

An investigation of the information provided to the parents of young people with mental health needs on an internet forum

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ABSTRACT

Background: Access to Children and Adolescent Mental Health Services (CAMHS) can be difficult, with lengthy wait times. Many of the young people and their parents are not signposted to any form of support during their wait for initial assessment or treatment and people are increasingly turning towards web-based resources for help and advice. However, there are some concerns about the quality of the information shared online. Research on the use and quality of information shared on online platforms for mental health inquiries is limited.

Aims: We aimed to investigate the content and quality of the responses shared by forum users on an online forum for parents of young people with mental health needs (Mumsnet 'Talk'). Forum users were primarily parents, but 8 posts were written by posters identifying as a healthcare worker, teacher, or autism spectrum specialist.

Methods: Qualitative methodology was adopted for this study. Forum content from Mumsnet was extracted in an anonymised form and thematic analysis was conducted to explore the content. Information shared in the online forum was assessed for quality by comparing the responses with clinical guidelines.

Results: Thread topics related to 16 mental health problems. "Autistic Traits/Autism Spectrum Disorder", "Obsessions and Intrusive Thoughts/ Obsessive Compulsive Disorder" and "Comorbid Anxiety and Depression" were the most prevalent thread topics, consisting 38.3% of the extracted content. The investigation focused on "Information Offered" as the general dimension. Based on the thematic analysis, there were four second-order themes regarding the information offered by forum users; referral, advice, anecdotal information and opinion on case. The quantitative assessment of responses found that 58.3% of the knowledge exchange on Mumsnet was congruent with evidence-based clinical guidelines.

Conclusions: Themes indicate that parents of children and young people with mental health needs seem to use online fora for informational support. It is promising that a significant proportion of the information shared within the extracted forum content is congruent with evidence-based knowledge. However, further investigation is needed to generate better understanding of the overall quality of mental health information available on online platforms.

1. Introduction

1.1. Background

Nearly one in eight children and adolescents in England was diagnosed with at least one mental disorder in 2017 (NHS Digital, 2017). Effective treatments for children and young people (CYP) mental disorders do exist (Das et al., 2016), however there is a world-wide concern regarding child and adolescent mental health needs and insufficient service provision (e.g., in Canada (Zayed et al., 2016), United States (Steinman et al., 2015; Olin et al., 2016), France (Cani, 2014)). In the

UK, fewer than one in every three CYP with a diagnosable mental disorder gained access to NHS care and treatment in 2018 (National Audit Office, 2018). Moreover, the average median wait time for UK CAMHS in 2017/18 was five weeks to receive an initial assessment and nine weeks to receive treatment (Crenna-Jennings and Hutchinson, 2018). A recent UK survey found that more than one in five CYP with a mental disorder waited over six months for contact with a mental health specialist (20.7%), a physical health specialist (21.6%) or for educational support services (21.9%) (NHS Digital, 2017).

YoungMinds (2018) reported that neither parents nor their children are being directed to any form of support during their wait for Child and

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Adolescent Mental Health Services (CAMHS). The Care Quality Commission (CQC, 2018) reported that services did not support CYP with autism, particularly during or after diagnosis, and their families were left to themselves. Prolonged waits for care or assessment, coupled with lack of support following diagnosis, may lead CYP's mental health to rapidly deteriorate or even reach crisis point (Care Quality Commission, 2017). Families may also lose hope in CAMHS and become less likely to engage in care (Schraeder and Reid, 2014). Parents are therefore turning to alternative resources to get help for their children with mental health needs. It is of paramount importance to investigate the potential benefits and harms of these alternative resources which include, first and foremost, the Internet.

1.2. Rise of the internet

With the rise of the Internet, the experience and management of illnesses have taken an interactive dimension and transformed into a public experience (Powell et al., 2003; Huh, 2015; Conrad, Bandini, & Vasquez, 2016). People are increasingly using the Internet for health-related enquiries (Powell and Clarke, 2006). They are also engaging in conversations about illness; not only with healthcare professionals and family members, but also with other Internet users (Powell and Clarke, 2006; Atkinson et al., 2009; Conrad et al., 2016).

Between the years 2004 to 2014, the prevalence of Internet use by caregivers of children ranged from 62% to 99% (Park et al., 2016). A cross-sectional study of Australian parents showed that the Internet (i.e. parenting websites) was used frequently (64.5%) as a source of parenting information, while General Practitioners and other health professionals (psychologist, nurse etc.) were less popular methods of accessing information (37.3 and 24%, respectively) (Baker et al., 2017). When necessary care and support are not provided by the health care authorities, people with mental health needs become more reliant on online platforms for informational and emotional support (Lal et al., 2016).

1.3. Caregivers' use of the internet

Parents are instrumental in identifying their child's difficulties and deciding to seek support or professional help (Cunningham et al., 2008; Van Der Gugten et al., 2016; Villatoro et al., 2018). When government agencies lack provision for CYP with mental health needs, parental participation in self-help resources increase (Carter, 2009). An audit of referrals rejected from Scottish CAMHS in 2017 confirmed that when the pre-referral period for the services was lengthy, parents sought advice or support from online resources (Scottish Government, 2018).

However, most studies to date investigating online information seeking and support for parents of children with mental health concerns have directed attention towards use of professionally managed online resources in terms of delivering education, information or interventions to the caregivers (Plantin and Daneback, 2009). A recent meta-analysis suggested that web-based informational or supportive group interventions were positively related to social support and self-efficacy (Parker Oliver et al., 2017). Scharer (2005)'s study to test the effectiveness of an Internet-based social support intervention for parents of mentally ill children concluded that parents were motivated to use electronic discussion boards to gain access to emotional and informational support. The Internet has allowed parents to take advantage of online platforms for social support and exchange of lay knowledge concerning their child's difficulties (Blackburn and Read, 2005; Van Der Gugten et al., 2016).

Parents may also use online resources that are not managed by professionals, such as open discussion fora. Participants of such online fora not only use online discussions to seek support, but also to offer support for other users (Elwell et al., 2011; Prescott et al., 2017). Over three-hundred messages posted in a computer-mediated support group for adolescents with cancer were coded as informational support and

emotional support and the thematic analysis suggested that the information provided within the data set was about 'treatment concerns', 'diet', 'continuing to play sport', 'cancer camps' and 'media' (Elwell et al., 2011). A study investigating how young people exchanged both emotional and informational support on a privately run online forum for emotional and mental health issues demonstrated that the support provided may be directive or non-directive. The study found that posters provided directive informational support most frequently, but they also exchanged non-directive support where they used their own experiences or stories to provide information (Prescott et al., 2017). The information posted by caregivers of Alzheimer's patients on the forum on Alzheimer's Association Charity's official website included advice to: contact professionals for assistance (11.97%); navigate information resources such as books, videos, and web sites (19%); find strategies to handle the patient (5%); and suggestions on doctor consultations (8.94%) and on patient medication (2%) (Scharett et al., 2017).

Research suggests that fostering peer support in the health care system generates hope, emotional growth and social wellness and improves social integration, self-confidence and resilience (Shalaby and Agyapong, 2020).

1.4. Information shared on the internet

Research on parenting discussions on Mumsnet.com revealed that most of the anecdotal information posted by the forum users remained unchallenged (Hine, 2014). As anecdotal information is frequently shared in discussion platforms, the Internet has reconfigured relations of expertise (Hine, 2014; Madathil and Greenstein, 2018). Online discussions and exchange of information have enabled parents to occupy positions of agency in knowledge construction and re-establish their parental caregiving role (Blair and Takayoshi, 1999; Harden, 2005; Madge and O'Connor, 2006; Eysenbach, 2008). Lay groups have started to construct new forms of expertise while bypassing the control of credentialled experts and eliminating the intermediary role of the healthcare professionals (i.e., apomediation) (Eysenbach, 2008).

Knowledge shared by lay groups on social media and peer support groups has heightened the risk of dissemination of unreliable information and healthcare decisions are no longer limited to the information and advice provided by medical professionals. (Madathil and Greenstein, 2018). As the Internet became the repository of experiential knowledge (Conrad et al., 2015), some of the unsolicited information offered online "expose[d] people to medical or alternative medicine interventions with a dubious benefit-to-harm balance" (Klemenc-Ketis and Kersnik, 2013, p. 280).

Online resources may fail to incorporate empirical knowledge and disseminate misleading or inaccurate health information (Kulasegarah et al., 2018; Daraz et al., 2019). Studies have assessed the consistency of the content of web-based health information on psychological trauma (Bremner et al., 2006), miscarriage (Hardwick and Mackenzie, 2003), tonsillectomy (Roshan et al., 2008), and cholecystectomy (Jayaweera and De Zoysa, 2016) with evidence-based guidelines and/or information derived from research findings and suggested that these websites offered inaccurate or potentially harmful information and did not correlate with the information provided by healthcare professionals or governmental agencies.

The mental health information available online is not always consistent with evidence-based guidelines. For example, a recent study on perinatal anxiety (Kirby et al., 2018) investigated website content on perinatal anxiety, excluding blogs and online discussion fora. The information provided ranged from poor to moderate quality, indicating little agreement between evidence-based practice and web-based information on perinatal anxiety.

Studies suggest that online peer-to-peer communication for mental health requires careful attention as there is an inherent risk associated with receiving information from peers with pseudonyms or unknown credentials and the reliability of advice communicated is open to doubt

(Naslund et al., 2016). Hardy and Sillence's (2016) review on the quality of online resources on Premenstrual Dysmorphic Disorder showed government and professional/academic journal sites had the highest average general quality ratings, whereas social media sites (i.e. platforms where users create, share or exchange information) were rated as medium quality (mean = 9.67 and 8.25, respectively). Similarly, an investigation of responses to health questions posted by mothers on a private Facebook group suggested that posts contained information that contradicted American Academy of Paediatrics guidelines (Kallem et al., 2018).

Despite doubts about the reliability of the information available online, Powell and Clarke's (2006) survey concluded that only 12% of the general public expressed scepticism about the accuracy of the mental health information they acquired from online resources. Lam-Po-Tang and McKay's (2010) survey with adult psychiatric outpatients displayed similar results since only 12% rated mental health information they sought online as 'neither reliable nor unreliable,' and only 1% reported it as 'unreliable.' Research suggests that standards related to reliability across different platforms delivering peer-based services needs to be set so that peer support can be widely recognised and promoted by health professionals (Fortuna et al., 2020).

1.5. Research goal and questions

To date, there has not been an investigation of the reliability or validity of information provided on online fora for child mental health difficulties. In a related study, we investigated the reasons that parents of children with mental health problems use an Internet forum (Croucher et al., 2020). The present paper reports on a complementary dataset but investigates the content and quality of the responses shared on the online forum for parents of children with mental health problems. The specific research questions were as follows:

- 1) What type of mental health related information is offered on the Mumsnet Children and Young People's Mental Health Discussion Forum?
- 2) How consistent with clinical guidelines is the mental health related information shared on the Mumsnet Children and Young People's Mental Health Discussion Forum?

2. Methods

2.1. Data sampling

The online forum that was investigated in this study was Mumsnet (<https://www.mumsnet.com>). Mumsnet is an independently owned business funded mainly by advertising (Mumsnet, 2020) and it is regarded as the most prominent parenting website in the UK as it offers wide range of parenting-related content and has more than 8.2 million visitors per month (Gambles, 2010; Hine, 2014; Mumsnet, 2019). Mumsnet's discussion forum (the Talk) is not pre-moderated and it allowed us a site for accessing interactive online discussions between forum users. Only members can post in the forum, but the content is openly accessible to all internet users. Membership is free, and everyone is welcomed to join; it is not exclusive to mothers or parents. Mumsnet users can start a new conversation about a talk topic established on the website. There are 28 main discussion topics ranging from work, education, money to health, becoming a parent and childcare. See Figure 1 for a screenshot of the landing page.

2.2. Ethics

Permission for the research was granted by Mumsnet. The study received ethical approval from the University College London Research Ethics Committee (ref: 15209/001) and R&D approval from UCL Joint Research & Development Office (19PP05).

2.3. Data sampling

The focus of this study was to gather the most recent discussions on Mumsnet Talk's "Child Mental Health" topic. However, online fora encourage asynchronous interaction and participants' contribution may be delayed or spread out in time (Im and Chee, 2006). To allow discussions and exchange of information under the threads to reach a saturation point, it was deemed appropriate to select threads started a year before the data collection. Threads were extracted in reverse chronological order, starting on June 25, 2018. In accordance with the qualitative research guidelines, data extraction was completed once the analysis reached data saturation and all possible themes within the selected content were determined (Fusch and Ness, 2015). The threads ($n = 50$) dated from February 25, 2018 to June 25, 2018 and generated 538 individual posts in total.

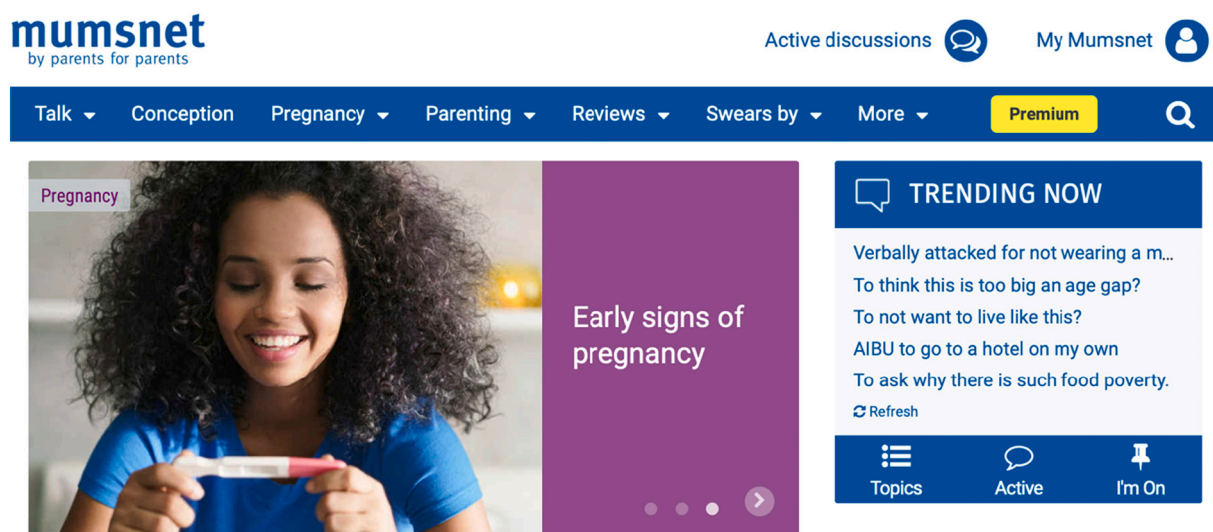


Fig. 1. Mumsnet.com (n.d.) Retrieved October 21, 2020 from <https://www.mumsnet.com>. Screenshot by author.

2.4. Inclusion/exclusion criteria

2.4.1. Inclusion criteria

- 1 Posts written in English
- 2 Posts shared under a thread that was started on or before June 25, 2018
- 3 Posts providing information as a response to the threads seeking information on a child or adolescent mental health need
- 4 Posts written by a parent/carer of a child or adolescent with mental health need
- 5 Posts written by someone who had similar experiences regarding the mental health need
- 6 Posts written by a person who identified themselves as a mental health professional

2.4.2. Exclusion criteria

- 1 Posts providing information as a response to a thread seeking information on a non-mental health related need
- 2 Posts providing information on mental health related need that did not involve the CAMHS age range (i.e. children and young people up to the age of 18)

2.5. Data extraction

Data were extracted by using a free online data scraping tool, Parschub, which allows automatic data mining from websites. All the data were extracted in anonymised form since the username section was not targeted as a command for auto-extraction. Each thread and all the posts shared under those threads were then copied into a Microsoft Word Document for further analysis. The initial number of threads collected from the Talk board was 50, generating 538 individual posts in total. All identifying information, including the usernames of the posters, were omitted. All potential posts were then screened by two researchers (EM & LC) and if necessary, deleted from the data set in respect of the inclusion and exclusion criteria.

2.6. Data analysis

2.6.1. Thematic analysis

This study analysed forum content using thematic analysis. Based on Braun and Clarke's (2013) guidelines, thematic analysis consisted of six steps. All the posts in the data set were read twice by the principal researcher. Note-taking during this stage allowed the researcher to begin to identify themes of interest that might relate to the research question and to create an initial list of codes (Braun & Clarke, 2013). As recommended, codes were generated from posters' own words in order to create themes that are derived from the data (Lewis & Ritchie, 2019).

In line with the research objectives, thematic analysis focused only on the information provided within the threads. Thus, the general dimension, "Information Offered", was identified before coding the data. Resembling codes were collated and sorted into first-order themes that were then synthesized into second-order themes. This code framework was reviewed by another researcher (SB) to promote reflexivity and discussion within the research team (O'Connor and Joffe, 2020). Following the discussion, there was minimal disagreement and the themes were agreed. The thematic map was finalised, and each theme was given a definition to specify what was distinguishing about it.

2.6.2. Interpretation and reporting

Information/advice shared under each thread was counted and evaluated based on the consistency of the information with clinical guidelines (i.e. quality of "Information Offered"). Clinical guidelines that were selected for comparison were published by National Institute of Care and Excellence (NICE) and PracticeWise, LLC.

NICE is responsible for providing national evidence-based guidance and advice to improve health and social care in the UK (NICE, 2014). Based on the hierarchy of evidence and the trade-off between the benefits and harms of interventions, NICE brings together, analyses and interprets the research evidence to make recommendations (Chidgey et al., 2007; NICE, 2019). Seven of the main mental health problem areas were identified to match the NICE guidance developed for CYP: Autistic Traits/ASD, Obsessions and Intrusive Thoughts/ OCD, Comorbid Anxiety and Depression, Attention Deficit/Hyperactive Behaviour/ADHD, Depression/Withdrawn Behaviour/Low Mood, Social Anxiety, and Generalised Anxiety Disorder.

For those threads regarding topics without corresponding NICE guidance (i.e. Traumatic Stress, Self-harm/Suicidality, Substance Use, Disruptive/Challenging Behaviour), the quality of the information shared was compared to the suggested interventions from the "Blue Menu of Evidence-Based Psychosocial Interventions for Youth" (PracticeWise, LLC, 2019). "Blue Menu" is based on a review of randomised clinical psychosocial and combined treatment trials for 11 different problem areas. There are five levels representing the strength of evidence behind the treatments for each of the problem area. Advice was considered congruent with guidance if it was considered by the Blue Menu to be Level 1 ("Best Support") or 2 ("Good Support").

Five main mental health problem areas had no comparability with any guidance published by NICE or PracticeWise, LLC (i.e. Specific Phobia, Intellectual Disabilities, Sleep Problems, Developmental Delays, Tic Disorders). The quality of information offered under these areas was assessed with the help of academic clinical psychologists (RS and SB) who evaluated the posts' consistency with the evidence base from randomised controlled trials.

Information offered on Mumsnet was coded as being either (i) clearly congruent with clinical guidance/research evidence, (ii) directly contradicting the guidance/research evidence, or (iii) neither clearly congruent nor directly contradicting the guidance/research evidence ('neutral').

Seven threads (20% of the final data set) were randomly selected and blind coded for quality by the secondary researcher (LC) using the clinical guidelines selected for comparison. Regarding the Cohen substantial 0.61 to 0.80 kappa statistic, 70% or above agreement rate between the coders was agreed acceptable for this methodology (Cohen, 2016). There was 72% agreement between the researchers and the remainder were resolved by discussion with the other members of the research team (RS and SB).

3. Results

Following the inclusion and exclusion criteria, 16 threads were omitted from the analysis. The threads that were deemed eligible for

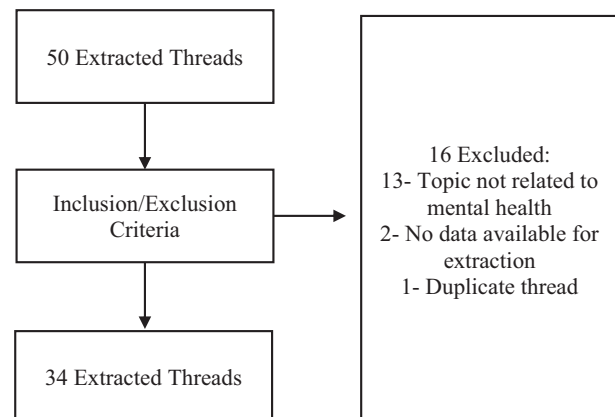


Fig. 2. Flow chart of eligible threads and reasons for exclusion.

analysis are displayed in the Flow Chart (see Figure 2). Overall, 34 threads with a total of 334 posts (mean = 9.82) were included in the analysis.

3.1. What is the content of mental health related information offered on the Mumsnet discussion forum?

The selected forum content covered 16 main mental health problem areas. 11 threads did not focus on a single mental health problem. Instead, forum users talked about several different problem areas within one thread or original posters listed symptoms/difficulties that they have observed with their child and were unsure about the symptoms or asked for a diagnosis. In those cases, the primary researcher (EM) consulted with the academic clinical psychologists (RS & SB) to match the threads with the selected problem areas. We were aware that demographic information on the posters could have provided better insight. However, as mentioned, we decided to de-identify the data at extraction for ethical considerations. As far as the investigator could establish from reading the posts, forum users were primarily parents, although 3 posts were written by posters identifying as a healthcare provider, 4 posts by teachers and 1 post by an autism spectrum disorder specialist. As data were de-identified, it is not possible to know how many users were healthcare workers.

“Autistic Traits/Autism Spectrum Disorder (ASD)” was the most frequently observed mental health problem as a thread topic (n = 5). The second most frequent thread topics were “Obsessions and Intrusive Thoughts/ Obsessive Compulsive Disorder (OCD)” and “Comorbid Anxiety and Depression” (n = 4, each). “Generalised Anxiety Disorder”, “Intellectual Disabilities”, “Substance Use”, “Sleep Problems”, “Tic Disorders”, and “Disruptive/Challenging Behaviours” each appeared once as a thread topic (see Table 1).

The mental health problem area that generated the greatest number of posts was “Comorbid Anxiety and Depression” (n = 104), followed by “Autistic Traits/Autism Spectrum Disorder (ASD)” (n = 39), “Specific Phobia” (n = 37), and “Obsessions and Intrusive Thoughts/ Obsessive Compulsive Disorder (OCD)” (n = 29). The mental health problem areas in which the least amount of posts was shared were “Intellectual Disabilities” (n = 1) and “Disruptive/Challenging Behaviour” (n = 3) (see Table 1).

However, more posts shared under one problem area did not necessarily mean that there was more information being offered within those threads since posters not only offered informational support but contributed to the discussions in other ways (e.g., offering emotional

Table 1

Frequency of mental health problem areas as thread topics, posts generated, and information offered.

Mental health problem areas	Threads (n)	Posts (n)	Information offered (n)
Autistic traits/ASD	5	39	63
Obsessions and intrusive thoughts/OCD	4	29	29
Comorbid anxiety and depression	4	104	71
Attention and hyperactivity behaviour/ADHD	3	20	18
Depression/withdrawn behaviour/low mood	3	19	12
Social anxiety	2	23	15
Specific phobia	2	37	53
Traumatic stress	2	16	12
Self-harm/suicidality	2	16	21
Generalised anxiety disorder	1	4	1
Intellectual disabilities	1	1	0
Substance use	1	4	3
Sleep problems	1	4	4
Developmental delays	1	6	7
Tic disorders	1	9	13
Disruptive/challenging behaviour	1	3	2

support). For this study, investigating the amount of information given by posters enabled us to make inferences about the areas which parents were more knowledgeable about or willing to share more information on. In total, there were 324 instances in which Mumsnet users offered information in the forum discussions. The amount of information offered for each mental health problem area correlated with the number of posts generated for the matching topics (see Table 1). For example, the mental health problem area that Mumsnet users shared the highest number of posts about was “Comorbid Anxiety and Depression”. It was also the topic that the majority of information exchange was related to (n = 71). It should be noted that in certain threads, the number of pieces of information offered was higher than the posts shared. This was the case when a poster offered more than one piece of advice or information within a single post.

Based on the thematic analysis, there were four second-order themes regarding the information offered by forum users: (See Fig. 3.)

3.1.1. Referral

There were 70 instances in which posters suggested that the child should be referred to a service or a healthcare professional.

3.1.1.1. Specialist. Speech and Language Therapists, Occupational Therapists, Specialist Psychiatrists/Psychologists (Clinical, Educational, or Counselling)/Paediatricians/Cognitive Behavioural Therapy (CBT) Therapists were coded as specialists. In total, referral to specialist was suggested 31 times:

“Your daughter needs to see a good CBT therapist who will use gradual exposure for her fears”

[Thread 9]

3.1.1.2. CAMHS. Referral to CAMHS was suggested 9 times:

“Please write to your CAMHS team noting your child’s symptoms, your concerns and the date of the first referral.”

[Thread 27]

3.1.1.3. School. Number of instances that the child was referred to the school or a professional within the school setting was 9:

“Have you spoken with school about the possible options?”

[Thread 27]

3.1.1.4. GP/HV. Referral to a General Practitioner (GP) or a Health Visitor (HV) was advised 22 times:

“It is worth visiting your GP”

[Thread 1]

3.1.2. Advice

There were 127 instances in which posters shared a specific piece of advice or discussed the benefits of a certain technique, resource, medication or supplement.

3.1.2.1. Technique. Cognitive/behavioural techniques or activities, social/communication or emotional skills and other similar tips were suggested 90 times:

“Even if he doesn’t have ASD, it would still be helpful to learn about strategies for dealing with difficult behaviour”

[Thread 21]

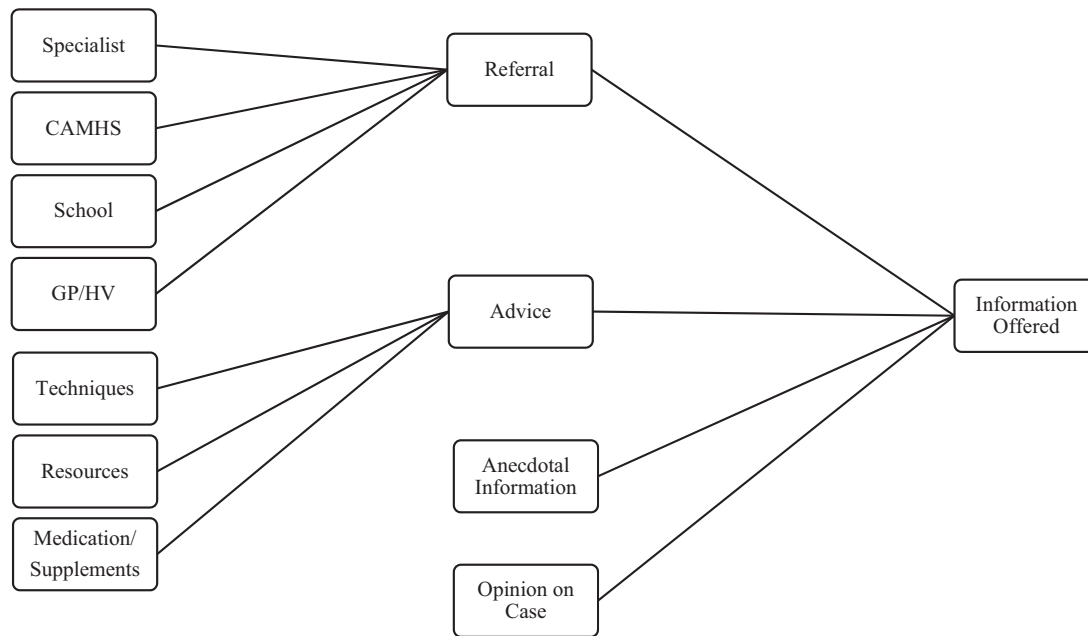


Fig. 3. First-order themes, second-order themes and general dimension.

3.1.2.2. *Resources.* Resources, including books, websites, helpline numbers, social support groups (e.g., charities and local/Facebook groups), mobile applications, TV/YouTube channels/shows were advised to be used 32 times:

“Some self-help info: websites (Moodjuice, Young minds, NSPCC), helpline numbers (Childline, Samaritans), Smartphone/ipad apps (SAM self-help for anxiety, Daylio)”

[Thread 11]

3.1.3. *Anecdotal information*

There were 80 instances in which posters offered information, strategies, techniques, medications, or services which they have found to be useful when dealing with their child or when they were experiencing similar mental health needs themselves.

“What you’ve described just sounds like my daughter. Please get help for your son as soon as possible and don’t wait like I did as it will get worse by time”

[Thread 38]

3.1.4. *Opinion on case*

There were 47 instances in which posters shared their own opinion on the case, speculated about the cause of a child’s difficulties and/or suggested a possible diagnosis.

“It sounds like he might have some developmental delays...Could also have been specific learning difficulties - which is a term that covers things like dyslexia, dyspraxia, ADHD etc.”

[Thread 50]

3.2. *How consistent with the clinical guidelines is the mental health related information shared on the Mumsnet children and young people’s mental health discussion forum?*

Table 2 summarises the extent to which information offered was congruent with guidance/the evidence base, separated by primary

Table 2
Quality of “information offered”.

Mental health problem areas	Congruence/contradiction of the “information offered” (%)		
	(i) Congruent	(ii) Directly contradicting	(iii) Neutral
Autistic traits/ASD	85.7	0	14.3
Obsessions and intrusive thoughts/ OCD	73.9	8.7	17.4
Comorbid anxiety and depression	50.7	9	40.3
Attention and hyperactivity behaviour/ADHD	100	0	0
Depression/withdrawn behaviour/low mood	66.7	0	33.3
Social anxiety	23.8	0	76.2
Specific phobia	45.3	0	54.7
Traumatic stress	77.8	0	22.2
Self-harm/suicidality	28.6	0	71.4
Generalised anxiety disorder	100	0	0
Intellectual disabilities ^a	–	–	–
Substance use	33.3	0	66.7
Sleep problems	0	0	100
Developmental delays	100	0	0
Tic disorders	100	0	0
Disruptive/challenging behaviour	0	0	100

^a There was only one thread generated under this problem area and it did not receive any responses/posts from other Mumsnet users.

mental health need. Category (i) is clearly congruent with clinical guidance/research evidence, (ii) directly contradicting the guidance/research evidence, (iii) neither clearly congruent nor directly contradicting the guidance/research evidence (‘neutral’). Fig. 4 demonstrates illustrative quotations from “Information Offered”. The information exchange related to “Opinion on Case” was not included in the analysis.

The quantitative assessment of “Information Offered” revealed that nearly two thirds (58.3%) of the knowledge exchange on Mumsnet was congruent with clinical guidelines. All of the information shared under “Attention and Hyperactivity Behaviour/ADHD”, “Generalised Anxiety Disorder”, “Developmental Delays”, and “Tic Disorders” was in line with the clinical guidelines/research evidence. Information provided for

Mental Health Problem Areas	Illustrative Quotations from “Information Offered”		
	(i) congruent	(ii) directly contradicting	(iii) neutral
Generalised Anxiety Disorder	“I’d let the GP decide...you must see a professional for the drug options” (T14)	--	--
Social Anxiety	“Take her to the GP and ask for a CAMHS referral” (T24)	--	“When she gets stressed out by crowded, noisy places we let her listen to her music on an mp3 player” (T24)
Specific Phobia	“Your daughter needs to see a good CBT therapist who will use gradual exposure for her fears” (T9)	--	“Teach her how to approach an animal” (T41)
Obsessions and Intrusive Thoughts/ OCD	“Do not encourage the compulsive behaviour” (T5)	“Search about herbal remedies. I’ve read about Inositol” (T46)	“Mindfulness exercises may be effective” (T46)
Learning Difficulties	--	--	--
Substance Use	“Ask the GP for help in stopping” (T32)	--	“Make her stop immediately, otherwise she will have to take it more and more to have the desired effect” (T32)
Traumatic Stress	“Get him assessed by someone specialised in child PTSD” (T48)	--	“Smother him with love” (T48)
Autistic Traits/ASD	“The first step is your GP. You may want to ask for an ASQ SE assessment” (T21)	--	“Changing things in the environment can improve things” (T37)
Attention and Hyperactivity Behaviour/ADHD	“Ask for the school to get an educational psychologist to do an assessment and involve SENCO” (T42)	--	--
Self-harm/Suicidality	“This reminds me a friend’s daughter who received help from CAMHS” (T38)	--	“Don’t leave him by himself for too long” (T44)
Depression/ Withdrawn Behaviour/Low Mood	“The first line of treatment should be in a therapeutic form” (T45)	--	“I would try to take time off work and be home more” (T11)
Comorbid Anxiety and Depression	“CBT did help my daughter, but Sertraline got her back on track” (T18)	“Try another option besides SSRIs, like betablockers or anxiolytics” (T18)	“Try doing nice things together...go shopping or to the cinema and have a relaxed time with no pressure” (T4)
Sleep Problems	--	--	“We stop using the screens half an hour before bed and give her melatonin” (T2)
Developmental Delays	“Educational psychologist would help assess her and work out what is going on” (T50)	--	--
Tic Disorders	“See the GP for advice and for an assessment to see if there’s any medical issue causing it” (T1)	--	--
Disruptive/Challenging Behaviour	“My GP has recommended counselling service” (T3)	--	“We try to go and spend a lot of time outside, no matter rain or shine” (T3)

Fig. 4. Illustrative quotations from “information offered”.

“Autistic Traits/ASD” and “Traumatic Stress” was also of good quality (85.7% and 77.8%, respectively).

38.8% of the information offered by posters was found to be ‘neutral’. In other words, more than one third of the knowledge exchange on Mumsnet discussions was neither congruent with evidence-based practice nor directly contradicted the guidance/research evidence

In total, only 2.9% of the information offered on the forum was found to directly contradict current guidance/research evidence.

4. Discussion

To answer the question of content of mental health related information provided by posters on an online discussion forum for parents of

children with mental health problems, it was found that 16 mental health problem areas were covered in total. Threads were more frequently about “Autistic Traits/ASD”, “Obsessions and Intrusive Thoughts/OCD”, “Specific Phobia” and “Comorbid Anxiety and Depression”, which do not correlate with the prevalence of mental disorders in England. In 2017, the most common mental disorder in CYP was behavioural disorders (5.5%), followed by hyperactivity disorders (1.9%) and other anxiety disorders (1.4%) ([Health and Social Care Information Centre, 2018](#)). This difference conveys that the topics of discussion on Mumsnet are not based on the prevalence of mental health problem observed within the community. In line with the previous research findings ([Conrad et al., 2015](#); [YoungMinds, 2018](#)), this might suggest that the parents of children with ASD, OCD, specific phobias, or

comorbid anxiety and depression are not receiving enough information or support from healthcare professionals or are not being directed to any form of guidance (Anderson et al., 2017).

In addition to corresponding to the prevalence of disorders, the amount of “Information Offered” for different mental health problems might convey the areas in which parents have mental health literacy about. Although previous research revealed limited parental knowledge about CYP mental health (Mendenhall and Frauenholtz, 2015), findings from the current study overlapped with earlier studies which have showed parents in general were more likely to recognise an externalising problem (ADHD) than an internalising problem (anxiety) when presented with vignettes of children and young people with mental health problems (Thurston et al., 2015) and a questionnaire study hosted on the Australian Broadcasting Corporation News website found that general public knowledge was higher for depression than other mental health difficulties (Cutler et al., 2018). There were no posts or information shared under the theme “Intellectual Disabilities.” Sahu et al. (2018) propose that parents may have poor knowledge and an insufficient amount of guidance about childhood intellectual disabilities. The current results may similarly suggest a lack of parental knowledge in this area. It may also be that fewer parents of children with intellectual disabilities use this forum and receive support from other platforms. Alternatively, they might be accessing professional support services more adequately.

The findings confirmed those of previous studies on the use of online fora as a platform to offer informational support (Elwell et al., 2011; Prescott et al., 2017). Concerning the themes generated under “Information Offered,” two second-order themes (“Referral” and “Advice”) as well as three first-order themes (“Techniques,” “Resources,” and “Medication/Supplements”) corresponded with Scharett et al.’s (2017) findings of the following themes: suggestions to contact professionals for assistance, navigate information resources, and find strategies to handle the patient and advice on patient medication. The act of responding to online health-related queries may therefore not be dependent on the specific problem being discussed.

Posts that offered diagnosis or speculated on a child’s issue were considered under the theme ‘opinion on case’. This second-order theme supported Huh (2015)’s findings suggesting that online health community members engage in discussions about medical information and contemplate on the symptoms provided. It also aligned with the views related to the reconfiguration of relations of expertise through the Internet (Hine, 2014; Madathil and Greenstein, 2018). As in other online fora, posters promote apomediation by sharing their own views on mental health problems and by constructing novel forms of expertise (Eysenbach, 2008).

Similarly, “Anecdotal Information” supported Hine’s (2014) analysis of the anecdotal format of advice offered on Mumsnet. Anecdotal information and the sharing of experiential knowledge are influential for constructing a collective discourse, in which personal experience becomes favoured over formal scientific knowledge (Irwin and Wynne, 1996).

Posters shared information about, or referred their fellow forum users to a healthcare professional/service that they have found to be helpful for that specific mental health need. The discussions revolving around “Referral” were mostly offering information on “Specialists,” “CAMHS,” “School”, or “GP/HV.” The finding that posters were giving advice to consult a professional was promising. However, there is a chance that the referrals might lead to a vicious cycle. Parents who go online to find help are usually the ones who have not received any form of support from the healthcare professionals (The Scottish Government, 2018), and some of the information their fellow forum users offer is about the same healthcare professionals/services who may not have not been useful in the first place.

As the second-order themes conveyed, posters have engaged in online conversations about childhood mental health and exchanged information. The advice and information they have provided revolved

around the themes “Techniques,” “Resources,” and “Medication/Supplements.” These themes demonstrated the ways in which forum users have generated lay knowledge and contributed to the discourse within the online community (Blackburn and Read, 2005; Van Der Gugten et al., 2016). Even though the demographic information of the posters was not collected, it is known that Mumsnet.com is a female dominated platform (Hine, 2014; Mumsnet, 2019). Thus, the act of offering advice or sharing opinion may be regarded as establishing a novel form of expertise (i.e., female-dominated expertise) (Maslen and Lupton, 2018), which reclaims motherhood and parental caregiving role from the male-dominated experts within the medical field (Drentea and Moren-Cross, 2005; Harden, 2005).

To address the question of consistency of mental health related information with clinical guidelines, it was found that all of the information shared under four of the mental health problem areas (“Attention and Hyperactivity Behaviour/ADHD”, “Generalised Anxiety Disorder”, “Developmental Delays”, “Tic Disorders”) was in line with the clinical guidelines. Information provided under two other problem areas (“Autistic Traits/ASD” and “Traumatic Stress”) was of good quality as well (~78–85% congruent with clinical guidance). Since the information provided was in line with the clinical guidelines, we might assume that parents’ knowledge regarding these mental health needs were consistent with the expert knowledge (i.e., evidence-based information).

This is contrary to some previous findings suggesting little agreement between evidence-based practice and online information (Kirby et al., 2018). Information exchanged on Mumsnet might be of better quality due to the intentions of forum users. A sense of community (Anderson et al., 2017) as well as joining online discussions for the purposes of offering support for other forum users (Lal et al., 2016) might have influenced posters to be cautious not to provide false information. The fact that posters were giving ‘good’ quality advice is promising. The results suggest that parents of CYP who cannot access CAMHS immediately may be referred to online fora for self-help or peer support.

However, over 40% of the information on Mumsnet discussions was not congruent with evidence-based knowledge. Some information in threads about “Comorbid Anxiety and Depression” and “Obsessions and Intrusive Thoughts/OCD” contained information that was contradictory to the information provided in clinical guidance/research evidence. Hence, this study partially confirmed Klemenc-Ketis and Kersnik’s (2013) concerns about the unsolicited forms of online information encouraging people’s exposure to alternative methods that have no evidence-base.

Only 2.9% of the information directly contradicted clinical guidance. For example, the following information was provided as a response for a query categorised as Obsessions and Intrusive Thoughts/ OCD: “Search about herbal remedies. I’ve read about Inositol”. This is contradictory with the NICE guidance that suggests (i) Guided self-help or Group or Individual CBT and (ii) Use of SSRI or Clomipramine. No other medication or herbal remedies are advised in the guidelines. Bearing in mind the adverse events caused by herb-to-drug interactions (Kennedy and Seely, 2010; Izzo and Ernst, 2009), the recommendation was classified as contradicting clinical guidelines. Forum users are encouraged to report posts that break the Guidelines. However, there is no guidance on reporting posts that contain misleading or harmful information. There is also no information about whether or how the editors review the posts if someone posts harmful information.

Overall, the finding that 97.1% of the overall knowledge exchange (i.e., anecdotal information, advice, and referral) on Mumsnet did not contradict evidence-based guidance is extremely encouraging and important; people can have faith in these sites as generally providing good information. This supports the suggestion that digital platforms, including social media, can be used to reach a wider audience and disseminate useful information and promote evidence-based mental health services (Naslund et al., 2017). However, the very small presence of information contradictory to the guidelines should not be overlooked. As most of the Internet users do not express scepticism about the

accuracy of the mental health information they acquired from online resources (Powell and Clarke, 2006), even only 3% of information which is against the expert knowledge may pose risk to individuals' well-being.

4.1. Study limitations

Even though no demographic data for the selected forum content was extracted, the researchers were aware of the overall relatively narrow demographic profile of Mumsnet forum users (Mumsnet, 2019). In relation to the whole population of Internet users, Mumsnet users are more likely to be female, full-time or part-time employed, in the 25 to 44 years age group, and have children (Hine, 2014; Mumsnet, 2019). As Im and Chee (2012, p. 3) point out, the "unique characteristic of online forums could be natural selection of specific participants because all the participants need to have access to the Internet and can use the Internet." Internet users are more likely to be well-educated, literate, predominantly white and from high-income households (Pew Internet and American Life Project, 2005; Pew Research Center, 2019). Thus, as level of education has been shown to positively correlate with health knowledge (Mutua et al., 2016), this is likely to have contributed to the quality of lay knowledge shared on Mumsnet.

Also, no identifying information was collected from the posters. As such, it was not possible to detect the number of individuals contributing to the online discussions, nor the number of instances a single individual shared a post. It could have been the case that a single poster was sharing the same information frequently in different threads, which in turn might have confounded the ratio of quality of the forum content. Similarly, 8 posts were from users identifying as a healthcare provider, teacher or autism spectrum disorder specialist but it is not possible to know how many users were healthcare workers.

The thematic analysis was not without its flaws. No qualitative software (e.g. NVivo) was used to support in managing the dataset in order to develop the framework. Using a manual method to conduct the thematic analysis may have increased the likelihood of human error and missed instances of particular usage. On the other hand, for smaller data sets such as this, manual searching enables a thorough and detailed interrogation of the data. Ideally, a combination of the qualitative software and manual scrutiny increases the accuracy and interpretation of the data (Welsh, 2002). The coding framework was reviewed by another member of the research team, yet it was not subjected to intercoder reliability testing that may have increased confidence in generalisability of the findings (Lombard et al., 2017). The findings of this study provide insight into how Mumsnet users exchange knowledge on CYP mental health. However, generalising these findings may be limited as the type of information support and the quality of the knowledge exchange of the selected forum content may not be representative of the information provided on Mumsnet for "Child Mental Health" over an extended time period, or of the alternative online platforms and fora parents of CYP with mental health needs consult.

4.2. Future directions

Future research may focus on the reasons why forum users choose to start threads on certain mental health disorders, how users interpret the advice given and how decisions are made on what advice to take. Exploring how parents perceive online fora after using it would help researchers to gain a deeper understanding of the impact of online discussion platforms for information for families who seek support. It may be useful for future research to investigate whether online fora can replace in person care or how they can complement existing professional services.

Considering the recommendations to consult healthcare/CAMHS professionals, further research needs to be conducted to explore whether the suggested referrals exacerbate parents' frustrations with CAMHS or if the suggestions are seen good and supportive options.

Importantly, given that some of the information was incongruent

with the evidence- base or contradictory to clinical guidelines, future research may address posters' perceptions of the quality of information offered in these discussions. Future research into the advantages and disadvantages of receiving information shared on such online fora is warranted so that the potential benefits and harms of alternative resources parents use to get help for their children with mental health needs are investigated.

Finally, given that many healthcare professionals do not implement evidence-based interventions (Gyani et al., 2012; Barbui et al., 2014), it would be interesting to have a comparison group for advice offered from CAMHS practitioners and explore if the proportion of evidence-based information offered by healthcare professionals exceeds that of Mumsnet.

5. Conclusion

Themes observed in the present study indicate that parents of CYP with mental health needs seem to use online fora for informational support, and, reassuringly, most of the information shared within these online discussions is congruent with evidence-based knowledge.

During the long wait periods for CAMHS, health professionals may consider referring parents to Mumsnet or similar online sites so that they can access information and receive support."

Declaration of competing interest

None.

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