Experiences of pathways to mental health services for young people and their carers: A qualitative meta-synthesis review

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Introduction

Most mental health problems have their peak incidence in adolescence and young adulthood. Delayed treatment of these problems can lead to poorer treatment outcomes, including lower remission rates and higher relapse rates [1-3]; and increased risk of complex symptomatology and/or comorbidity, which early treatment seeks to prevent [2, 4].

Despite growing recognition of the high prevalence of mental disorders in youth and the importance of early treatment, youths' service utilization rates remain low. Prior research has explored barriers along the pathway from symptom onset to treatment commencement [5]. Among youths, most such research has focused on help-seeking delays, i.e., delays between the emergence of a mental health problem and seeking help. A systematic review of youths' help-seeking delays identified low mental health literacy and stigma as major barriers [6].

Effectively addressing mental health problems depends not only on timely help-seeking, but also on a rapid and appropriate response by the mental health system. The observation that substantial delays occur after individuals contact mental health services has spurred interest in youths' modes and routes of accessing help. These "pathways to care" have been defined to include the

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attempts that distressed individuals and/or their carers make to seek help, and care providers' and organizations' responses to that help-seeking [7]. Pathways to care intersect with social, cultural and systemic factors that shape their direction and duration [7]. Our recent systematic review of quantitative literature (45 studies) revealed that youths' pathways to mental health services are generally complex, and involve diverse and often numerous informal and formal contacts and lengthy delays [8].

While quantitative indices yield an overview of pathways to care, a cohesive understanding of how youths and their families/carers experience them is largely missing. A recent focus on lived experience has infused emerging healthcare research and reform strategies with patient-orientation. Still, 'visible, constructive and generally efficacious gateways and pathways to mental health services'[9] are unlikely to develop if young people's views and those of their carers, particularly on the accessibility and acceptability of care, go unheeded. We therefore undertook a systematic review and meta-synthesis of qualitative studies of pathways to mental health services, from the perspectives of young people and their carers.

Methods

Meta-synthesis

The review protocol was developed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA)[10] and registered at the PROSPERO Centre for Reviews and Dissemination (ID: CRD42016039208) in June 2016.
The use of qualitative meta-synthesis is growing in the literature on youth mental health [11, 12]. Qualitative meta-synthesis is a technique for reviewing, translating, and integrating findings from qualitative studies to form novel, powerful interpretations [13, 14]. To achieve this, authors' original findings, using their terms, were listed for each included paper. From these summaries, key concepts were identified, and relationships between concepts were compared. This juxtaposition helped identify homogeneity of and discordance of concepts. This allowed us to elicit links between studies and map how each study contributed to the understanding of the topic. Further readings elicited patterns across studies that we juxtaposed and integrated to identify key concepts.

Search methods

Consulting researchers with expertise in youth mental health and a university librarian, we generated search terms that were related to pathways, service use, help-seeking, and mental disorders (see Supplementary Material 1). Pertinent studies were identified on the electronic databases MEDLINE (1946 onwards), Embase (1947 onwards), PsycINFO (1967 onwards), HealthSTAR (1966 onwards), and CINAHL (1937 onwards). Additional articles were identified by backward and forward citation mapping using Web of Science, as well as hand searching. The search was conducted in July 2016 and again in April 2020.

Screening

Two authors [KM; NFA] independently screened titles, abstracts, and full texts for inclusion and resolved disagreements by consensus. Articles were included if they were peer-reviewed; written in English or French; and reported on qualitative studies of experiences of pathways to mental health services, regardless of the presence or absence of formal diagnoses. Further, at least 50% of study participants had to be 11 to 30 years old. We excluded studies of youths with chronic physical ailments or a primary diagnosis of intellectual disability.

Quality appraisal

Quality appraisal was implemented with the Critical Appraisal Skills Programme (CASP) Qualitative Checklist [15]. First, two authors [KM; NFA] independently assessed the included studies' quality, and resolved disagreements through discussion and re-rating, reaching consensus for all studies. A third researcher [MF] with substantial expertise in qualitative methodologies reviewed the final ratings. Quality ratings are presented in Supplementary Material 2.We did not exclude any studies based on quality assessment, as recommended by experts like Sandelowski et al.[13, 16] and Atkins et al. [17].

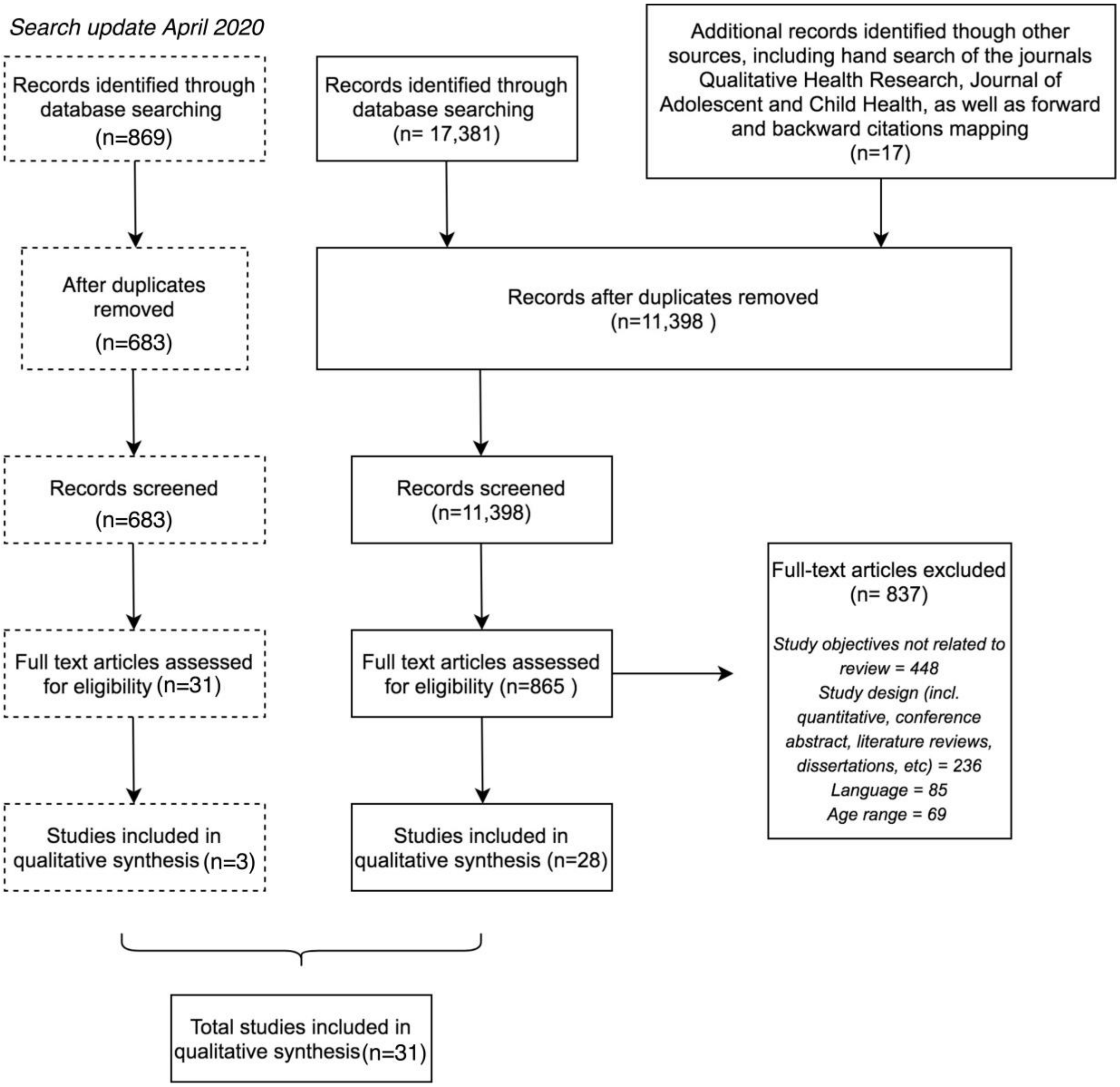
Results

Study selection and characteristics

12,081 studies were reviewed at the title and abstract stage. 896 full texts were screened, including 17 found by hand search. Of these, 31 studies met our inclusion criteria (see Figure 1). *Geographic and healthcare systems*: Except for one study from India and one from Bangladesh, all studies were conducted in high-income, mostly Western countries. With few exceptions, all countries where the reviewed studies were conducted have universal, primarily publicly funded healthcare systems. (See Table 1) Most studies were conducted in urban settings, though three studies specifically focused on experiences of youths growing up in rural communities [18-20]. *Study service settings:* Fourteen studies were conducted in specialized psychosis services (including two inpatient units); eleven in general mental health services; two in ultra-high risk for psychosis programs; and one each in a substance use treatment facility; a crisis inpatient unit; an integrated youth service; and with youths with ADHD.

Participants: Thirteen studies focused solely on youth perspectives, while seven explored carer experiences. Nine studies combined both. One study was conducted with service providers. One was conducted with youths, families, and their service providers. Notably, although we used the term 'carer' to encompass all caregiver roles (parents, siblings, friends, etc.), the carer perspectives in most studies were those of mothers.

Many studies reported on the ethnic backgrounds of their participants, though very few explored the impact of ethnicity in their analysis. While the gender composition of participants varied greatly between studies, most studies did not discuss gender in their results (See Table 1). Only one study specifically focused on the role of gender in pathways to care experiences [21]. Many studies reported participant characteristics such as income or deprivation indices, though these factors were not commented on further in the studies' analyses. Two studies specifically focused on low-income[22] and uninsured [23] youths.



Synthesis

The synthesis of key concepts yielded three core themes describing participants' pathways to mental health services: initiating contact with mental health services, response from services, and appraisal of services. For each of these themes, subthemes relating to youth and carer perspectives were identified (See Figure 2).

The importance in our synthesis of these three core themes is in line with prior work on dynamic models of adolescent help-seeking. More specifically, the themes that we developed align significantly with the 'action' stage described in Rickwood et al.'s help seeking model [24]. This action stage has been further elaborated upon by others [25, 26] to incorporate stages including intention formation, i.e., deciding to seek services; contacting services; and service appraisal. Our synthesis adds to the evidence that such stages do not occur in a linear fashion but are dynamic in nature, and based on the complex interaction between individuals, their support circle, and the healthcare system.

Theme 1: Initiating contact with the mental health system

This theme represents the efforts made by youths and their carers as they initiate contact with the mental healthcare system.

1.1: Mental health literacy

"I didn't know this was a condition that you could seek medical treatment for."[27]

Youth,
First-episode psychosis service, Montreal, Canada (Urban)

Mental health literacy, defined as knowledge and beliefs about mental disorders which aid their recognition, management or prevention' [28, 29] was a prominent theme across the reviewed studies. Youths and carers often reported not realizing that services existed for the problem they faced or where to find appropriate services [19, 20, 25, 27, 30-39]. Especially when help-seeking was initiated by carers, many young people reported being unaware of their problems until after their first contact with mental healthcare or after treatment began [31, 38, 40]. Both, youths and carers described dismissing distress as 'teenage angst' or attributing atypical behaviours to the developmental stage [31, 32, 37, 38, 41-44].

Cos like you see like on that, movies and people went to therapy . . . I thought I was going kinda cuckoo. . . . I thought they [friends] would have called me crazy.[45]

Female youth,
Youths at risk for psychosis, Greater London, UK (Urban)

Expectations about mental health services influenced whether youths or carers contacted services. Negative attitudes and stigma about mental illness and help-seeking prevailed among young people [18, 19, 25, 27, 32, 38, 41-46] and carers, who sometimes denied that their families were affected [20, 32, 36, 44]. Across contexts, such attitudes reduced the likelihood of symptom disclosure and help-seeking.

Concerns about privacy were common [18, 19, 33, 45]. Knowing that formal healthcare providers were bound by confidentiality facilitated disclosure for some [45]. Service providers described the struggle to balance confidentiality and safety, suggesting that legal constraints like mandatory reporting hindered the disclosure of behaviours like self-harm [22].
Mental health literacy was affected by past experiences with the healthcare system [23, 25, 30, 32, 36, 41, 47]. Positive past experiences helped people recognize signs and symptoms[32, 36] and identify whom to reach;[23, 25] or increased the likelihood of help-seeking.[30, 41, 47] Conversely, *negative previous experiences such as perceived lack of improvement [32], or a negative first encounter at a hospital [39] delayed future help-seeking as youth were less willing to contact these services when care was needed again.*

1.2: Structural and systemic characteristics

A prominent theme in initiating contact with the mental health system pertained to its structural characteristics, which often contributed to delays.

"It's hard to get around if you don't have a car… if I lived just out of town, that would be hard if I had to go to an appointment every week cause my mom works….''[18]

Female youth,
Child and Adolescent Mental Health Services, Australia (Rural)

Transportation was a commonly cited issue[18, 20, 22, 25, 33], especially where public transit was scarce[18, 39], and youths lived far from services [33] and in rural areas [18, 20]. Further, for some participants, the decision about where to first seek help was based on distance to the provider.[39]

Cost was cited as a prominent barrier [20, 33, 35, 36, 39], especially by accompanying carers who described having to take time off work and pay for gas, parking, and accommodations. Some carers described considering private treatment, but lacking the requisite financial resources [20]. Other parents, in studies based in the United States, spoke of lacking insurance coverage [23, 25, 48].

1.3: Social support

Youths' sources of social support were critical in initiating contact with the mental health system.
''I told her [mother] all about it; I explained her everything ... and then the day after she called my GP and we went over and saw him .''[46]
Youth,
Specialized first-episode psychosis service, Region Zealand, Denmark

Overwhelmingly, parents' involvement in youths' pathway to services was seen as crucial. Parents' roles were wide-ranging — from being the first ones to whom youths disclosed symptoms [25, 31, 40, 43] to suggesting, initiating and pushing for care [22, 23, 25, 27, 31, 32, 39-41, 43, 46, 49, 50].

"Services… are extremely fractured and extremely hard to access, and I am a forceful, pretty highly educated, middle-class person with some resources and the ability to be an advocate and push against the system for my family members…. It's this thick, impenetrable soup of inaccessibility and… you have to invest an incredible amount of time in educating yourself and finding out what your resources are."[35]
Carer,
Carers of youths receiving mental health services [not specified], Indianapolis, USA (Urban)

Among carers, the theme of negotiating/advocating for access to services was prominent [20, 34, 35, 41, 47]. First-time carers described difficulties in negotiating admission to services and educating themselves about resources. Some carers felt that they had not been able to access services because they had not pushed hard enough [20]. They reported that their own social circle (friends, neighbours, colleagues) helped them advocate for their child [20, 25, 37, 39, 49,

51]. Their difficulties with such advocacy were exacerbated by cultural and language barriers [27, 34, 50].
Further, some carers reported that advocating for involuntary hospitalization had been "*traumatic yet necessary*"[48].

''My putting him in the hospital was my cry for help too. I just felt I couldn't handle it anymore, and I saw that instead of getting better, he was just getting worse. So I said that's it."[48]

Carer,
First-episode psychosis service, New York metropolitan area, USA (Urban)

Theme 2: Response from services

The mental healthcare system's responses to help-seeking were identified as among important factors that influence help-seeking, engagement with care, and outcomes.

2.1: Complex pathways

"We'd get stuff piecemeal here and there… but didn't really know what resources were available in this community… it was like everybody had their own little niche, but nobody had the overall perspective."[37]

Carer,
First-episode psychosis service, Ohio, USA

Youths and carers described the complexity of navigating mental health services after establishing first contact. Many young people reported contacting multiple mental health services before obtaining care [22, 23, 27, 31, 33, 34, 36, 38, 41, 42, 44, 46, 47, 49, 51, 52]. These pathways were described as confusing, unsatisfactory, and frustrating [31, 42]. Youths and carers also resented having to 'tell their story multiple times'[31, 52].

Carers described interacting with the system under a 'cloud of uncertainty,' not knowing what high-quality care should look like or how treatment should progress [42]. Others described navigating the healthcare system as time-consuming and difficult, a characterization that service providers and government officials have echoed.
"… a bit of an unfortunate characteristic of the mental health system… a lot of time it is about keeping clients out, and when they do get in, get rid of them as quickly as you can and you refer on to other agencies."[22]

Non-government mental health service provider,
Services in low-to-middle socio-economic areas, Perth, Australia

Informal support contacts (e.g., family, friends, support groups, self-help) were described as helpful throughout youths' pathways to care [37, 47, 52]. In some studies [25, 35, 36, 44, 46, 47] youths and carers reported using the Internet to research symptoms and services before seeking formal help.
Some participants attributed the complexity of their pathways to misdiagnoses or dismissals by general practitioners [25]. Others criticized the poor connections and 'territorial squabbles' between different services whose clinicians had difficulty cooperating to help youths [20].

Others described service providers' inability to connect with appropriate resources when problems escalated [37].

Numerous studies, including the three studies based in inpatient units, described police encounters along their pathway to services [23, 25, 31, 32, 40, 48, 53]. For some, this contact was deemed 'helpful' and precipitated entry to services [23, 32, 40]. For others, this represented a coercive or traumatic experience along the journey to care [44, 48].

2.2: Eligibility

"They [county mental health services] denied me, like three times… then they diagnosed me with depression, and that was like my ticket in the door.''[23]

Female youth,
Short-term inpatient crisis stabilization unit [following a visit to a crisis emergency centre], USA (Urban)

In some studies, services only admitted cases meeting specific eligibility criteria. Some participants described being ineligible for age-restricted [20] or diagnosis-specific services (e.g. only for depression or psychosis) [23, 34]. Others reported not qualifying for certain services because their symptoms were not severe enough [20, 33, 34, 37, 39, 47]. Participants described being turned away because they were deemed 'too functional'[21, 48], an issue which, in one study, was reported solely among female participants and identified as a key aspect in understanding gender differences in pathways to care [21]. In some cases, services only became available when crises emerged [18, 20, 23, 33, 49], leaving some carers relieved when youths' behaviours escalated enough to warrant emergency care [35].

2.3: Waitlists

"I sort of felt that you… had to overdose or do something to harm yourself to get in here fairly quick cos there's such a demand for these services… But I did it the hard way [attempting suicide]… six months waiting list otherwise."[18]

Youth,
Child and Adolescent Mental Health Services, Australia (Rural)

Frequently, even when services were identified and available, long waitlists delayed the commencement of treatment [18, 20, 23, 30, 34, 52]. This was especially so in rural communities,[18, 20] where recruiting and retaining mental health professionals was difficult. Interestingly, participants in several studies [18, 23, 30, 33-35] opined that accessing mental healthcare through emergency or crisis services could result in a substantial reduction in waiting times.

"It's the fastest way in to the [outpatient clinic] eligibility, because eligibility takes up to a year. But if you go to the hospital, you get a therapist and a psychiatrist right away."[23]

26-year-old female youth, crisis service, Texas, USA

2.4: Lack of continuity of care

"Once she hit the magic age of 16, there's nothing… too young for adult services, too old for kids' services."[20]

Carer,
Children's community mental health agency, Ontario, Canada (Rural)

Fragmented care was prominent across studies, especially with age-based transitions [20, 30, 31, 34, 41]. Other difficulties included lack of planned discharge from hospital services [25, 42, 48] and transitions between services or from inpatient to outpatient or emergency to hospital settings [25, 41, 42, 48]. Some decried discontinuity between providers, even within the same setting [31]. In one study, both youths and parents had difficulty describing the different roles of and relationships between clinicians providing their care.[50]

"We kept getting sick of telling our same story to different people. We probably saw three different psychiatrists in the time that we were there [inpatient unit]."[31]

Carer,
Child and adolescent mental health services, Auckland, New Zealand (Urban)

Theme 3: Appraisal of services

A key component in the process from help-seeking to eventual engagement with care is youths' and carers' appraisal of that care. Both positive and negative encounters were discussed.

3.1: Positive appraisal

"[the service] was helpful because one of their comments was, if she won't come to see us, she obviously needs help and we'll come out to see her"

Parent of youth with unspecified mental health problem, Australia

Commonly appreciated aspects of service encounters included providers who were perceived as resourceful, knowledgeable, providing useful information [19, 37, 47, 48], caring, supportive, non-judgmental or trustworthy [19, 31, 42, 47]. Youths described positive relationships with providers who related to their problems [45] by drawing on their own experiences or being close in age. For youths, learning of health professionals' confidentiality obligations was reassuring [19, 22, 45].

Families greatly appreciated being informed about youths' treatment and progress, and being included in decision-making [31, 42, 47]. Families also appreciated culturally appropriate care, including by providers or interpreters [50] who shared their language or culture [20, 30]. Youths and carers highlighted the importance of services being available and rapidly accessible [19, 31, 37, 47]. Many described flexible services positively, noting instances where service providers offered transportation, made home or community visits, and remained available by means like text messaging and email [20, 22, 31, 50].

Both, youths and carers described the experience of receiving a diagnosis as difficult but "*helpful*", a "*relief*" or '*essential'* [37, 43, 47, 52].

Contrasting their frustrations at being stymied by professional squabbles, many spoke positively of instances in which services had collaborated effectively [22, 51] or professionals like general practitioners or school counsellors had referred to appropriate services promptly [34].

3.2: Negative appraisal

"I think they treat you more like a number. And I think, being treated like a person instead of a number or a case, because, if you're a case, you're like 'I'm schizophrenic', you're not a person anymore."[32]

European-origin youth,
First-episode psychosis services, Ontario, Canada

Across contexts, young people shared experiences of frustration when they felt misunderstood, dismissed, or underestimated by service providers [25, 27, 32, 48, 52]. Other negative experiences included hospitalization or coercion [31, 44]; exposure to unwell peers[31]; and encountering staff who seemed insensitive or negative [25, 31, 32, 44, 48]. Others bemoaned feeling 'disrespected,' 'labelled,' left in the dark [32] or unable to trust providers, especially when appointments were cancelled or rescheduled [20]. Carers perceived services most negatively when they felt excluded or insufficiently informed [20, 37, 42, 47, 48]. They also criticized difficulties in scheduling appointments or contacting providers [48, 54]; absence of diagnoses [37, 47, 52]; providers not appreciating their knowledge or not seeing them as partners [20, 35, 52]; and uninformed or insensitive providers [34, 38]. They expressed frustration with receiving 'brief encounters' (e.g., one-three sessions) for problems that they felt warranted more care [20]. Emergency or inpatient entry points were often described as traumatic [48, 54].

'I don't remember them being very forthcoming at the hospital.... In fact, every piece of information that we found out there was almost [a] tooth and nail pull....''[37]

Carer,
First-episode psychosis service, Ohio, USA

Stigma exacerbated youths' frustrations with treatment [27, 45], led to refusal of care [42] and contributed to families' difficulty in accepting services [48]. Perceived stigma was aggravated when service providers' attitudes seemed stigmatizing [48], with carers and youths describing feeling 'blamed' for the illness [35].

Participants in six studies described concerns with school-based mental health services. Privacy and confidentiality were the main concerns for youth [44, 45, 50] while carers were concerned about the lack of mental health training and support from staff [19, 35, 52].

Discussion

Across clinical diagnoses and study settings, young people from various backgrounds and their carers reported a range of similar experiences when seeking and obtaining help for mental health problems. Difficulties and traumatic experiences in this regard were attributable to issues of the awareness, availability, accessibility, navigability, appropriateness and acceptability of mental healthcare.

The findings of our meta-synthesis align with models of help-seeking like the Revised Network Episode Model [55], which conceptualizes health service use as a product of interactions between individuals, social networks, and the healthcare system. This synthesis broadens our understanding of youths’ pathways to care beyond their quantitative features, the focus of our previous systematic review ([8]), which described pathways as complex, instead of simple, linear progressions. The current qualitative synthesis broadens our understanding of the drivers of this complexity. Specifically, we found that the most prevalent structural barriers to care were waitlists, strict eligibility criteria, and fragmented, inaccessible care. These factors, compounded with known help-seeking barriers such as mental health literacy, stigma, and self-reliance [6, 24], contribute to significant delays prior to youth engaging with appropriate services. These delays to treatment are known impact clinical recovery [56, 57] and can impede the attainment of personal, educational, and vocational milestones [58, 59]. On the other hand, strong social supports, flexible services, and positive perceptions of care were key factors in accepting treatment.

A finding common across many reviewed studies was the identification of mental health literacy as a prerequisite to initial contact with health services. Improving literacy involves enhancing youths’ and families’ ability to recognize mental health issues, to cultivate attitudes that facilitate help-seeking, and to navigate the healthcare system.
Across contexts and settings, the role of caregivers in facilitating pathways to mental health services was evident in both youth and carer perspectives. Carers often sought help from varied sources and spoke of the inhibitory role of stigma in judging the need for treatment. Thus, a greater recognition of caregivers’ roles and needs is crucial. Our work and that of others [60, 61] has consistently shown that carers (predominantly parents), despite often initiating help-seeking, lack support in obtaining help.

It should be noted that the included studies reflect the perspectives of youths and families who attend mental health services, and therefore represent a minority [62] of youth with mental health problems who are engaged with care. Importantly, even amongst this group, the reviewed literature reflected largely negative experiences of accessing care, and of the services received. This is in line with previous reports [63-66] and may help explain the levels of unmet mental healthcare needs of youth around the world [67, 68], and their high rates of treatment disengagement [59, 69]. This further underscores the importance of youth and carer participation to shape youth-friendly mental health services [70], as current co-design efforts are attempting [71].

As with our quantitative systematic review [8], a large proportion of studies were conducted in early intervention services for psychosis. We investigated the differences between studies conducted in these settings [[21, 25, 27, 31, 32, 34, 36-38, 42, 43, 46, 48, 49] compared to studies with youths presenting all other mental health conditions [[18-20, 22, 23, 33, 35, 39-41, 44, 45, 47, 50-53]. Our first finding was that the systemic characteristics of waitlists, eligibility, and fragmented services were less often cited by studies set in early intervention for psychosis settings. (Supplementary Material 3). This may be due in part to the emphasis of the early psychosis field to standardize certain aspects of care, including establishing benchmarks [72] for wait-times to reduce treatment delays and advocating for consistent case management for two years after illness onset. Further, mental health literacy, while an important theme across all reviewed studies, was especially noted within the context of early psychosis. This may be because while psychotic symptoms are well-defined, they remain relatively unknown within the general population, pointing to the need for increased early identification efforts within community settings

Service and policy implications

Our synthesis revealed that, across contexts, young people and carers call for service delivery improvements to simplify pathways, assure confidentiality, clarify provider roles, and reduce repeated evaluations. If bureaucratic complexities cannot be dismantled, service providers should, at least, improve communication with youths and caregivers to dispel perceptions of being left in the dark. Inter-service transitions should be minimized or, at least, follow clear protocols for coordinating care and sharing information about diagnoses and treatment between youths, families, service providers, and agencies [73].

Familial alienation from services often prolongs pathways by contributing to disengagement and negative appraisals of services. Family engagement can be improved by acknowledging carer perspectives; clear protocols for information sharing, shared decision-making and confidentiality; and family-focused interventions.

The consistent identification of mental health literacy and self- and social stigma as key factors in care pathway experiences indicates a need for youth-focused mental health awareness and stigma reduction efforts. Too often, access to services was contingent on having an assertive, knowledgeable advocate to negotiate entry into complex healthcare systems. This additionally disadvantages already-vulnerable groups like immigrant, uninsured, homeless and culturally and linguistically diverse youths. Equity necessitates making services accessible without requiring persistence or advocacy. Policies on the training of general practitioners, police officers, teachers, emergency room and other frontline workers should include mental health literacy and capacity-building.

Youths' and carers' eligibility-related concerns warrant reflection. Many specialized services are organized around tightly defined acceptable 'cases.' Because youth mental health problems are often transient and protean, overly restrictive eligibility criteria can impede access to early intervention. However, new transdiagnostic approaches based on pluripotent trajectories of youth mental health presentations may need to consider that many youths and their families considered receiving a 'label' or diagnosis a helpful component of their care.

Our findings point to the need for such services to be easily accessible by public transport. Given that the cost of care was often identified as a barrier to access, youth services should operate on the principle of universal coverage [74]. The difficulty in providing and accessing mental healthcare in rural and remote areas that we found can be mitigated through technology-enabled solutions, to which young people are known to be amenable [75].

Finally, investments in youth-centered care should be grounded in the perspectives and needs of young people and carers. Across many reviewed studies, youths were asked to identify what could ease pathways to mental health services. Their responses included:

1. *Confidentiality and relatability*: Youths' perceived alliance improved when providers emphasized confidentiality and were relatable. One participant described how a counselor disclosing her own experience of similar problems facilitated disclosure.[76]
2. *Integrated services*: Integrating mental health services with general healthcare could alleviate stigma-related concerns by making the nature of help-seeking youths' problems less obvious [77]. Further, youths who have availed any kind of care from an integrated youth service may be likelier to seek help for a mental health problem in a timelier manner or to have such a problem noticed early on by a service provider.
3. *Sensitivity training*: General practitioners, emergency room staff, police, detention center staff, and other frontline workers should be trained about mental health, available resources, biases, and stigma.[32]
4. *Service improvements*: Services should be enhanced by de-crowding waiting rooms to make them less intimidating to youths with paranoia or social anxiety; providing peer support; improving communication between providers to reduce the need for repeating stories; shortening inpatient stays; limiting the use of coercion; and providing leisure activities during hospitalizations. Youths described the importance of stability of "people and places (e.g., not switching rooms)" and a personalized, warm welcome upon entry. [50, 78, 79]

Limitations and future research directions

Despite providing rich data on participants' ethnicity, gender, sexual orientation, etc. and contextual information on rurality, healthcare system characteristics, etc., most studies, barring few exceptions [18, 20, 23, 32], did not explore the role of these factors. This despite such factors being known to shape access to care [80, 81]. As such, our ability to meaningfully comment on how social, structural and contextual realities impact upon the equitability of access to and experiences of seeking mental healthcare was limited. This limitation was perhaps exacerbated by the meta-synthesis method, which, in including studies from different contexts, runs the risk of overlooking important explanatory context information within each study [82]. To mitigate this risk, we gleaned as much contextual information as possible from the studies. Ultimately, design and methodological decisions made by authors of the included studies would also be reflected in this synthesis.

Assessing the quality of qualitative research is critical in meta-synthesis reviews but can be problematic due to the limitations of quality appraisal tools. The CASP [14] tool we used offers a simple and flexible method to assess qualitative studies but does not capture nuances related to different qualitative research traditions and practices [83]. Overall, the quality of the included studies is cause for optimism about the value of qualitative methodologies in the pathways to care field.

To advance research on youths' and families' experiences of pathways to mental healthcare, we outline some key recommendations informed by our meta-synthesis:

1. The perspectives of youths experiencing a wide range of mental health problems is needed. Further, integrated, transdiagnostic youth mental health services, with shared core service design principles, including well-publicized, easily accessible portals of entry, are rapidly being developed around the world [84]. Our synthesis included only one study from such a hub [33]. The promise of this model in simplifying youths' pathways to care — in terms of both initial contact and subsequent connections to needed services — needs further empirical investigation.

2. Future research should focus on youths less likely to access care, such as gender minorities; homeless youths; youths not engaged in employment, education, or training [85], etc., as well as the perspectives of the many youths who do not reach formal services or seek mental health supports elsewhere. For population-scale insights, qualitative approaches should be integrated into examinations of pathways to care in community samples, thus increasing the sample size for studies of this nature.
3. Questions remain about how positive and negative encounters along the pathway to care may shape whether and how individuals engage with services. Longitudinal studies starting at the onset of help-seeking may allow a more thorough unpacking of the dynamic and non-linear nature of steps from help-seeking to appraisal to engagement with care.
4. Most of the world's young people live in low- and middle-income countries. Few studies from these countries were excluded from our synthesis based on language of publication. There is an urgent need to address the striking knowledge gap around how young people and their families in these countries access and navigate mental healthcare.
5. Most of the included studies used an inductive approach, which allows themes and theoretical understanding to emerge from the data. The use of a deductive approach [55, 86, 87] could advance existing theoretical frameworks of help-seeking and pertinent social theories (e.g., stigma theories).

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Table 1. Study Characteristics

Study	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Anderson et al. [28]	Montreal, Canada	FEP clients at an early intervention program	To describe the experiences of patients with FEP on their pathway to care and to identify factors that help or hinder help-seeking efforts	16 service users (75% male)	5/16 visible minority; 11/16 non-visible minority	NS	Median 22.5	Structured and semi-structured interviews	Specialized service using open referral system with
Aisbett et al. [19]	Victoria, Australia	Rural child and adolescent mental health service users	To explore Australian rural adolescents' experiences of accessing help for a mental health problem in the context of their rural communities	3 service users (all female)	NS	2/3 participants in school, 1/3 employed	Range: 15–17	Semi-structured interviews	Horsham and Ararat are rural cities with some restriction in the availability of goods and services
Boulter and Rickwood [47]	Canberra, Australia	Parents of children with any mental health concern in local care services	To gain an insight into parents' experiences of seeking help for their children with mental health problems	15 carers, (6.7% male)	NS	Family income:1/15 = < 50,000; 7/15 = 50,000–100,000;7/15 = > 100,000	Under 18	Semi-structured interviews	NS
Boyd et al. [20]	Victoria, Australia	University students from rural background with any mental health concern	To explore Australian rural adolescents' experiences of accessing help for a mental health problem in the context of their rural communities	6 service users (16.7% male)	NS	NS	Mean 20, range 17–21	Semi-structured interviews	Rural communities in Australia
Boydell et al. [21]	Rural Ontario, Canada	Children and youth with a diagnosis of emotional and/or behavioural disorder in local mental health agencies	To examine issues of access to mental health care for children and youth in rural Canadian communities from the family perspective	30 carers representing 35 service users (20% male)	NS	18/30 carers employed	Mean 11.6, range 3–17	In-depth semi-structured interview with parents	Publicly funded health system with provision of medical and hospital services to all citizens
Boydell et al. [41]	Urban Canadian city	Ultra-high risk for psychosis clinic	To identify the ways in which youth at ultra-high risk for psychosis access mental health services and the factors that advance or delay help seeking	10 service users (2 male) and 30 significant contacts	3/10 Chinese; 6/10 European; 1/10 Interracial	Family income:2/10 = 40000-60000;3/10 = > 60,000; 4/10 = NA	Mean 17, range 14–20	In-depth qualitative interviews	The clinic receives weekly referrals of individuals who may be at risk for psychosis and allows direct referral
Cabassa et al. [42]	NYC, USA	FEP clients at an early intervention clinic	To understand the pathways to care from the onset of a first episode of psychosis to entry into a specialized early intervention service	20 service users (55% male) and 10 carers	11/20 Hispanic; 5/20 African-American; 2/20 Non-Hispanic; White; 2/20 Asian	NS	Mean 23.7 SD 4.4	Semi-structured interviews	NS

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Cadario et al. [31]	Auckland, NZ	FEP clients at child and adolescent mental	To examine by qualitative means the experience of first-episode psychosis and the experience of	12 service users (58.3% male) and 12 carers	7/12 NZ European; 4/12 NZ Māori; 1/12 NZ *Māori*/C	NS	Range 15–18	Unstructured and semi-structured interviews	An in-patient unit for children and adolescents and three community-based child and adolescent mental health

		health services	accessing effective treatment, from two perspectives—that of the adolescents and that of their primary caregivers		ook Island *Māori*				services. One of the services included a team that ran an early intervention service for psychosis in adolescents
Carr-Fanning et al. [52]	Republic of Ireland	Young people with ADHD and their parents	To explore stress and coping in pathways through care for young people and their parents	15 service users (60% male) and their parents (total 32)	NS	Range of socio-economic backgrounds	Mean 12.8, SD 3.09, range 7–17	Semi-structured interviews triangulated with other sources	NS[a]
Chen et al. [26]	NYC USA	FEP clients in a psychiatric hospital adolescent inpatient service	To develop a pathway model of parental help seeking for adolescents experiencing FEP and identify crucial time points for intervention	12 service users (62.8% male) and 16 carers (19% male)	9/12 Caucasian; 1/12 African American; 4/12 Hispanic. 2/12 Asian	Income: 12.5% = 0–20,000; 6.3% = 20000–40000; 18.6% = 40000–60000; 28% = 60,000–80000; 37.5% => 100000	Mean 18.8, SD 2.3	Semi-structured interviews	NS
Ferrari et al. [32]	Ontario, Canada	FEP clients at an early intervention program	To explore young peoples' and their family members' journeys of seeking help for psychosis	25 service users (52% male) and 9 carers	16/25 European; 5/25 African;4/25 Caribbean	NS	Not described	Focus groups, interviews, chart review	NS[a]
Ferrari et al. [22, 32]	Ontario, Canada	FEP clients at an early intervention program	To investigate the role of gender in pathways to early intervention programs	25 service users (52% male)	16/25 European; 5/25 African; 4/25 Caribbean	NS	Mean 26	Focus groups and individual interviews, chart review	NS[a]
Gerson et al. [48]	New York metropolitan area, USA	Young people with recent-onset, non-affective psychosis, from inpatient or outpatient	To understand the experiences of families seeking treatment for young people with recent-onset psychosis	13 families (77% male)	5/13 Caucasian; 4/13 Hispanic, 3/13 African American; 1/3 Asian	NS	Mean 20.7 SD 3, range 16–24	Open-ended interviews	NS

Table 1. Study Characteristics

References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Gronholm et al. [45]	Greater London, UK	Young people at ultra-high risk for psychosis in primary schools	To explore stigma in relation to pathways to care among young people putatively in an early stage of increased risk of developing psychotic disorders	29 service users (34.5% male)	19/29 White; 9/29 Black; 1/29 Asian	NS	Mean 15.7	Semi-structured interviews	NS[a]
Jansen et al. [46]	Denmark	FEP clients at an early intervention program	To explore service users' experience of an early detection service and transition to specialized treatment service, including pathway to care	10 service users (50% male)	All participants of ethnic Danish background	2/10 in school; 2/10 in part-time employment; 2/10 unemployed; 4/10 not in school or work due to illness	Median 21, range 18–27	Semi-structured interviews	NS[a]

Jansen et al. [43]	Denmark	FEP clients at an early intervention program	To describe service-users' experiences with and understanding of their illness and pathway to care	11 service users (54.5% male)	All participants of ethnic Danish background	NS	Median 20, range 15–24	Semi-structured interviews	NS[a]
McCann et al. [34]	Melbourne, Australia	Caregivers of FEP clients at an early intervention program	To describe the lived experience of first- time primary caregivers of young adults with FEP, with a focus on how they access specialist FEP services	20 carers, (15% male)	NS	NS	FEP clinic range 14–30	Semi-structured interviews	NS[a]
McCann and Lubman [33]	Melbourne, Australia	Youth with depression at an integrated youth service (headspace)	To examine the experience of young people with depression accessing one of these services, with a focus on understanding how they access the service and the difficulties they encounter	26 service users (38.5% male)	NS	7/26 paid employment; 19/26 no paid employment	Mean 18, range 16–22	Semi-structured interviews	Integrated youth service providing physical health assessment and treatment; evidence-based interventions; and improving service integration through co-location with other services[a]
Nadeau et al. [50]	Montréal, Canada	Migrant youth accessing care at a community health clinic	To better understand quality of care, including factors improving access to care and collaborative services use, efficacy and satisfaction	5 service users (80% male), 5 carers and 5 service providers	3/5 South Asian,1/5 South east Asian. 1/5 Canadian/European	4/5 with low socioeconomic status 1/5 with medium socioeconomic status	Mean 14, range 12–17	Semi-structured interviews	Primary-care, community based health and social service center offering YMH services as part of a collaborative care model involving multi-disciplinary teams and on-site child psychiatrists

Table 1. Study Characteristics

References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Narendorf et al. [24]	Texas, USA	Young adults admitted to a short-term crisis inpatient unit	To examine psychiatric crisis care with a group of young adults who all lack insurance	55 service users (54.5% male)	15/55 White;15/55 African American;11/ 55 Hispanic; 11/55 multi-racial; 3/55 Asian/American-Indian	NS	Range 18–25	Semi-structured interviews	The psychiatric emergency center is the only public facility designated exclusively for psychiatric crisis in a large urban county in Texas. The unit was exclusively for those without insurance, and all admissions were voluntary
Novins et al. [53]	Southern United States	Adolescents at a residential substance abuse treatment center	To explore how Aboriginal Indian adolescents entering/receiving treatment described their pathways to care	89 service users (60.6% male)	All participants of American Indian background	NS	Range 16–18	Surveys, interviews, and chart reviews	The program, operated by a Southern AI tribe and funded by the Indian Health Service (IHS), is designed to provide specialized treatment of patients with substance use disorders, including those with comorbid psychiatric disorders
Nuri et al. [39]	Dhaka, Bangladesh	Patients at the NIMH institute (variety of diagnoses)	To understand the care pathways of patients with mental illness	40 service users (57.5% male)	NS	16/23 of adults unemployed	Mean 25.5	Semi-structured in-depth interview guide and a structured questionnaire (WHO encounter form)	Based at the NIMH, the only mental health institute of Bangladesh, which caters to whole country. Mental health patients have direct access to psychiatric services in Bangladesh hence general practitioners and hospitals are not gatekeepers
Oruche et al. [35]	Indianapolis, USA	Caregivers of children having	To identify what caregivers of children with diverse mental	20 carers, (50% male)	16/20 Caucasian; 2/20 African	Median household	Mean 12	Semi-structured focus group	NS

		received any mental health services in the past year	health needs say they need to help them improve their personal well-being		American; 1/20 Asian; 1/20 Pacific islander	income 50,000			
Pescodolio et al. [40]	Indiana, USA	Young people with any mental health concern at a public, voluntary facility	To systematically consider the different social processes through which people come to enter psychiatric treatment	109 service users (32.1% male)	82/109 White; 27/109 African American	NS	Mean 30.5	Semi-structured interviews	Public hospital

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References	Location	Setting and population	Study objective	Sample, including gender	Ethnicity	Socio-economic status	Service user age	Method	Healthcare context, as described in paper
Platell et al. [23]	Perth, Australia	Disadvantaged youth with any mental health concern	To identify barriers and enablers to professional mental health service utilization for disadvantaged	8 service providers	NS	Service providers of adolescents of lower socio-economic background	Adolescents, age not specified	Semi-structured interviews	NS[a]
Sadath et al. [36]	Bangalore, India	FEP clients from inpatient and outpatient units	To explore the experiences in caring and help-seeking in carers of patients with first episode psychosis	11 carers, (72.7% male)	NS	2/11 working; 4/11 irregular work; 5/11 not working	Mean 22.3 SD 3.6, range 18–30	Semi-structured interviews	Tertiary public mental health care centre located in Bangalore, India
Schnitzer et al. [51]	Antwerp, Belgium	Parents who consulted any mental health services for their child	To explore how ultra-Orthodox Jewish parents make the decision to consult regular services for their child	21 carers	All participants of Orthodox Jewish background	NS	Under 19	Semi-structured interviews	Flemish statutory services, Flemish centres for school counselling co-operating with Jewish schools, Jewish services within the mental health and educational sector (i.e. support teams in schools)[a]
Skubby et al. [37]	Ohio, USA	FEP clients at an early intervention program	To understand the experiences of parents as they sought psychological and specialized medical services for a loved one with psychosis	11 carers	7/11 White; 4/11 Black	NS	14–30	Semi-structured interviews	Provides comprehensive, individualized, and appropriate interventions for individuals experiencing a first episode of a schizophrenia disorder. NS if public, private
Tanskanen et al. [38]	North London, UK	FEP clients at an early intervention program	To investigate service users and carers experiences of the onset of psychosis and help-seeking	21 service users (71.4% male),9 carers	7/21 White 8/21 Black 4/21Asian, 2/21 Mixed	NS	Mean 26.5, range 18–35	Semi-structured interviews	NS[a]
Webster et al. [44]	Sydney, Australia	Young people with any mental health concern in two community agencies	To explain how young people experience the onset of mental illness and manage their initial interactions health system	20 service users (40% male)	NS	NS	Mean 21, range 18–25	Semi-structured interview	NS[a]
Wong [49]	Hong Kong	FEP clients at an early	To identify the roles and functions played by the key individuals in	Service users (34.5%	NS	NS	19	Semi-structured interviews	Clinics provide inpatient and com- munity mental health services for young

		intervention program	the help-seeking pathway of Chinese caregivers with relatives suffering from psychosis	male) and carers					people between the ages of 15 and 25[b]

ADHD attention deficit hyperactivity disorder, FEP first-episode psychosis, NS not specified, SD standard deviation, UHR ultra-high risk [a]*Services come from countries with universal, primarily publicly funded healthcare systems* [b]*Another paper (Tang et al. [81]) outlining this service describes the program as part of the public healthcare system*

Supplementary Table 1. Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Studies

	Section A: Are the results valid? Is it worth continuing?		Section A: Are the results valid?				Section B: What are the results?			Section C: Will the results help locally?
Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Anderson et al. 2010	+	+	+	+	+	-	+	+	+	+
Aisbett et al. 2007	+	+	+	-	+	+	+	+	+	+
Boulter et al. 2013	+	+	Can't tell	+	+	-	+	+	+	+
Boyd et al. 2006	+	+	+	Can't tell	+	+	+ *	Can't tell	+	+
Boydell et al. 2006	+	+	+	+	+	-	+	+	+	+
Boydell et al. 2013	+	+	+	+	+	+	+	+	+	+
Cabassa et al. 2018	+	+	+	Can't tell	+	-	+	+	+	+
Cadario et al. 2016	+	+	+	+	+	+	+	-	+	+
Carr-Fanning et al. 2018	+	+	+	+	+	-	+	+	+	+
Chen et al. 2014	+	+	Can't tell	-	+	-	+	+	+	+
Ferrari et al. 2015	+	+	+	+	+	+	+	+	+	+
Ferrari et al. 2016	+	+	+	-	+	+	+	+	+	+
Gerson et al. 2009	+	+	Can't tell	-	+	-	+	-	+	+
Gronholm et al. 2014	+	+	+	+	+	+	+	+	+	+
Jansen et al. 2015	+	+	+	+	+	+	+	+	+	+
Jansen et al. 2015	+	+	+	+	+	-	+	+	+	+
McCann et al. 2011	+	+	+	- +	+	-	+	+	+	+
McCann et al. 2012	+	+	+	+	+	+	+	+	+	+
Nadeau et al. 2017	+	+	+	+	+	+	+	+	+	+
Narendof et al. 2017	+	+	+	+	+	+	+	+	+	+
Novins et al. 2012	+	+	+	+	+	-	+	+	+	+
Nuri et al. 2018	+	+	+	+	+	-	+	+	+	+
Oruche et al. 2012	+	+	+	+	+	-	+	+	+	+
Pescodolio 1998	+	+	+	-	-	-	+	+	+	+
Platell et al. 2017	+	+	+	+	+	+	+	+	+	+
Sadath et al. 2014	+	+	+	-	+	-	+	+	+	+
Schnitzer et al. 2011	+	+	+	+	+	- +	+	+	+	+
Skubby et al. 2015	+	+	+	+	+	-	+	+	+	+
Tanskanen et al. 2011	+	+	+	-	+	-	+ *	+	+	+
Webster et al. 2009	+	+	+	+	+	-	+	+	+	+
Wong et al. 2007	+	+	+	+	+	-	+*	+	+	+

* Authors contacted, confirmed ethics approval.