while others desired further support from their parents when needed (32–34, 42, 44). This ambivalence contrasts with parents' perspectives on autonomy, which were more strongly shaped by concerns about safety, service quality, and the young person's readiness for self-management. For many parents, reducing involvement was conditional rather than absolute, depending on whether they trusted AMHS care and perceived their child as sufficiently prepared (44). By contrast, young people more often framed autonomy as the ability to decide for themselves whether, when, and to what extent parents should be involved (30, 37). Taken together, these findings indicate that autonomy should not be conceptualized as simple parental withdrawal, but as a negotiated and developmentally sensitive redistribution of responsibility between young person, parents, and services.

Strengths, limitations, and future directions

This narrative review has several strengths and limitations that should be considered when interpreting the findings: A key strength is its focus on parental perspectives during children's mental health care transitions, an under-researched area compared to somatic care transitions. The review also highlights parents' needs, which are often underrepresented in the literature prioritising children's perspectives. By synthesising evidence on parental roles and comparing these with children's experiences, it provides a more comprehensive understanding of family involvement in mental health service transitions. The inclusion of mixed-methods studies further allowed for a broader interpretation of experiential and contextual factors, although quantitative evidence remains limited.

Several limitations should also be noted. Restricting inclusion to English- and German-language publications may have introduced language bias, while the exclusion of preprints and unpublished studies limits the ability to rule out publication bias, potentially overrepresenting more extreme findings (50). The included studies were generally of moderate or low quality, which may affect the robustness and transferability of the findings. In addition, some studies originated from overlapping research groups and samples, potentially reducing variability in parental perspectives. Also, all included studies were conducted in Europe or North America, with a strong representation from the United Kingdom, which may limit transferability to other sociocultural and healthcare contexts. Further, the absence of dyadic parent-child studies prevented meaningful direct comparison between parental and child perspectives. Finally, the frequent involvement of parents in both care and outcome assessment may obscure the distinction between parental and youth perspectives, complicating the interpretation of transition readiness and independence.

Conclusion

This systematic review highlights persistent shortcomings in the transition from CAMHS to AMHS as perceived by parents, particularly inadequate preparation, poor continuity of care, limited communication, and uncertainty regarding parental involvement (8, 29–31, 35–37, 42, 44, 45, 48). These findings suggest that, despite growing awareness of transitional care, families continue to face substantial barriers during this period (2, 4, 7, 21, 47). Parents emerged as important partners who frequently compensated for service gaps while supporting their child's developing autonomy (8, 29, 31, 43, 44, 48). Future transition models should therefore explicitly address this mismatch by integrating parents conceptually into care designs, rather than implicitly relying on their involvement while promoting youth autonomy.

Abbreviations

AMHS
Adult mental health services
CAMHS
Child and adolescent mental health services
CASP
Critical Appraisal Skills Programme
PROSPERO
Preregistered with the international prospective register of systematic reviews

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

All authors consent to the publication.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

None to declare.

Funding

The project was funded by the Federal Ministry of Education and Research (Bundesministerium für Bildung und Forschung, BMBF) as part of the German Center for Child and Adolescent Health (DZKJ) under the funding code 01GL2403C

Authors' contributions

MK and LA conceived the research questions and study design. MK conducted the screening and performed the initial analysis. SB, RS, and TI conducted the final analysis. MK, RS, and LA drafted the initial manuscript. LA coordinated the project. All authors reviewed and approved the final manuscript.

Acknowledgements

The authors would like to thank Cheyenne Kuhn, Jette Giese, Vivian Klempau and Aleksander Szpotanski for their support in screening the publications for the review.

Ethics Statement

Informed consent and ethical approval were not retrieved, as the paper details a literature review.

Preregistration Details

The systematic literature review was preregistered with the international prospective register of systematic reviews (PROSPERO, ID: CRD42024559592; (1)) on 05.07.2024: <https://www.crd.york.ac.uk/PROSPERO/view/CRD42024559592>

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Footnotes

1. For the sake of simplicity and comprehensibility, in this text we use the term ‘parents’ to refer to both biological and adoptive parents, as well as legal guardians

Table 1

Table 1 is available in the Supplementary Files section.

Figures

Figure 1

PRISMA Flow Chart of the Study Selection Process

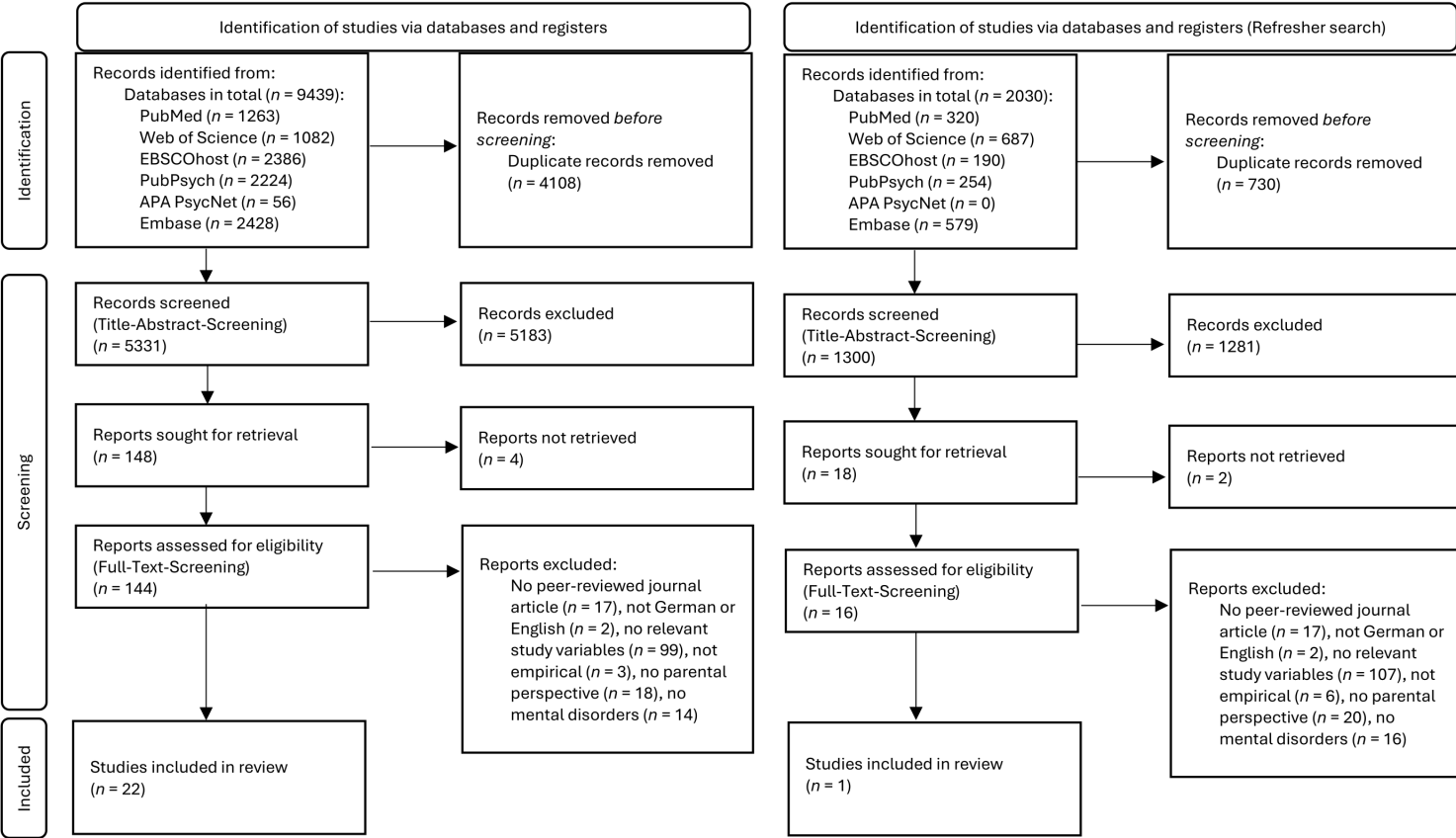


Figure 1

See image above for figure legend

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