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## **Understanding parent-reported factors that influence children and young people's anxiety and depression presentations to Emergency Departments: A multi-site study.**

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**Short running title:** Why children come to ED for anxiety and depression

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## **Abstract**

**Objective:** Victorian emergency department (ED) data show increased presentations for anxiety and depression in children. We aimed to determine parent-reported factors contributing to these presentations.

**Methods:** Qualitative study with parents of children and young people aged 0-17 years who attended one of four EDs across Victoria between October 2017 and September 2018 and received a primary diagnosis of anxiety or depression (excluding self-harm or suicide attempt). Eligible parents completed semi-structured phone interviews, which were audio-recorded and transcribed. Transcripts were coded and qualitatively analysed using thematic analysis.

**Results:** Seventy parents completed interviews. The average age of children and young people was 14 years (SD 2.4) and 63% (n=44) identified as female. Thirty (43%) children received a primary diagnosis of depression, compared to 40 (57%) children who received a primary diagnosis of anxiety. The majority of respondents were mothers (n=59; 84%). Key themes as to why families presented to EDs included: listening to trusted professionals; desperation; a feeling of no alternative; respecting their child's need to feel safe; and to rule out a potentially serious medical condition.

**Conclusions:** Parents bring their children to the ED for many reasons. Policy makers, managers, and clinicians should work with parents to develop alternative approaches that provide families with community-based support, particularly for younger children and after hours, in order to provide an appropriate source of care for children and young people with anxiety and depression.

**Key words:** Anxiety; Child; Depression; Emergency Service, Hospital; Mental Health

Author Manuscript

## Introduction

The number of children and adolescents presenting to the emergency department (ED) with mental health problems is rising. In the state of Victoria, Australia, mental health presentations to the ED increased by 6.5% annually in children and young people aged 0-19 years between 2008/09 and 2014/15, with a sharp rise in anxiety and depression in those aged 10 years and older.<sup>1</sup>

Victoria's 10-year Mental Health plan and Mental Health workforce strategy launched in 2015 aims to guide better investment and drive better mental health outcomes for Victoria.<sup>2,3</sup> However, the plan and workforce strategy largely ignore children. Further, most Australian children with mental health problems do not receive mental healthcare in the community which may in turn lead to increased presentations to the ED.<sup>4</sup> The Australasian College for Emergency Medicine (ACEM) has recognised mental health as a key issue, at least for adolescents and adults.<sup>5</sup>

Few studies have examined why children and young people with mental health problems present to the ED, and there have been no studies exploring parent-reported factors.<sup>6-8</sup> A 2018 poll of 2,032 Australian parents showed that over half (56%) did not know where to seek help if their child was experiencing mental health difficulties,<sup>9</sup> suggesting that poor parent mental health literacy may play a role.

We therefore aimed to determine, from the parent's perspective, the main factors contributing to children and young people presenting to the ED with anxiety and depression.

Understanding why parents bring their child to the ED for anxiety and depression could

inform new policies and practices to ensure appropriate care is available that allows families to manage anxiety and depression outside of the ED. This is likely to benefit the child, their family, and the broader healthcare system.

## **Methods**

### ***Study design, recruitment and data collection***

This was a multi-site, qualitative study. We recruited a consecutive sample of parents of children and young people aged 0-17 years who presented to one of four ED settings (including two major referral paediatric hospitals, one urban district mixed adult/paediatric and one regional mixed adult/paediatric ED) for a 6 month period at each site, between October 2017 to September 2018. Families were eligible if their child received an ED discharge diagnosis within the categories of 'Mood (Affective) Disorder' (F30-39) or 'Neurotic, Stress-related or Somatoform Disorder' (F40-48), as classified by the International Classification of Diseases 10th edition, Australian Modification (ICD-10-AM), together with a clinician diagnosis of anxiety or depression, made by the treating clinician at each site.

Exclusion criteria are detailed in Table 1.

ED clinicians at each site identified potentially eligible families through a rolling series of electronic medical record searches for the discharge diagnosis throughout the recruitment period. All eligible families were mailed a recruitment letter by the participating hospitals. Families were given two weeks to opt out of hearing more about the study. If they did not, the ED clinician passed the family contact details on to the research team who then telephoned parents to explain the study, confirm eligibility, obtain verbal consent and conduct the

interview. Other than the ED diagnosis, no other diagnostic information was forwarded to the research team.

All participants were asked a series of questions from a semi-structured interview script (Table 2). With permission from the participants, interviews were audio recorded, transcribed by an external transcription service, reviewed by two of the authors (ASC, KD) and imported into NVivo version 12 Analysis Software (QSR International Pty Ltd. Cardigan UK) for analysis. Approval to conduct the study was granted by the Royal Children's Hospital Human Research Ethics Committee (HREC 37147A) and each site provided site-specific approval.

### *Data analysis*

Child and family descriptive measures (e.g. age, sex, presentation details) are presented as the number and proportion of presentations. Family home postcode was mapped to the Australian Bureau of Statistics (ABS) 2011 Remoteness Areas,<sup>10</sup> which are based on the Accessibility/Remoteness Index of Australia (ARIA+) and Statistical Area Level 1 (SA1).

We adopted a descriptive phenomenological approach as our methodological framework, to understand the experiences of parents or carers of children and young people living with anxiety and depression. Descriptive phenomenology is a qualitative methodology that affords researchers an opportunity to understand the issues of interest through the experiences of those who have lived through them.<sup>11,12</sup> Responses to the transcribed interviews were analysed using inductive thematic analysis, in which we aimed to identify, analyse and report patterns or themes in the data. Initially, we performed open coding to examine, compare, conceptualise and categorise the data. Then, axial coding was applied to group the data based

on patterns within and among the categories identified.<sup>13</sup> This resulted in the final themes and these were used to explain the lived experiences of the study participants.

## Results

Across the 4 participating hospital EDs, we identified 364 potentially eligible consecutive presentations. Of these, 133 presentations were eligible for inclusion, and a total of 70 interviews were ultimately completed (of 90 eligible and contacted, see Figure 1). Interviews ranged in length from 25 – 60 minutes. Table 3 shows sample characteristics. The average age of children and young people was 14 years (SD 2.4) and 44 (63%) identified as female. 57% (n=40) of children were given a primary ED discharge diagnosis of ‘Neurotic, Stress-related or Somatoform Disorder’ while the remaining 43% (n=30) were ascribed a diagnosis of ‘Mood (Affective) Disorder’. The majority (84%) of study participants were female (n=59 mothers).

Five recurrent themes emerged as key to understanding why parents made the choice to present to the ED which included: listening to trusted professionals; desperation; a feeling of no alternative; respecting their child’s need to feel safe; and to rule out a potentially serious medical condition. These themes are described below, and examples of direct quotes from participants are included in Table 4.

### *Listening to trusted professionals*

Many families presented to the ED following the explicit advice of a health professional (including primary and secondary care providers), emergency services or their child’s school.

For most of these families, parents had been dealing with their child's mental health issues for some time and had taken the appropriate step of seeking a medical assessment. While some of these parents were encouraged to 'wait and see', all were ultimately advised to present to the ED if their child's condition deteriorated, or if they found themselves unable to adequately/safely manage at home.

In other cases, parents sought the advice of a health professional or emergency services after their child exhibited physical symptoms that parents believed were serious or potentially life-threatening. Where the health professional had concerns about the child or young person's immediate physical wellbeing, these families were referred to the ED and only there did parents discover their child's physical symptoms were psychogenic.

### *Desperation*

For many parents, desperation and exhaustion drove them to the ED. In the large majority of cases, these children and young people had a prior history of mental health concerns and an established relationship with a medical or mental health professional. For some of these families, presenting to the ED was seen as a formality for gaining admission to the inpatient mental health unit. This was particularly true when they felt they had exhausted all other options, and both parent and child were desperate for the respite and safety that a hospital admission may provide.

Families in which the child or young person had comorbid autism spectrum disorder (ASD) or attention deficit/hyperactivity disorder (ADHD) comprised a high proportion of the families who reported desperation as a reason for presenting to the ED. These families had

presented to the ED and other community-based services on multiple occasions without receiving the help they needed for their child.

*No alternative*

Some parents reported they would have presented to their GP or sought an emergency appointment with a secondary care provider (e.g. psychologist), however, they resorted to the ED given the incident occurred outside of standard business hours and there were no suitable alternative services.

In acute situations, some families had no alternative but to resort to the ED because their child was too young (<16 years) to access a mobile crisis assessment team (CAT). However, some parents of young people who were aged 16 and over, and who were highly distressed and/or threatening to self-harm, were also told their child was ineligible for CAT assistance, leaving them no alternative but to call emergency services or present directly to the ED.

*Child seeking safety*

Many parents presented to the ED because their child had made it clear, either directly or indirectly, that he or she did not feel safe and wanted to be cared for and protected in a hospital. In some of these instances, parents may have pushed for an alternative to ED but ultimately respected their child's need to seek reassurance that he or she was not in any physical danger. Across all responders, it was rare for a child or young person to resist going to the ED.

*Rule out serious medical condition*

Among those who presented to ED with a medical issue, many parents had genuine concerns their child's symptoms posed a serious risk and felt the ED was the right choice given the severity of the symptoms they observed. Some of these parents were unaware their child's condition was psychosomatic. Others suspected it might have been but felt an error of judgement could have had potentially life-threatening consequences for their child, and this was a risk they were not prepared to take. In some of these cases, the child or young person had a chronic illness (such as asthma) and the parents were unsure whether the symptoms their child was experiencing were related.

In more than half of these presentations, parents were either referred to ED by a medical professional or presented in an exasperated state having been through multiple tests to try and find a diagnosis for their child. Others observed physical symptoms in their child that they had not encountered before and felt they needed a medical opinion. In some of these cases, parents acknowledged they would have presented to their GP or a medical centre had the incident occurred during business hours.

## **Discussion**

This is the first study to ask parents about their reasons for presenting to the ED with their child who received an ED diagnosis of anxiety and depression in the absence of self-harm. We identified five key factors which influenced parents' decision to present to the ED, including: listening to trusted professionals; desperation; a feeling of no alternative; respecting the child's need to feel safe; and to rule out a potentially serious medical condition. Parents were hoping to get several things from the ED including admission to an

inpatient unit, after hours help, reassurance for their child, or confirmation that their child did/did not have a serious medical illness.

While recent studies have established that many parents have a very limited knowledge of how childhood mental health issues present, how best to manage them, and where to seek help,<sup>8,9,14</sup> our study revealed that only a minority of parents were unaware of their child's mental health issues at the time of their presentation to ED. The majority of children and young people (80%) who presented to ED had accessed community mental health services at least once in the preceding months or years.

Whilst about half of the families presented to ED based on the referral of a healthcare provider, school or emergency services officer, only a quarter of children and young people presented with physical symptoms which were deemed as urgent. Our findings, based on parent report, suggest that there may be a shortage of service alternatives in the community, particularly for younger children and after hours.

#### *Strengths and Limitations*

Our study was multi-site, ensuring a spread across regional, urban and major referral paediatric hospitals/mixed paediatric-adult ED settings, although the sample of regional participants was small. Limitations include possible selection bias although the demographic data captured on the 23 eligible patients who declined participation is largely comparable to that of those who took part. As eligible families were identified using hospitals' electronic medical record, miscoding of anxiety and depression could have resulted in an under representation of these conditions. This could explain the small number of participants from

one hospital. Additionally, by excluding families with insufficient English, information on additional barriers experienced by culturally and linguistically diverse families was not captured.

### *Conclusions*

Parents bring their children to the ED for reasons including following advice from a trusted professional, desperation, after hours support, respecting and reassuring their child, and to rule out a serious medical condition. Future research should seek to replicate this study in families with English as a second language and in larger rural samples. In the meantime, policy makers, managers, and clinicians should work with parents to develop alternative approaches that provide families with community-based support, particularly for younger children and after hours, in order to provide an appropriate source of care for children and young people with anxiety and depression.

## **Acknowledgements**

**Ethics approval:** Approval to conduct study was granted by the Royal Children's Hospital Human Research Ethics Committee (HREC 37147A), and each site provided site-specific approval. All persons gave their informed consent prior to their inclusion in the study.

**Data sharing and accessibility:** Non-identifiable study data are available on request.

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**Competing interests:** None declared.

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## Tables

**Table 1. Exclusion criteria**

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1. Child or young person did not present to ED with a parent or guardian;
2. Child or young person presented following an episode of self-harm and/or had made a suicide attempt, thereby requiring medical treatment;
3. Parent had insufficient English as determined by EMR flag for “Interpreter Required”;
4. Parent/carer had previously been contacted about the study; or
5. Postal address or phone number was not listed in the child/young person’s records.

**Table 2. Semi-structured interview guide**

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1. What led you to take <child's name> to Emergency on this occasion?
  2. What were you hoping the emergency department would be able to do for <child name>?
  3. Before your recent visit, had you tried to access any other services for <child name's> <anxiety/depression>?
  4. Do you know about services aside from the hospital emergency that are available for children's mental health?
  5. Is there anything <else> within family life that may have impacted your ability to get the help you needed for <child's name>?
-

**Table 3. Sample characteristics overall and for each participating site.**

	Royal Children's Hospital n (%)	Monash Children's Hospital n (%)	Ballarat Base Hospital n (%)	Sunshine Hospital n (%)	TOTAL n (%)
Total interviews completed	30	27	6	7	70
<i>Child / young person characteristics</i>					
Age, mean (SD)	13 (2.2)	15 (2.1)	15 (2.3)	14 (3.0)	14 (2.4)
0-4 years	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
5-9 years <sup>†</sup>	1 (3)	0 (0)	0 (0)	1 (14)	2 (4)
10-14 years	20 (67)	8 (30)	3 (50)	3 (43)	34 (48)
15-17 years	9 (30)	19 (70)	3 (50)	3 (43)	34 (48)
Gender, female <sup>‡</sup>	18 (60)	15 (56)	4 (67)	7 (100)	44 (63)
<i>Diagnosis</i>					
Mood disorder (F30-39)	6 (20)	17 (63)	5 (83)	2 (29)	30 (43)
Neurotic stress (F40-48)	24 (80)	10 (37)	1 (17)	5 (71)	40 (57)
Referred to ED	15 (50)	15 (56)	2 (33)	4 (57)	36 (51)
Presented during business hours	17 (57)	10 (37)	2 (33)	3 (43)	32 (46)
Previous ED visit for mental health	11 (37)	11 (41)	2 (33)	4 (57)	28 (40)
Admitted after attending ED	3 (10)	8 (30)	2 (33)	2 (29)	15 (21)
<i>Parent (respondent) characteristics</i>					
Mothers	28 (93)	21 (78)	5 (83)	5 (71)	59 (84)

<sup>†</sup> Note, zero children/young people were aged 5, 6 or 7 years old.

<sup>‡</sup> One child/young person identified as transgender male, included in male count

**Table 4. Summary of recurrent themes and representative examples of direct quotes from study participants†**

<b>Themes</b>	<b>Examples</b>
<b>Listened to trusted professionals</b>	<p><i>She didn't want to live anymore and she'd been feeling that way for a while but she was starting to feel like she could actually do it... So I took her straight to her psychiatrist.... Her psychiatrist said if you feel like you can't cope and she's not safe, take her to hospital. (daughter, 14 yrs)</i></p> <p><i>When we did find him ... he said he was going to try and drown himself in the creek. And, on another occasion, I caught him trying to take a knife into the bathroom. I have taken him to the GP and they suggested I come up to the hospital because he's crying out for attention. (son, 14 yrs)</i></p> <p><i>He had chest pains and was extremely anxious ... we went to the GP &lt;and&gt; they wanted us to follow it up and to go to the Children's ... it was a bit confusing because the GP thought that there might have been something else wrong ...whereas, when I got to emergency, he was like, "I can't believe that your GP didn't pick up that it was anxiety". (son, 12 yrs)</i></p>
<b>Desperation</b>	<p><i>I just didn't know who to turn to or what to do. The private psychologist wasn't working, the medication was taking a bit of the edge off but still things were just really, really spiraling downhill ... I just needed help. I didn't know how to deal with her and help her. (daughter, 16 yrs)</i></p> <p><i>...we had over a period of escalating violence in the home ... and it got to a point where I called the police. The police attended and &lt;child&gt; disclosed that he was going to shoot himself. So being 16 I think they were required to...call an ambulance. So it kind of spiralled quickly and he had no choice, I had no choice. It all kind of just happened. (son, 16 yrs)</i></p> <p><i>We were just seeking someone to help us out. These panic attacks were so severe, and they were so frequent, that it totally exhausted us, and stretched us to the limit. ... For us, it was a real emergency. (son, 15 yrs)</i></p>
<b>No suitable and/or available alternative</b>	<p><i>... a couple of times ...we've managed to get an emergency consult with his psychiatrist ... but other times, if it's a critical situation we've had to present to emergency. I'm guessing we've had to go to emergency maybe eight to ten times in the last six months. (son, 17 yrs)</i></p> <p><i>...we wanted to see what would happen off medication ... but timed with Christmas near everybody was gone. And we didn't have any &lt;Allied Health&gt; support at the time so I think that was really the reason we ended up at the Children's - because all of our other possibilities were not there. We didn't have any help. (daughter, 10 yrs)</i></p>

**Respected child's need to feel safe**

*She was very hopeful that somebody could help her because, in her words, somewhere deep down in there she doesn't want to hurt herself, she doesn't want to die. The reality is at that point in time she could see no other avenue. She just wanted the sadness and the pain to stop. (daughter, 14 yrs)*

*Yes, and doubt in <child's> mind, which was more important, because, he needed to feel like he knows what's happening to him. He wasn't convinced that it was just anxiety. (son, 15 yrs)*

*<Child> asked to go to the emergency department at The Royal Children's ... he said to them, "I need you to help me." He was begging them for help, literally begging them. ... He said, "I cannot take this any longer. I do not understand what's going on with my body. ... You need to do something because you're the only ones that can do anything. (son, 8 yrs)*

**Rule out serious medical condition**

*We were out having dinner and <child> was having difficulty breathing. She described tightness in her chest ... we tried to calm her down with some breathing exercises ... I then decided to call an ambulance when the area around her lips appeared to be turning blue. I had no idea at that point in time what was wrong with her and we later found out that it was a panic attack. (daughter, 14 yrs)*

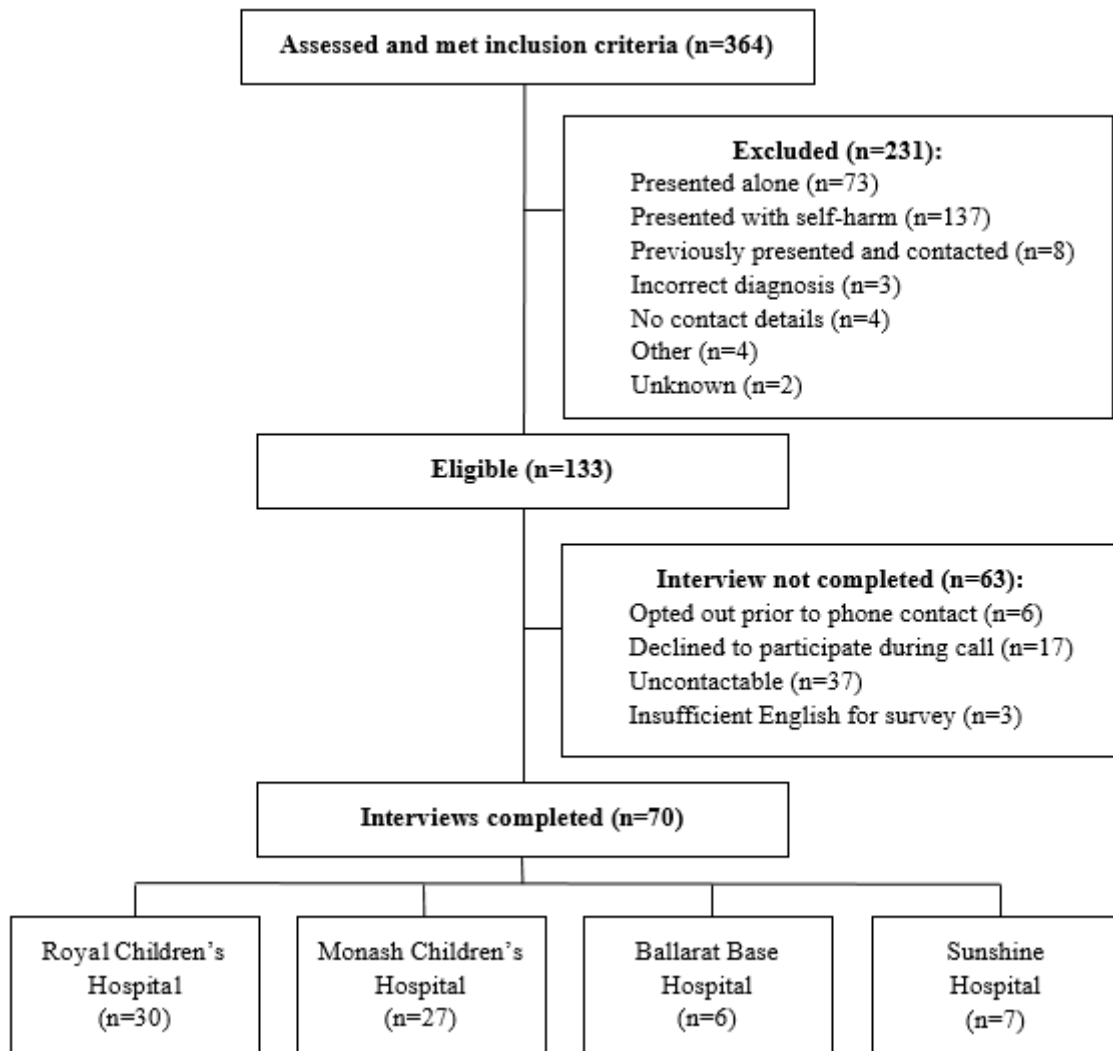
*She has had a lot of fainting episodes but she had just started having seizures. We had been to the hospital and they didn't really give us any answers. Just that if the seizures last over a certain amount of time, I would need to bring her back in. It was something I wasn't comfortable with because I wasn't quite sure what to do in the event of a seizure. (daughter, 11 yrs)*

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† These representative examples of participants' verbatim responses have been de-identified to preserve their confidentiality and protect their identity.

## Figure Legends

### Figure 1: Participant Flowchart



EMM\_13486\_Figure 1 - participant flowchart.tif

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