#### RESEARCH ARTICLE



# Support needs and experiences of young people living in families with mental illness

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#### **Abstract**

**Introduction:** Children and adolescents living in families affected by mental illness are at elevated risk of developing mental health problems. A range of interventions have been designed to help these young people; however, the effectiveness of these programs is, in some cases, mixed. Our aim was to understand in detail the support needs and experiences of a group of Australian children and adolescents living in families with mental illness.

**Methods:** Our study is a qualitative in nature. In 2020–2021, we interviewed 25 Australian young people ( $M_{\rm age} = 13.60$ , SD = 2.26, 20 females and 5 males) living with family members affected by mental illness to understand their (the young people's) experiences, and to identify the types of support that these young people considered important or effective. We conducted reflexive thematic analyses of interview data, underpinned by interpretivist assumptions.

**Results:** We identified seven themes within two higher-order categories reflecting our aims to understand (1) lived experiences within families affected by mental illness (i.e., increased responsibilities, missing out, and stigmatization), and (2) support experiences, needs, and preferences (i.e., respite, shared experiences with like-minded others, education, and flexibility).

**Conclusions:** Our findings hold substantial practical value by informing services, interventions, and conversations that better support young people living in families affected by mental illness.

#### KEYWORDS

children of parental mental illness, COPMI, mental health, qualitative

## 1 | INTRODUCTION

In Australia, roughly a quarter of children live in families affected by parental mental illness (D. Maybery & Reupert, 2018). Researchers have shown that these children—often referred to as "children of a parent with mental illness"—display an elevated risk of developing mental health problems in comparison to their peers (e.g., Hancock et al., 2013; Pakenham & Cox, 2014). In addition, children of a parent with mental illness have also been shown to be at a greater risk of substance abuse (Mowbray & Oyserman, 2003), behavioral and developmental problems (Leschied & Whitehead, 2005; Reupert & Maybery, 2016), dropping out of school (Farahati et al., 2003), socioemotional difficulties (Maughan et al., 2007), and self-harm or suicide (Hashir et al., 2019).

As noted previously, parental mental illness appears linked to child mental health problems. Indeed, parents often have been the focus within the broader study of children of a parent with mental illness (e.g., Hancock et al., 2013; Pakenham & Cox, 2014). However, mental illness among other family members (e.g., siblings and grandparents) may also be a catalyst for

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adverse outcomes for the child. Wolfe et al. (2014) demonstrated that siblings of individuals with mental illness may experience poorer educational and employment opportunities and experiences. Further, Cents et al. (2011) reported that grandparents' lifetime anxiety and depression predicted both internalizing and externalizing problems in their 3 year old grandchildren. Critically, a recent review (see Reupert et al., 2021) suggests that children of parents with mental illness experience stigma, affecting their mental health by preventing both children and parents from seeking support. Further, children appear motivated due to stigma experiences to conceal parent's mental illness, and experience guilt, bullying, embarrassment, and social isolation. As a result, regardless of the focal individual (i.e., the person who is living with mental illness), mental illness of a close relative can impact a child's life in numerous ways (Pölkki et al., 2004).

Given the prevalence of children and adolescents living in families with mental illness, and the associated mental health risks, early intervention and support is critical for this group. There are numerous examples in the literature of interventions designed to promote protective factors and mitigate risk factors for children and adolescents living with parental mental illness, including peer support groups (Foster et al., 2014), family-based interventions (Valdez et al., 2011), brief psychoeducation interventions in clinical settings (Kristensen et al., 2022), online support programs (Woolderink et al., 2015), online mental health and psycho-education resources (Cavanaugh et al., 2021) and bibliotherapy (Grové et al., 2015). Despite the common broad goal of providing support for young people in families with mental illness, these interventions vary markedly in their development, specific aims, and evidence base.

Peer support programs are a common method of intervention for young people in families with mental illness, aiming at connecting young people with others in similar circumstances (see, e.g., Van Santvoort et al., 2014). Another approach revolves around minimizing family dysfunction and maximizing young people's support networks and competencies, such as the US "Keeping Families Strong" program for mothers with depression and their 9–16-year-old child (Valdez et al., 2011). Similarly, researchers have developed and evaluated home-based interventions, such as the BROSH program in Israel, a holistic, multidisciplinary therapeutic intervention program aimed to prevent parent hospitalization and children's out-of-home placement (Oppenheim-Weller et al., 2021). These approaches have been effective in increasing children's perceptions of support, among other important psychological and interpersonal benefits. Critically, peer support programs can reach large numbers of individuals by being delivered online, transcending geographical limitations, such as *Kopstoring* (Woolderink et al., 2015) and *SurvivalKid* (Drost et al., 2010), two noteworthy Netherlands-based online interventions. Less formalized (or structured) online support programs exist, such as online self-help groups (e.g., Trondsen & Tjora, 2014). Broadly, online interventions can be accessed anonymously, at any time, and enable young people to receive and share information and support in a way that suits them.

Researchers have identified several key considerations for programs designed to support children and adolescents living in families with mental illness (e.g., Marston et al., 2016; Reupert & Maybery, 2010). Tapias et al. (2021) recent systematic review concluded that psychoeducation was a key component of interventions for this at-risk group. Other strategies include skill training (i.e., social skills and problem-solving), parent support, and peer support (Goodyear et al., 2009; Marston et al., 2016). Researchers also highlight the benefits of shared experience and coping skills development through supportive peer relationships (Foster et al., 2014) and family approaches (Robson & Gingell, 2012). Evidence suggests early intervention programs support positive outcomes for young people. Siegenthaler and Egger (2012) meta-analysis of preventive interventions for children of a parent with mental illness found that interventions, which commonly included cognitive, behavioral, and psycho-educational components, may reduce the likelihood of child mental illness by up to 40%. However, some researchers suggest the evidence for these programs is mixed. Thanhäuser et al. (2017) argue that there is only some empirical support that interventions for children of a parent with mental illness might be effective, highlighting a need for more high-quality intervention studies for children of a parent with mental illness. Evidence for these early intervention approaches remains at a somewhat developmental stage—there is little consensus regarding the most appropriate intervention targets (e.g., the child, the parent, and parent-child relationship), content, or structure of programs for children of a parent with mental illness (Reupert & Maybery, 2015). Further, scholars (e.g., Grové et al., 2016) have highlighted concerns that young people's views regarding their support preferences in this context have rarely been solicited.

Our approach in this study rests on the premise that young people's voices are essential for any investigation designed to understand the support preferences of this population. Effective intervention depends on an understanding of the knowledge and experiences of the intended beneficiaries of research or intervention (Clarke et al., 2015; Larsson et al., 2018). Abel et al. (2019) argue that to develop effective interventions for children (and adolescents) with a parent experiencing mental illness, we need to consult children. And, recently, Reupert et al. (2022) highlight, among several principles and recommendations for practice, the need to understand the perspectives of experiences of children in what they term a "bidirectional relationship" between parents with mental illness and their children's mental health. Building on this recommendation, our primary aim was to allow children and adolescents living in families affected by mental illness to identify their early intervention support needs and experiences (without focusing on clinical mental health support or "treatment" methods). To provide a contextual "backdrop" for our understanding of those support needs and experiences, and to allow children and adolescents to "share their story" as part of the data collection process, we also sought to encourage participants to share information about their experiences of living in a family affected by mental illness.



Our aim in this study is to understand the "lived experiences" of children of a parent with mental illness, and their support experiences, needs, and preferences. We aimed to solicit insight from an "information-rich" group of children and adolescents by recruiting participants who were attending or had attended an existing multicomponent support program in Australia. We did so to ensure that we collected data with young people who (a) were living with a family member with mental illness, (b) had sought help, and (c) had experienced various support or interventions methods. Importantly, our focus on these children and adolescents also enabled us to solicit information about their support *needs* as well as (and that was informed by) their actual support *experiences*.

#### 2 | METHODS

# 2.1 Philosophical underpinning

We adopted an interpretivist perspective (Lincoln et al., 2011) in the design and conduct of the study. The interpretivist approach is based on the notion that multiple realities exist, can be explored, and are constructed through human interaction. This perspective emphasizes the importance of understanding "lived experiences" and contends that meaning develops and is expressed through language and shared understanding. In line with this interpretivist approach, we used a qualitative method—namely semistructured interviews followed by reflexive thematic analyses—to address our research aims. Critically, interpretivism rests on subjective epistemological (i.e., knowledge is constructed) and relativist ontological (i.e., in social terms, at least, there is no single, separate, "objective" reality under study) assumptions (Sparkes & Smith, 2013). In essence, our view is that knowledge generated, particularly in relation to social phenomena, are constructed between interviewer and interviewee, and temporally and culturally located. We describe in further detail our reflexive approach to data analysis below.

# 2.2 | Participants

Inclusion criteria included young people who had (a) a family member who had a mental illness, (b) previously (or currently) taken part in the Kookaburra Kids Connect Program, and (c) assented (and had a parent/guardian consent for them) to participate. Exclusion criteria included children or adolescents who declared they had a diagnosed mental illness or experienced significant mental health difficulties, or any person who (for any other reason) felt that the interview may cause psychological distress. We recruited 27 children and adolescents over a 6-month period. One participant was excluded from analysis due to minimal engagement during the interview, and another withdraw shortly before interview. The final sample of 25 young people included 5 males and 20 females ( $M_{\rm age} = 13.60$ , SD = 2.26; range 10–18 years). Participants were located across Australia, including New South Wales (n = 16), Queensland (n = 5), Victoria (n = 2), Australian Capital Territory (n = 1), and Western Australia (n = 1).

### 2.3 | Program description

All participants were former or current participants in programs administered by The Australian Kookaburra Kids Foundation (AKKF)—a nationwide non-profit support program for children (aged 8 to 18 years) living in families affected by mental illness. AKKF provides free, evidence-based, age-appropriate prevention and early intervention mental health support, embedded within a peer/social and activity-based format. AKKF achieves this by providing (a) support—single-day, in-person chat groups and activities coordinated by experienced volunteers that provides children with an opportunity to learn about mental illness and how it affects families, share their experiences, and improve coping skills and resilience, (b) camps and activities—interactive discussion and group activities alongside other children, and (c) Connect—an online, clinician-led group chat session with peers.

#### 2.4 | Procedures

Upon receiving ethical approval from the Human Research Ethics Committee at the lead author's institution (2020/ET000134), parents/guardians of prospective participants were approached by email—through AKKF's clinical service coordinator—based on their child(ren)'s involvement in their program. Potential participants and parents/guardians were (a) informed that their (child's) participation was voluntary and that their decision would have no influence on their involvement in AKKF programs, (b) provided with an outline of the project, (c) assured of anonymity, and (d) notified that



they (their child) could withdraw at any time. Upon receiving consent from parent/guardian and children, a semi-structured, one-on-one interview was scheduled and conducted remotely (and recorded in Zoom). Interviews were conducted over a 6-month period from February to July 2021. Following participation in interviews, participants were provided with a gift card (value \$20) via email to compensate for their time.

## 2.5 Data collection

We designed a semi-structured interview guide to explore participant's experiences living in families affected by mental illness, and their support needs and experiences. Example questions included, "Please could you share your experiences of living with a family member with mental illness?"; "What does (or would) good support look like for you?"; "Could you tell me about your experiences of support?"; and "If there was a young person who found out they have a family member with mental illness, and you could speak to them, what would you say?." Probing questions were used to gain understanding and insight (Ritchie et al., 2013). Most interviews were conducted with one participant and one interviewer (i.e., [AH]). In four interviews, one coauthor was also present. In the remaining interview, the interviewer met with two participants (siblings) simultaneously. At the end of each interview, participants were thanked and invited to ask any questions.

At the time of data collection, we were guided by the notion of "pragmatic saturation." Data saturation refers to the point at which information being gathered in later interviews repeats itself—the point at which conducting additional interviews is unlikely to yield novel information pertaining to the research question (Sparkes & Smith, 2013). Given commentary in the literature regarding the possible (in)consistency between this notion and a reflexive approach to thematic analysis (Braun & Clarke, 2019; O'Reilly & Parker, 2012), it is important to qualify that we applied a pragmatic lens to any interpretations regarding saturation in this study. Our conception of saturation, therefore, is not a "realist" one—we do not claim to have "finalized" the range of children's lived experiences and support preferences when ceasing data collection. It is, of course, possible that conducting more interviews, or conducting follow-up interviews with the same participants, would yield novel findings or interpretations. As such, we were guided by pragmatic considerations and ceased data collection at the point where all authors agreed that coherent, representative, interpretable, and justifiable data (i.e., through sufficient raw data) had been collected. On average, interviews lasted 22 min (SD = 12.07).

# 2.6 | Data analysis

Interviews were audio recorded and transcribed verbatim. All audio-recordings were reviewed by (AH) to ensure accuracy of transcription. Notes were made during and following the interviews and during the transcription process to facilitate coding and initial interpretations. To ensure anonymity, all potentially identifying participant information was changed. All transcripts were imported into QSR International NVivo 12 software. An inductive, reflexive thematic analysis approach was adopted, following Braun et al. (2016) guidelines. Given the relative paucity of research focusing on children's perspectives regarding their support needs and experiences, this approach was considered suitable for informing practical and insightful conclusions. Themes were identified inductively (i.e., on the basis of insight rather than any established theory)—this approach allowed information to be gained from participants without imposing preconceived ideas. Analyses included an initial stage of familiarization with the interview transcripts, listening to audiorecordings, and generating an initial code guide. Initial codes were created by identifying units of text that referred to the same or very similar semantic (i.e., a unit of text directly expressed an idea or experience) content, although this was supplemented by exploring, in some cases, the latent meaning (i.e., coding for implicit ideas or meaning behind what was explicitly stated) of participant responses. Following this initial familiarization, the entire data set was then systematically coded by the lead author, and a tentative framework of themes was identified. Beginning at the point at which the lead analyst ([AH]) was familiarizing himself with interview transcripts, a series of "critical friends" discussions were held involving all coauthors (Sparkes & Smith, 2013). During this process, meaning and interpretations were discussed, themes were reordered, redefined, recategorised, restructured, and represented, and some abandoned, based on discussions around how themes fit with the aims of the study.

Throughout data analysis and manuscript preparation, we were guided by the notion of reflexivity (Sparkes & Smith, 2013). A reflexive approach involves "thoughtful, self-aware analysis of the intersubjective dynamics between researcher and researched" (Finlay & Gough, 2008, p. ix). With our reflexive approach in mind, it is worth noting briefly that the individual who conducted the interviews, and the analysis underpinning this project, has lived experience in this context (i.e., a sibling with a diagnosed mental disorder). This experience allowed the researcher to reflect on some shared experiences (and to empathize) with participants. Further, all coauthors, including the lead author, who are experienced "qualitative researchers," also have lived experience of family members or close friends who have experienced mental illness. The lead analyst

(i.e., [AH]) who conducted the interviews, has a different ethnic origin and nationality (i.e., Asian Singaporean) to all participants, was older than participants (i.e., aged 25), and identifies as male. No substantial language barrier was evident; however, it may be presumptive to assume that certain words have identical meanings across Australian and Singaporean cultures. As a result, some of the critical friends' discussions with coauthors (four of whom are dual Australian-other nationality citizens) were focused explicitly on issues of understanding and interpretation.

#### 3 RESULTS

Table 1 provides a description of participants' and their family members' mental illnesses. Interviews generated 146 pages of 12-point, single-spaced text. We identified seven themes (some with subthemes) within two higher-order categories according to the aims of the work, namely, to explore participants' (a) lived experiences within families affected by mental illness (i.e., increased responsibilities, missing out, stigmatization), and (b) support experiences, needs, and preferences (i.e., respite, shared experiences with like-minded others, education, and flexibility). We consider the two aforementioned higher-order categories to be interrelated, so rather than attempting to distinguish between those categories, we hope that readers will gain some sense of how they combine to form a complete "whole" (e.g., how children's lived experiences might inform, and be informed by, their support needs and support experiences). Meaning units are presented in-text below to support reader interpretation—additional illustrative meaning units are also provided in Supporting Information: Materials S1 and S2.

**TABLE 1** Description of children and adolescents (n = 25).

Characteristic	Value/s	%
Child age (years)		_
Mean	13.60	-
Standard deviation	2.26	-
Range	10–18	-
Child sex		
Female	20	80
Male	5	20
Family member with mental illness <sup>a</sup>		
Father	12	46.2
Mother	11	42.3
Siblings	3	11.5
Family member diagnosis (self-reported) <sup>b</sup>		
Anxiety	10	23.26
Depression	10	23.26
Bipolar disorder	8	18.60
Post-traumatic stress disorder	8	18.60
Adjustment Disorder	2	4.65
Attention deficit hyperactivity disorder	2	4.65
Obsessive-compulsive disorder	2	4.65
No response	1	2.33
Involvement with Kookaburra Kids		
More than 12 months	17	68
Less than 12 months	8	32

<sup>&</sup>lt;sup>a</sup>Some children have more than one family member experiencing mental illness.

<sup>&</sup>lt;sup>b</sup>Comorbid diagnoses have been included here.



## 3.1 Lived experiences

We identified three common themes reflecting participants' lived experiences within families affected by mental illness—namely *increased responsibilities*, *missing out*, and *stigmatization*. These themes provide a "backdrop" to understand the support needs and experiences presented later and are not designed to capture "all" that it means to be a young person living in a family affected by mental illness.

# 3.2 Increased responsibilities

Participants describes adopting additional responsibilities within their family. Participants described needing to "step up" for their younger siblings (such as when their mother went into hospital), or feeling that they "matured at a much younger age" than their siblings. Relatedly, children described adopting caregiving responsibilities for younger siblings, having to "take full responsibility, making sure that everything stays on timetable...[which] gets a bit overwhelming for me because I feel like it's my responsibility as the big sister." One participant described caring directly for her father (with mental illness): "It's always kind of a little bit of an issue because whenever my dad's angry for absolutely no reason, even in the car sometimes he always scares me but then I always need to find a way to calm him down." These responsibilities sometimes took precedence over children's own well-being or time for personal activities:

I guess with it being too overwhelming, like an individual you would stop, you would put aside what your needs are, focusing on what your parents need—meaning you will lag down on education, you will not socialize as much, because you're too overwhelmed.

# 3.3 | Missing out

Participants described missing out on "normal" experiences and opportunities as a result of growing up in a family affected by mental illness. To illustrate, one participant said, "[...] since mum went in [hospital], since then, I kind of like, missed out on fun opportunities and stuff. Because I would like, say, 'Oh, I'm busy visiting mum'." Another participant added, "We weren't allowed to visit [mum], meaning we can't see her for Mother's Day or any of our birthdays." Participants also expressed how their family member's mental illness affected their opportunities to be with (and experience the same things as) their peers:

Growing up, I always remember, like, doing activities that dad could do before the brain injury and couldn't do after, which always really made me feel upset that he wouldn't be able to do that with me [...] he couldn't go to the beach anymore because he'd get tired, he couldn't go to the park because it was too overwhelming with the screams and stuff [...] you have all your friends whose dad would take them to the park and everything, and you so want to relate to that. So, that's why it was always quite tough growing up.

Parents play a pivotal role in shaping their child(ren)'s values and life skills, and because parents experiencing mental illness were often not present at home (e.g., in health-care facilities, separated from the child), children felt their parents were sometimes unable to impart those values or skills. One participant shared: "Often, with boys, the dad's the person that teaches them the life skills, like with cars and all that stuff. So, I don't see my dad that much, I don't have much opportunity to learn this stuff." While describing "missing out," participants often reflected on the emotional stress that accumulated from these missed opportunities. In some sense, children and adolescents were (at times) "missing out" on a balanced or "typical" emotional development trajectory. Crucially, some children experienced self-blame: "Sometimes I feel like I'm to blame for my mum getting too overwhelmed with her mental illness. I sometimes feel it's my fault."

## 3.4 | Stigmatization

Children and adolescents frequently described experiences of stigmatization. For example, one participant mentioned, "If they [friends] met my dad, they would assume that he was always drunk all the time, which isn't the case for most families with parents who drink alcohol. It's like they don't really understand." Another participant added, "I think the bad part, people joke about people having mental illness." Participants felt that this stigmatization stemmed from a lack of understanding of or awareness about mental illness:

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I think, sometimes, it's usually the people that are unaware of, like, the situation and they'll make a joke. A lot of time, they're not aware it's going on within my household or other households. So, I guess they all think it's a nice funny joke and it's not going to hurt anyone and it's not going to affect anyone.

Furthermore, participants felt that this perceived stigmatization sometimes resulted in others treating them differently. To illustrate, one participant mentioned, "I think they would treat me differently because I'm not like a 'normal' kid. Because some kids don't actually have their parents going through PTSD or anything like that." Another participant reinforced this notion, stating, "They would treat me differently because they might think 'oh there's something wrong with him'—they might see it as a shocking thing that's not normal, there must be something wrong."

# 3.5 Support needs and experiences

We identified four themes reflecting participants' support needs and experiences—here, participants described their recommendations for early intervention or ongoing support, and/or their previous experiences in various services or programs. The key elements outlined in these themes included *respite*, *shared experiences with like-minded others*, *education*, and *flexibility*.

# 3.6 Respite

Participants highlighted that a period of rest or relief from their stressors (e.g., caregiving responsibilities and emotional stress) would help (and had helped) alleviate their distress or feelings of missing out. Some participants mentioned, for instance, the benefit of "getting their mind off the situation" being helpful, whereas others drew on positive experiences in the program, which meant she "pretty much just [forgot] about home and [could] just focus on what was happening [at Kookaburra Kids]." Broadly, this theme captures participants' reflecting on the idea of (general) rest or relief, rather than a desire for any specific activity itself. For example, one participant elaborated:

Well, it gives us that time to just have a break, so we're not always overwhelmed. Because living with a parent with mental illness, it makes you a little overwhelmed, so, like, having that time to just have a bit of relax is good.

In some cases, though, participants expressed a desire for respite in the form of activities that they felt they "missed out" on due to their family member's mental health. For example, one participant mentioned, "They [Kookaburra Kids] also do activity days, and at the early stages of the brain injury that was really good because it meant that we're able to do stuff during those hard times." For another participant, Kookaburra Kids enabled him to experience "stuff that dad couldn't do" such as traveling long distances for program surfing days.

# 3.7 | Shared experiences with like-minded others

Participants felt that sharing experiences with like-minded others was an important aspect of good support. We identified four sub-themes within the broad notion of shared experience, including (a) good conversations, (b) connectedness and relatability, (c) reassurance, and (d) learning from shared experience.

With respect to good conversations, participants valued or desired conversations with other children in similar circumstances. Participants believed that conversations with others in similar situations had helped (or would help) them express themselves more fully, work through doubts and anxiety, and relieve emotional stress: "Honestly, just listening to, like, your experiences with it, and just letting you know that it's normal what you're going through, and there is help for it. That's probably the best type of support you can get for these things." Another participant reinforced this notion, explaining the importance of good conversations with like-minded others:

I like being able to talk to other people who are kind of in the same situation and, like, know what's going on. It's easier to talk to them compared to your friends because a lot of them, like, don't understand the troubles you face at home. Like, my friends can't really understand that.

Participants also expressed that although it might not be comfortable or easy talking to others, it was effective. One participant mentioned:

It's hard to think about it, and it's hard to do it [talk] when you're really sad, but it does actually help, talking to somebody. A lot of the time, you won't like it, you won't want to do it, but when you actually do it, you realize that it actually helps.

Captured within the subtheme *connectedness and relatability*, participants indicated that being able to connect with others who understood them is an important form of support for children and adolescents living in families affected by mental illness. To illustrate, one participant mentioned, "I feel, like, it's really good to be able to know that somebody else is sort of going through the exact same thing as you... and knowing that there's always a person there that knows what you're going through." Another participant reinforced this notion, stating:

It's good to have that kind of connection with other people who understand. Because not many people at my school understand what I go through, which obviously makes it hard, but having those other people out in the community that understand it, it's really good support to have.

Participants also described a sense of *reassurance* being made possible by being around those with shared experiences. Reassurance appeared to help allay doubts or fears that these young people experience and was desired as a way to normalize their situation. For example, one participant mentioned, "Well, to know that there are people in my age, going through stuff that I go through on a daily basis, kind of helps to know that." One participant reinforced this notion, stating:

I think it's really helpful to know that this is a normal thing. Like, I thought that I wasn't normal because I was growing up with someone like that. And, knowing that a lot of other kids that struggle with, like, having parents that struggle with that was really helpful for me.

Finally, participants shared that by interacting with like-minded others, they were (or felt they would be) able to learn practical strategies and share information about ways of tackling their own challenges at home. Captured within the subtheme *learning from shared experience*, participants revealed that they could learn, adapt, and practice coping strategies from similar others' experiences. One participant mentioned that "I'd find it useful that you could know what they are going through and how they deal with those situations. You gain greater understanding of how you can deal with those situations that come up in your life." Another participant echoed, "I would think good support looks like people talking to each other and people telling other people how to cope with stuff."

It is important to caution that participants occasionally also expressed concern about the less adaptive coping behaviors that might also be shared during such interactions. To illustrate, one participant indicated:

One kid shared that his dad wasn't really good to him, and I don't think he dealt with it well. Because the kid said, I just swear at him. I don't think that helps. So, I don't think that makes either of them better because the kid thinks it's better to swear than just go to your room and just have a little calm down. That's what I'd do.

Although modeling and sharing of "effective" behaviors from like-minded others might be the most desirable "learning" experience, it is possible that learning may occur through hearing about (and looking to avoid) others' less adaptive strategies.

## 3.8 | Education

Participants described their desire for raising awareness regarding mental illness, particularly by normalizing mental illness, increasing others' mental health knowledge, and improving participants' coping strategies. We identified two subthemes in this section, namely (a) education for others, and (b) education for self.

Under the subtheme *education for others*, participants highlighted the importance of improving others young people's mental illness education, with the goal of raising awareness and understanding. One participant expressing the following:

Them [people at school] not understanding, they might be just giving me advice that might not actually work because they might think your mum might just be tired or something... "just give some time to herself, you'll be ok." They don't understand there's more to what's wrong with them that they could never imagine, because they don't have parents who go through the same things.



Participants felt that educating others and raising awareness would help normalize the situation, and in turn, reduce felt stigmatization. Further, participants felt others could normalize the situation:

I think there are, like, so many kids that go through this and don't really know. Schools could really just, like, talk about like the different mental illnesses that, like, people might go through. And, just saying, like, that it's ok and that almost everyone has family member or friends that they know that go through this.

Crucially, education for others could be humanizing for people with mental illness:

Mental illness is not bad. It's bad to have mental illness but it doesn't change that person, and when you get diagnosed with mental illness it doesn't mean that you just get it then. It means probably they have it for a while and that it doesn't change that person or make that person dangerous. It doesn't make them any less human or any more human.

Under the subtheme, *education for self*, young people indicated that they would personally benefit from more information about mental health and mental illness. One participant expressed:

For me, the most thing that I'd like to get with support would be actually getting, like, good knowledge to actually understand it. Because, like, I've been taught by my mum what her mental illness is, but I have actually not much knowledge about what it is and what causes it—knowing how medication can help, why it helps, what things cause it, and just really more about it.

By improving (what might be termed) their "mental health literacy," children felt they were (or would be) better able to "make sense" of what was going on in their family. One participant shared how he could better comprehend the situation using the lessons acquired at a support program:

[...] we learnt like the basics of mental illness in school. But Kookaburra Kids have really just deepened your understanding of it. It kind of alerts you to what's happening. This way, you can really make the connection between dad's daily life and mental illness.

Others expressed the need for, or importance of, education about effective coping strategies that they could use in certain scenarios. For example, one participant mentioned they would like more information about "How you can deal with certain situations and, if you need to move away from a situation or if you're in a bad relationship with someone else, what to do in those circumstances."

# 3.9 | Flexibility

Participants described their desire for an array of different support methods (e.g., peer support and online support). Participants felt that the ability to access support in a flexible manner allowed (or would allow) them to receive support at the right time and in the right way. In one participants' words:

[...] joining online and having an option to talk or not is really nice to have that option. I can still socialize and meet people and view different opinions and experience other people's lives whilst still not having to be physically going anywhere and feeling very anxious. I have a lot of anxiety, so the online space is nice.

Flexibility in support offerings may allow these young people to access support as frequently as needed (which may not be possible, for example, if waiting for in-person meetings or groups). To illustrate, one participant mentioned, "If I needed them when my dad is going through something, there's always that option to be going into a [online] support group."

#### 4 DISCUSSION

Children and adolescents in families with mental illness experience pervasive challenges, but the effectiveness of current intervention strategies aimed at supporting this population is mixed. Our aim in this study was to broadly identify this population's early intervention support needs and experiences. Participants' desire for respite and shared experience underscores the value of using activities, excursions, or camps to connect young people with empathetic others. Similarly,

these important support needs also hold promise for informing research that identifies (a) the pathways through which respite and shared experience align with wellbeing and coping outcomes (e.g., mediating mechanisms), and (b) which elements of respite and shared experience most strongly augment the positive effects of these support elements.

Importantly, our participants discussed in detail the value of education—expressing their desire for strategies that enable others to be more understanding and that increase their own mental health literacy (see, e.g., Grové et al., 2016). Our participants identified that more readily available mental health information would aid their own and others' understanding of family mental illness. Research suggests that many children and adolescents lack a detailed understanding of mental health concepts, and may not possess accurate, practically useful, or stigma-free information on mental health issues (Riebschleger et al., 2017). In a review of barriers, facilitators, and interventions supporting help seeking among young people with parents affected by mental illness, Davies et al. (2022) highlight that internalization stigma produces complex patterns impairing "help seeking" behavior. Notably, Davies' and colleagues' review suggests that children's experience of stigma prevents help seeking from "formal sources"—highlighting a particular fear among children, due to internalized stigma—that seeking help from professionals may lead to children's separation from their parents—sometimes due to prior experiences in foster care. Focusing on improving mental health literacy enables people, and young people in our context, to better recognize, understand, monitor, and potentially prevent mental health disorders (Kutcher, Wei, Coniglio et al., 2016; Kutcher, Wei, Costa et al., 2016). Among young people, mental health literacy appears to be related to wellbeing and general help-seeking behavior (Ratnayake & Hyde, 2019). Further, young people in this study also expressed a desire to learn about effective coping strategies that may help alleviate their emotional load. D. J. Maybery et al. (2013) found that young people living in families affected by mental illness may employ suboptimal coping strategies, such as avoidance, withdrawal, or distancing. Educational strategies that allow young people to identify and tangibly implement effective coping methods may support mental health literacy and wellbeing outcomes. To realize the practical value of the "education" concepts that were discussed in this study it is important that researchers investigate how and where effective mental health education might be delivered for young people. Most young people spend a large proportion of their time at school, and the school environment is considered a key site for mental health promotion opportunities (Pinheiro et al., 2017). Skilled educators may be well placed to identify children who are experiencing difficulties, and there is likely value in broad school-based approaches to raising general awareness, understanding of, and destigmatizing, mental illness (Bibou-Nakou, 2004). Further work focusing on the design and evaluation of such trials would be worthwhile.

Recent research (see Parkinson et al., 2021) reinforces our findings regarding the value of children of parents with mental illness participating in peer support programs due to the opportunity they afford children to discuss *shared* experiences. Parkinson and colleagues identify several broad aims for peer support programs for children of a parent with mental illness, namely to (a) educate children about mental illness and the value of talking with others in similar situations, (b) to learn skills including help seeking, problem-solving, and managing feelings, (c) to have fun and experience respite, (d) to, broadly, realize they are not alone in their experience, and (e) to feel braver and stronger. These are the explicit and implicit goals of such programs, and our participants independently reinforced this notion. Peer support programs allowing children to discuss shared experiences normalizes children's experiences (combating self-stigma), and promotes experiences of acceptance and belonging, according to Parkinson et al. (2021).

Young people expressed a desire for flexibility in early intervention approaches. Our study population is by no means homogenous—not all parenting is "compromised" by mental illness, nor will all children be impaired or struggle to cope with family life (Steer et al., 2011). "One-size-fits-all" models of early intervention and support are inadequate. Our participants shared that they may, at times, feel uncomfortable interacting in face-to-face interventions (e.g., due to social anxiety; see Van Doesum et al., 2016). Further, face-to-face programs are typically timetabled at fixed days/times, posing challenges for this population. Service providers may, therefore, focus attention on supplementing in-person approaches with online support platforms. Digital technologies are increasingly integrated in young people's lives, and young people are largely receptive to the idea of accessing mental health support online (Elizabeth et al., 2009). Of course, adverse interactions (e.g., bullying, sharing negative coping strategies) are still possible online, and not all young people have access to the internet or suitable devices. Regardless, online mental health interventions may reach populations that simply would not be reached by traditional interventions (Elizabeth et al., 2009). Recently, Price-Robertson et al. (2019) identified that online peer support programs for young people could occupy an important role in the evolving selection of services for Australian families affected by mental illness. This is consistent with Grové et al.s' (2016) conclusion that our study population desires avenues for confidential, online support. Finally, recent research suggests such approaches are effective, including when young children become young adults. Reupert et al. (2020) recently implemented a 6-week, online, professionally moderated support intervention for young people (aged 18-25 years). Although older than most of our participants, the authors report positive outcomes including improved self-reported depression, stress, well-being, social connection, and coping as a result of participating in the program.

Our study has notable strengths, including the selection of an information-rich participant group. Young people living in families affected by mental illness have previously been referred to as an "invisible" or hard-to-reach population (Gladstone, 2015). Further, participants had experienced one (or more) support program in Australia and had done so for an extended

period (i.e., 68% of participants for 12+ months). Participants were, therefore, well-informed, and were able to articulate what *they* considered important and effective methods of early intervention and support. Further, participants' family members experienced an array of mental illnesses (see Table 1). This variety in focal mental illness may support the transferability and generalizability of conclusions beyond specific conditions. Finally, we were guided by implementation science and codesign literatures, and by gaps in the literature, to design a study focused on soliciting information directly from members of the focal population.

Balanced against those strengths, we are mindful of study limitations. First, we acknowledge that our recruitment strategy (i.e., recruiting "information-rich" young people who had experienced some form of early intervention support) provides limited insight into some subpopulations in this area. It is possible that young people who have *not* sought out any form of early intervention support may experience different support needs to those we recruited. The resources available for our participants to attend support groups may not be present in those *not* represented in our sample. For example, Price-Robertson et al. (2019) note that the four most cited reasons for young people not attending peer support programs are (1) issues related to access, (2) time pressures (e.g., competing priorities), (3) lack of referrals to programs, and (4) limited resources (e.g., financial means). Given our sampling strategy our results do not inform our understanding of the ways through which researchers or service providers might best "activate" help-seeking behavior among young people living in families affected by mental illness who have *not* taken, or perhaps, due to circumstances mentioned above, may not be *able* to take, steps to seek help. Second, we solicited information from only *one* member of a family unit (i.e., children). We did so purposefully because we aimed to understand the needs and experiences of *young people*. In the future, it would be valuable to solicit similar input from *other* members of the family (e.g., siblings, parents, and romantic relationship partners). Doing so may provide for a more comprehensive understanding of consistencies and discrepancies in the support needs across a "whole" family unit (see, e.g., Reupert & Maybery, 2007b).

Finally, most of our participants identified as female (i.e., 80%). Females may be over-represented in this population, and evidence suggests girls may be "more likely to seek and intend to seek help" (Rickwood et al., 2005; p. 11). Therefore, our gender balance may be representative of the broad makeup of early intervention participants. Regardless, in future, researchers ought to determine whether this imbalance is a function of the imbalance of such programs or recruitment strategies. Both explanations may be partly accurate. It is important future work (a) seeks to recruit a representative sample of young people who are seeking help for this issue, and (b) considers barriers in this area (to help-seeking and/or research participation) specifically among young males (and other underrepresented population segments).

In closing, we hope our results contribute to the literature on young people's experiences living in families affected by mental illness by contextualizing some challenges faced by young people in these families. Importantly, our results tell, in part, young people's stories about the forms of support that have been or may be effective in supporting early intervention efforts. Such strategies include those that connect, educate, and provide respite directly for children and adolescents living in families affected by mental illness, as well as the mass, community-wide (e.g., school-based) approaches that may help to educate the community at large about this important and pervasive family health issue.

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#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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