The lived experience of mental disorders in adolescents: a bottom-up review co-designed, co-conducted and co-written by experts by experience and academics

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We provide here the first bottom-up review of the lived experience of mental disorders in adolescents co-designed, co-conducted and co-written by experts by experience and academics. We screened first-person accounts within and outside the medical field, and discussed them in collaborative workshops involving numerous experts by experience – representing different genders, ethnic and cultural backgrounds, and continents – and their family members and carers. Subsequently, the material was enriched by phenomenologically informed perspectives and shared with all collaborators. The inner subjective experience of adolescents is described for mood disorders, psychotic disorders, attention-deficit/hyperactivity disorder, autism spectrum disorders, anxiety disorders, eating disorders, externalizing disorders, and self-harm behaviors. The recollection of individuals' past histories also indexes the prodromal (often transdiagnostic) features predating the psychiatric diagnosis. The experience of adolescents with mental disorders in the wider society is described with respect to their family, their school and peers, and the social and cultural context. Furthermore, their lived experience of mental health care is described with respect to receiving a diagnosis of mental disorder, accessing mental health support, receiving psychopharmacological treatment, receiving psychotherapy, experiencing peer support and mental health activism, and achieving recovery. These findings can impact clinical practice, research, and the whole society. We hope that this co-designed, co-conducted and co-written journey can help us maintain our commitment to protecting adolescents' fragile mental health, and can help them develop into a healthy, fulfilling and contributing adult life.

Key words: Adolescents, lived experience, first-person accounts, mood disorders, psychotic disorders, attention-deficit/hyperactivity disorder, autism spectrum disorders, anxiety disorders, eating disorders, externalizing disorders, self-harm behaviors, mental health care, recovery

Recent meta-epidemiologic findings indicate that the onset of the first mental disorder occurs before the age of 14 in one-third, before the age of 18 in almost half, and before the age of 25 in about two-thirds of individuals, with a peak age at onset of 14.5 years across all mental disorders[1]. Most adult mental disorders originate during adolescence (i.e., between 10 and 19 years of age[2]), when rapid growth and development take place in the brain[3]. The incidence of mental health problems in adolescents is reported to be increasing worldwide[e.g.,4].

Early onset is a main driver of the high personal burden of most mental disorders, compounded by frequent comorbidities[5,6], and reflecting a complex etiopathological interplay of genetic and environmental factors[7,8]. A related driver is the global crisis of the mental health care system[9], which is typically split around the age of 18[10] (children and adolescent vs. adult mental health care), leading to a lack of continuity of care.

These drivers lead to suboptimal recovery and lifetime chronicity[11], and contribute to the decreased life expectancy (up to 10-15 years) associated with several mental disorders[12-16]. The above picture has been magnified through the lens of the COVID-19 pandemic, which has substantially disrupted young people's mental health[17-20].

Despite their large and long-lasting effects throughout life, the mental health problems of adolescents are typically neglected. In particular, the subjective nature of their experience of mental disorders has been usually siloed in academic investigations lacking first-person perspectives or in autobiographical accounts lacking in-depth analyses.

To fill this gap, we conducted the first bottom-up review of evidence on the lived experience of mental disorders in adolescents. The study was co-designed, co-conducted and co-written by junior experts by experience – representing different genders, ethnic and cultural backgrounds, and continents – and academics, refining an earlier method developed by our group to investigate the lived experience of psychosis and depression[21-23].

We established a collaborative core team of experts by experience (patients, their family members and carers) and academics to co-design the study protocol. The study was then co-conducted by these partners across the subsequent stages. We performed a comprehensive systematic search of Web of Science, PubMed and EBSCO, from inception until May 1, 2023. The search terms were (adolesc* OR youth) AND (qualitative OR "focus group" OR "grounded theory" OR "content analysis" OR etnograph* OR phenomenol* OR "lived experience") AND ("mental health" OR "mental disorder*" OR "mental illness" OR "behavioral disorder" OR "behavioural disorder").

We included qualitative studies providing first-person accounts that involved adolescents (range: 10-19 years of age[2]) with a current ICD/DSM diagnosis of a mood, psychotic, neurodevelopmental, anxiety, eating or externalizing disorder. We did not include intellectual disability, because of the language and expressive difficulties that characterize this condition. We added an extra category of self-harm behaviors.

Studies investigating people grouped on the basis of symptoms, experiences or other self-reported features, rather than a diagnosis, were not included. However, the retrieved papers frequently contained the recollection of individuals' past histories, thus indexing the prodromal (often transdiagnostic) features predating a formal psychiatric diagnosis[24].

All included articles were uploaded on NVivo, a qualitative data analysis software[25]. Independent researchers performed a thematic synthesis of selected sources based on line-by-line coding of the text in the Results/Findings sections of the articles, and generation of a preliminary list of descriptive themes and sub-themes of the lived experience of mental disorders in adolescents. Further sources – such as websites, blogs, or social media material written by experts by experience – were consulted at this stage, and relevant items were included.

The material was then shared across the collaborative core team and preliminarily classified across three overarching descriptive sections: "The inner subjective experience of mental disorders in adolescents", "The lived experience of adolescents with mental disorders in the wider society", and "The lived experience of adolescents with mental disorders in receiving mental health care". Each section comprised several themes and sub-themes. Some themes were further enriched by incorporating the parents' and carers' perspectives, as applicable.

In a subsequent step, we promoted a collaborative and iterative sharing and analysis of the preliminary experiential themes and sub-themes in three workshops. These involved a wide group of experts by experience from the Global Mental Health Peer Network (https://www.gmhpn.org), representing the lived experience of youth from over 40 countries; the children and adolescents' Mental Health Advisory Group (https://www.kcl.ac.uk/research/ypmhag), representing the perspective of youth in the UK; and the Outreach and Support in South London (OASIS) clinical service (https://www.meandmymind.nhs.uk)[26], representing the perspective of adolescents with emerging mental disorders. Overall, we involved 18 young experts by experience of variable gender, age and ethnicity from three continents, encompassing Europe (UK), Asia (India) and Africa (Botswana, Kenia, Zambia, Zimbabwe).

In a final step, the selection of experiential themes and sub-themes was enriched by phenomenologically informed perspectives[27-43] drawn on the included articles, workshops and academic expertise. Academics were also of variable age, gender and ethnic background, as well as from various continents (Europe, North America, South America, Asia and Oceania). The broader group of experts by experience and academics collectively interacted to draft and review the manuscript via a shared Google Drive platform. All experts by experience actively participating in the manuscript elaboration were invited to be co-authors. Experts by experience were offered reimbursement for their time adhering to available guidelines for

participatory research[44].

In line with our previous publications[21-23], the words written or spoken by experts by experience are reproduced verbatim in italics. Commentaries from participants in our collaborative workshops are anonymized as personal communications. As previously indicated[21-23], this study outlines the most paradigmatic ways by which mental disorders express themselves across the majority of experts by experience on a global scale. However, we neither assume that the reported experiences are exhaustive nor that they are systematically applicable to all young individuals or their parents and carers. On the contrary, we frequently address in this paper the high phenomenological heterogeneity of the lived experience of mental disorders in adolescents.

THE INNER SUBJECTIVE EXPERIENCE OF MENTAL DISORDERS IN ADOLESCENTS

This section explores the inner subjective experience of mental disorders in adolescents. Different sub-sections focus on mood disorders, psychotic disorders, attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorders, anxiety disorders, eating disorders, externalizing disorders, and self-harm behaviors.

The inner subjective experience of mood disorders

Experiencing a change in one's personal identity

Adolescents undergoing a depressive episode often describe a change in their experience of self, that they have difficulties to explain: *"like you don't feel yourself"*[46]. This feeling ranges from a loss of confidence to a persistent and negative sense of lost identity[46-49].

The comparison between how they used to be and their current experience is extremely painful, affecting all areas of life, particularly their relationship with schoolmates and friends: *"I used to be a really good friend, and now I'm not"*[47]. Some of them feel that the good aspects of their identity have been replaced by unpleasant ones: *"There is something wrong with me"*[47].

The weakened perception of the self may lead to a feeling of imminent personal failure: *"I'm going to fail in everything"*[47]. A sense of estrangement may be reported: *"My depression is like being a different person… it's like it's part of my personality, but it's overshadowing who I am"*[47].

The manic episodes are instead marked by an experience of consolidation of personal identity and possibilities: *"I felt like I could do everything, that I would still be the best at whatever I decided to do" (personal communication)*.

Experiencing overwhelmingly intense emotions

Adolescents often experience mood episodes as a chaos of intense emotions. During the depressive phases, they report feelings of mental pain and anger (*"I find dark elements in my life: sadness, anger, desperation and pain"*[50]), which may be so intense that they feel like drowning: *"With the depression spiral, you just keep going down and down"*[49]. Sadness is described as being *"to the deepest summit"*[51], often becoming an inconsolable *"cry for no reason"*[47].

During the manic phases, the intensification of all emotions is often perceived as confusing: *"I had so many thoughts and so many emotions in my mind; they all mixed together" (personal communication)*. Anger not rarely predominates over euphoria and enthusiasm: "*My immense rage increased at the same time as my desire to break everything, to feel things fall*"[52]. Anger and irritability may be experienced as an overflowing river "*that has always been present*"[53].

As adolescents have not typically developed mature coping strategies to contain their overwhelming irritability, they may resort to verbal or physical aggression towards themselves or others (*"I feel really angry, it's just like little things that get me irritable... I'll literally go mad… It's like I shout at them or punch things or just say stuff I don't even like really mean"*[47]) or bullying behaviors ("*I was turning into a bully but didn't want to turn into a bully"*[47]).

In severe depression, rather than experiencing an intensification of their emotions, adolescents may experience a profound numbness and inability to feel any emotion at all: *"I didn't really feel anything, like there was no happiness or excitement, but there was also no sadness. It was just like everything was grey"*[46].

Feeling trapped in their own minds

Adolescents in a depressive episode often describe feeling trapped: *"It is a disease that's like a black hole. It is hard to get out of it, and everything around us is dark"*[54]. They may also report feeling "*flooded*" by recurrent negative thoughts, self-doubts and ongoing ruminations: *"I'm thinking about more and more things, so it's like piling on top, so, the mood just kind of keeps going down"*[55].

During a manic episode, there may be an experience of unprecedented availability of the surrounding world, as if everything is easily achievable and within reach: "*The world was my playground*" *(personal communication)*. However, the sense of omnipotence is frequently chaotic and accompanied by racing thoughts and impulses: "*You can tell that you were jumping from one thing to the next and not concluding sentences and things like that*"[56].

Therefore, adolescents may eventually experience a painful sense of being trapped in

their minds during both depressive and manic episodes. This feeling is amplified by an abnormal perception of the subjective time, which is stagnant in depression (*"It feels like life goes on a loop every day, everything feels tired, nothing feels fresh anymore"*[54]), and accelerated in mania ("*It was as if everything couldn't stop running"*, *personal communication)*.

Seeing the surrounding world fading away

During depressive episodes, adolescents may experience their surrounding world as fading away: *"I'm separated from everyone else"*[47]. They usually do not share the entertainment of their peers, and this makes them feel alone and isolated: *"Everything is just harder to get through, and you want to isolate yourself"*[49]. Isolation may become an unpleasant necessity: *"'I forget that everyone else exists… I'm invisible and I like that'"*[47].

The sense of isolation from the surrounding world may also be related to an altered perception of the lived body, which is characterized by heaviness, tiredness, and lack of energy: *"I was always really tired, and I had no energy to do anything"*[47].

During manic episodes, adolescents may report greater ease in social interaction ("*I had always been shy but now I wasn't anymore*", *personal communication*). However, this sense of being more in tune with the surrounding world is only apparent and transitory[31]. They are not able to pause and stop to properly meet their schoolmates and friends, because thoughts and body are in continuous excessive movement.

Therefore, both in depression and mania, adolescents may ultimately experience the surrounding world fading away. Everything turns into a pointless and hopeless stagnation of personal purpose ("*What is the point anymore? There is no point!"*[48]) and boredom (*"Just try and do a lot of different things, think I was interested in them then get bored, and just get into a cycle of boredom"*[46]), or into a senseless race without a goal ("*I felt like I was in a video game*", *personal communication*).

The inner subjective experience of psychotic disorders

Experiencing a pervasive change in the lived world and self

Adolescents who experience psychosis for the first time often describe a pervasive change in their lived world and self. They typically struggle to understand the world distorted by the psychotic symptoms. The surrounding environment loses its familiarity and becomes a sinister place, full of unknown threats, whose signs must be reinterpreted[28,39,57]: *"I knew something was wrong"*[56]*.* Unusual perceptions (*"I shared space with faint voices and a grim loss of reality"*[52]), frank hallucinations (*"I started seeing and hearing stuff, having some unusual*

smells"[58]*)* or delusions (*"I've got feelings that people are trying to plot against me"*[57]*)* emerge*.* The pervasive change in the lived world is insidious and mirrored in a profound change in the self that is difficult to explain.

During the first episode of psychosis, adolescents may feel that the world they inhabit is very different from that of their peers: *"Psychosis to me is just being absolutely drowned off the planet, like floating in space sort of thing, with no idea what is going on"*[59]*.* Because of the altered perception of reality, they feel that they cannot trust their mind as they did before: *"it is like a friend who betrayed you once, and you don't know if you can ever trust them again" (personal communication).*

Feeling like a fish out of water

Because of the experiences described above, adolescents with psychosis may feel extremely uncomfortable with others, *"like a fish out of water" (personal communication)*. They may describe a sense of radical fear and loss of familiarity when entering social contacts, and a significant detachment from self and the world: *"I was mentally disturbed, confused and not well, my mind was not my own"*[60]. These feelings are amplified by their painful awareness of being different from their peers and being addressed as weird, triggering persecutory interpretations: *"People are looking at me like I'm different"*[61]*.*

The fear of social interactions and the feeling of being different from peers can often originate in childhood: *"I didn't really have any close friends"*[62]*; "I want friends, but I don't know how to make them"*[63]*.* In early-onset psychosis, the sense of being different is particularly marked, and may be reinforced in a vicious circle by the decline of school performance: *"In the first grade, I was in the top reading group... by the third grade I was in the bottom reading group"*[63]. These negative experiences may lead the individual to abandon school: *"I hated going to school and made up many excuses to stay home"*[64]*.*

In other cases, this sense of being different from others can intensify and trigger an abnormal perception that the world is centred on the individual *("If I'm in crowds of people, especially if I don't know them, I'll sort of feel like people could be talking about me, people might be about to come up to me"*[57]*),* or prompt delusional fears (*"I felt unsafe. I felt like someone was going to kill me"*[60]*).* Adolescents may prefer not to share these feelings with others because they fear rejection: *"Don't bother trying to explain to my family or friends, I just keep it to myself... they're gonna think you're going mad"*[61]*.*

A common related experience is perceived stigma (*"if I told someone that I have a risk of developing psychosis and perceive strange things, he would be disturbed and treat me differently"*[65]), exacerbating social withdrawal and isolation (*"After I got back from the hospital, I really couldn't get along with anyone... I like to play by myself best. I make up stories and*

fantasies"[63]*).*

The inner subjective experience of attention-deficit/hyperactivity disorder

Perceiving one's neurodiversity

Adolescents with ADHD may perceive it as a part of their personality present from birth[66-68]: *"Some people mistakenly see it as a condition or a disease or something. It's rather* a *trait that makes people neurologically different*"[69]. It may be felt as a constitutive element ("*If I didn't have ADHD, I don't think I'd be me*"[67]), or as a complementary but separate part ("*Part of me is because of my ADHD, that I'm the way I am, but other than that I definitely have my own personality*"[70]).

Some of these adolescents do not experience their neurodiversity as an impairing condition ("*I just lead a normal life*"[67]), identifying benefits such as having more energy, less need for sleep, and being more outgoing in social situations *("We are always the life of the party… we're cool; we know how to have fun"*[71]).

However, others may perceive their neurodiversity as a parallel dysfunctional version of themselves, which is difficult to integrate and accept (*"I get angry because my ADHD starts to kick in. If it's a really bad day, you see the angry [side] of me"*[66]), leading to "*outbursts of anger sometimes"*[66]*.* Some adolescents may rather conceptualize ADHD as a disorder that occurred to them[66-68], particularly when they notice the significant improvements associated with medical treatment: *"[Tablets] make me a bit good*"[66].

Feeling a lack of control

Adolescents may sometimes experience ADHD as a fluctuating condition[66,67], whereby subtle environmental triggers amplify a feeling of lack of control, and impaired concentration and attention[66]: "*When I am forced to stay still… it gives a build-up in my stomach, and it almost makes me feel like screaming*"[72]. More frequently, their experience of the disorder is completely unpredictable, and they report being "*on a roller coaster*"[72]. Consequently, they frequently experience a lack of control over "*the way [their] brain works*"[67].

Some adolescents may be aware of their inability to control their disorder. Consequently they strongly feel that their dysfunctional behaviors are "*not actually [their] fault*"[66,68], regretting other people's judgement that their behavior is deliberately planned[72]. Given this lack of control and difficulty in communicating it to others, adolescents may actually perceive the ADHD label as *"an easier way to explain*" their condition to other people[70].

The lack of control may also generate the feeling of being left behind: "*I wish people*

understood, I'm not stupid... I'm not as fast as you"[72]. Moreover, a typical experience in adolescents with ADHD is the need for ongoing help in controlling, organizing and planning their own lives and *"keeping things together"*[71].

The inner subjective experience of autism spectrum disorders

Feeling neurodivergent in a puzzling word

Adolescents with autism spectrum disorders typically feel very different from their peers: "*It is like... American people write back and forth, and Chinese [people] write up and down*"[73]. Sometimes they explain their neurodiversity in terms of a biological condition: "*Just the paths of how things transmit in a neuro-typical brain and an autistic brain*"[73]. In other cases, they may need to label their condition to understand it fully: *"I'd rather be different and have a reason for it than not be different"*[74].

However, profound interindividual differences exist[75]. Some of them do not accept their neurodiversity ("*I hate myself who cannot do well like others"*[76]); others eventually accept it and would not like to change "*because it's the reason why I am who I am*"[74], and they "*like being different*"[74] and are "*proud*" of it[75].

Neurodiversity makes the lived world of adolescents with autistic spectrum disorders an extremely challenging place, particularly when confronted with the neurotypical world ("*This world is still a puzzle to me, like how people act and how rules are*"[73]; "*I'm working my brain harder than anyone else"*[76]). They may feel their mind "*moving into chaos, like a messy office*"[77].

Their inability to understand the surrounding world may also lead to pessimism and depression: "*[Autism] can cause problems in your life that you may never be able to fix"*[78]*,* where *"the negatives outweigh the positives"*[78]. Their puzzlement may be amplified by their sensory alterations, which can alter even positive perceptions of the surrounding world ("*[The sunshine] is too bright*. *When the weather is fine, it's painful for me; it's like I can't stand it anymore"*[76]), and trigger vicious circles of feeling uncomfortable and detached from reality *("if a baby really upsets me via crying I will go outside and I will start noticing that my clothes are annoying me. So, I will start itching and scratching, and it gets really annoying. And then I'll start sweating, and then that annoys me. And it just all triggers everything*"[77]).

For this reason, they rather enjoy the calming effect of structured routines and minimal changes with reduced sensory stimulation: "*I just don't like rushing about or like, people, like springing surprises on me. I live life at my own pace"*[77].

Longing for human warmth and connections

Several adolescents with autism feel that "*loneliness in itself isn't great"*[73]*.* Rather*,* they long for few and warm connections: "*I do prefer having fewer people in my environment.... I'd rather have a few close friends rather than just more friends"*[73]*.* Nevertheless, social relationships are simultaneously experienced as overwhelming: "*After a while, I find people a bit draining*"[75], because of difficulties reading, interpreting and understanding others' emotions[75]. It may be easier for them to interact with peers similarly affected by autism: "*They all have... their special way of fitting into reality, just like me*"[77].

In general, they worry about losing social relationships, "*messing things up with people*"[77], experiencing rejection and stigma, and feeling "*humiliated or embarrassed*" in social situations[77]. These experiences are particularly pronounced when they are required to show some emotional closeness or support, which they are unable to deliver: "*If someone is really upset… and they're asking me to help make them stop crying and I don't know how and… I'll just say, I'm sorry, I can't, and then I have to walk away, and of course I feel terrible"*[77].

The inner subjective experience of anxiety disorders

Experiencing the tsunami of an anxious body

Anxiety is described by several adolescents as an experience of physical oppression, of drowning in intense bodily emotions. Among the various metaphors used, some emphasize the bodily feeling of carrying a burden, such as having *"a heavy backpack"*[79] or *"a black sludge"*[79]. Others instead describe an experience of suffocation (*"You know how like you're underwater and your lungs start to get tight"*[79]; *"You can't breathe properly"*[81]), or physical pain (*"Anxiety hurts; well, for me it hurts physically"*[80]).

They typically perceive anxiety as *"an uncontrollable force"*[82], *" a big scary monster"*[83], or *"a malevolent tsunami that has engulfed my soul"*[82]. They may find themselves at the mercy of these intense and overwhelming bodily emotions, with no way out: *"You feel like you can't get out"*[81]. During episodes of intense acute anxiety (e.g., panic attacks), the experience of suffocation is often accompanied by an imminent need to escape the situation: *"The only thing that you're trying to think is you have to get out of here, you have to run... you have to go somewhere else"*[81].

Overall, adolescents with anxiety disorders typically feel stuck in their bodies: *"Everyone else's life is like fleeting by, and you're just sort of stuck in your own body"*[82].

Losing control of the anxious mind

Adolescents with anxiety disorders often experience a lack of control of their minds, sometimes described as a sense of inner conflict: *"It feels like a war against yourself"*[83]. For example, in cases of generalized anxiety, anything can produce an intense worry, and making decisions becomes an insurmountable nightmare[79], leading to a sense of not being able to live as anyone else: "*You kind of feel like you're not living the way that everyone around you is"*[83].

In the case of a panic attack, adolescents may describe the perception of subtle or sharp bodily sensations that set off an alarm in their mind (*"Your mind goes into like... the sirens on an ambulance... it goes into an emergency and it's thinking well there's a danger"*[81]) and then spread to the whole body (*"It normally starts in your fingertips and your toes go all really tingly and then like it just starts spreading up your legs"*[81]).

Living in a shrinking and unpredictable box

Adolescents living with anxiety disorders may also dread the world as a shrinking and unpredictable box. They typically describe a general sense of claustrophobia and the feeling of being surrounded by worries: *"It is like living in a box, and the box keeps on going smaller and smaller every single day"*[79].

Because of the sudden nature of their anxious states, they live on constant alert, unable to predict when anxiety will take over. Consequently, they may feel different from their peers (*"'like a bit of a weirdo"*[82]), and are convinced that others cannot understand their experience (*"obviously they won't understand"*[81]). At the same time, the attention of others may amplify their feelings of shame: *"It just brings attention to you, and you don't want attention"*[81].

For this reason, adolescents often hide their anxiety symptoms from others. Failure to do so may further increase their lack of control: *"While you're trying to manage a panic attack, you're also trying to look like you're not having one because you don't want people's judgement, and even afterwards you're embarrassed because everyone just saw you freak out"*[81].

The inner subjective experience of eating disorders

Controlling food to control oneself

Adolescents with eating disorders often report feeling overwhelmed by intense and disturbing emotions that they struggle to control. This experience encompasses many aspects

of their lives: *"I feel that different areas of my life are out of control, and I'm not happy about other areas of my life, and so I look for another way to feel in control, to feel happiness"*[84]. They typically control their food intake and weight as a means to regain a sense of agency over their lives (*"One way you can guarantee control is through food, through weight, through exercise"*[84]) and to silence their inner feelings (*"When I experience a violent and uncontrollable whirlpool of fear and anger, I open the fridge and consume everything I find... the feeling of my stomach bursting brings a sense of relaxation"*, *personal communication)*.

Their dysfunctional control of food is needed to avoid unknown or overwhelming feelings, bringing a sense of security in their lives: *"This is safe because it's familiar, I know how I feel, there are no emotions I don't know"*[85]. However, controlling food often isolates adolescents from the rest of the lived world, triggering feelings of detachment from reality: *"You feel like you're not in the loop... yeah you feel like you're missing out... coz life's going on without you"*[86].

Desperately searching for an idealized identity

Adolescents with eating disorders often strive for an idealized image of themselves, originating from deep feelings of inadequacy. Even small details are scrutinized as they strive for an unattainable and unrealistic ideal and desperately attempt to recover their identity: *"I wish I had her body"*; *"Look at her legs, I wish mine were like that" (personal communication)*. Their sense of inadequacy is intensely expressed through a constant search for recognition and a need to define themselves as if their identity composition was a never-ending task.

This experience is so pervasive that they can even identify themselves with their eating disorder to be somebody or to establish a sense of identity: *"At first, I was completely taken over by the eating disorder because I was unaware of it"*[87]. In other cases, their disorder can be perceived as an external or inauthentic aspect of their identity, "personified" as an inner "voice": *"If I'm eating, it's like [hearing a voice saying]: 'should you really be doing that?' and 'don't do that, you're going to have to make yourself sick'"*[85].

The relationship between the self and the eating disorder dynamically changes over time: *"It's an inauthentic part because it's not me... but over time, it has gotten more closely connected to me"*[87].

The inner subjective experience of externalizing disorders

Feeling like a bottle full of rage

Adolescents with externalizing disorders typically experience very intense anger, which they are not able to understand, and which overtakes any other emotions: *"When I'm getting*

angry... it all happens fast... I was very much out of control. I got angry very quickly and very badly"[88]. Their outbursts and lack of control dominate their lives, to the point that they are frightened of their own behavior: *"I go mad. I've scared myself. My emotional state is wonky"*[88].

This lack of self-regulation is frequently experienced as an impulsive behavior, hindering their ability to consider negative consequences: "*I'm always quick to take actions without considering the consequences"*[89].

Adolescents with externalizing disorders may struggle to tolerate frustration, further fuelling their anger: "*When things don't turn out my way, I do whatever I want"*[90]*.* They may also feel vulnerable to criticism and advice, leading to frequent arguments and confrontations: *"When my friend advised me not to do bad things, I did not listen to him, and then we started to argue"*[91].

Feeling misunderstood and rejected

Adolescents with externalizing disorders often feel misunderstood and pressured by adults. This amplifies their sense of frustration and intensifies their anger, which may be violently expressed in out-of-control acts: *"[My mother] is always saying terrible things and that everything is my fault… I don't like that. They have to understand that you have problems"*[92].

They often report poor relationships with their parents, who may consider them incapable, further triggering their outbursts: "*My father thinks I cannot do anything; when I wanted to repair a pot or lighter, he grabbed them and said give it to me you cannot do it, so I smashed them"*[91]*.*

The absence of familial understanding is often perceived as an insurmountable rejection, fostering emotions that are too intense and complex to handle outside verbal or physical outbursts and deviant behaviors: "*I'm stressed. I sometimes don't go home but stay at my friend's place taking drugs just to ease the stress. I go through this at home because my parents are very strict and harsh to me"*[89]*.*

The inner subjective experience of self-harm behaviors

Transforming psychic into physical pain to control it

Adolescents who manifest self-harm behaviors often describe an urge to make psychic pain more tolerable, turning it into physical pain: *"It takes my focus away from another kind of pain, like the pain inside, like the way I feel. So, it overtakes that, so I kind of forget about the other sort of pain"*[93]. This is associated with the impression of better controlling affective states and modulating them through physical pain[94].

In other cases, they feel the need to overcome an indefinite psychic numbness and to perceive pain to feel alive: *"I am doing it to feel pain, to remind myself that I can still feel pain because at the moment I feel nothing. I feel numb, and it's my only way that I am reminding myself that I am still here, that I am still alive, by seeing the blood"*[93].

Self-harm may be perceived as having a protective purpose against even more serious behaviors (*"I think it's a way of taking care of yourself, because I feel in a way like self-harm stops you thinking about suicide as well"*[93]) or as bringing order to uncontrollable mental chaos ("*Self-harm collects those feelings. Then many painful things happen, and you can't understand... you just feel so much at once, it's like a storm – it's much easier to collect it all in one physical pain"*[95]).

Therefore, self-harm behaviors may be accompanied by an intense sense of relief: *"My body knows; I have that craving, it's like it will not stop until like I hurt myself"*[93]; *"It would be a relief from basically everything that was going on; the stress"*[94].

Self-harm behaviors may also become one of the few stable experiences in the lives of adolescents, while everything else is constantly changing, and are therefore associated with the confidence of having something they can count on: *"I did it when I couldn't do anything else. It was something to rely on"*[95].

However, in other cases, self-harm may actually index a desire for self-punishment: *"I become sad and feel a pressure to harm myself. I must do it because I have been bad, in a way"*[95]; *"I say it to myself, that I am a disappointment and need to be punished for that, so 'for this mistake you need to be punished' and I accept that"*[96].

Shouting for help without words

Self-harming behaviors may also represent an implicit cry for help in the context of expressive and communication difficulties: *"When I did it for attention, it was because I did not know how else to get help"*[97]. These behaviors are aimed at securing support: *"People should be interested in what's behind self-harm. I use self-harm to get someone worried"*[95].

However, self-harm is often conducted in secret due to fears of rejection or negative judgement from others: *"People who self-harm often go to great lengths to hide the damage. It's personal, and they don't want to be judged for it"*[97]. As such, several adolescents who self-harm do not accept the idea that it may represent an "attention-seeking" strategy, reiterating the authentic nature of their mental suffering: *"People who self-harm are expressing deep pain! The pain is real!"*[97].

THE LIVED EXPERIENCE OF ADOLESCENTS WITH MENTAL DISORDERS IN THE WIDER SOCIETY

This section explores the lived experience of adolescents with a mental disorder in the wider society, looking at three overarching narrative themes of this interpersonal dimension: a) the experience in the family, b) the experience in the school and among peers, and c) the experience in the social and cultural context. For a) and c), we also cover the parents' perspective.

The experience in the family

Suffering a painful lack of understanding

The subjective suffering of adolescents is enhanced by the parents' lack of understanding or acknowledgement of their mental disorder[98,99]: *"The first thing they [the parents] felt was like 'this is not a real illness', 'you should not be telling us about this'... I felt I was being put under the rug*" *(personal communication)*. They may not feel accepted for who they are with the existing disorder, struggling to meet their parent's expectations: *"My dad says things like 'I didn't raise you to be sad, I raised you to be strong because this is something from a weak person'"*[51]. Sometimes they need to resort to drastic measures to convince their parents to recognize and accept their mental suffering: "*I literally had to take myself to a mental hospital for my mother to listen*" *(personal communication)*.

As the identity of adolescents is particularly fragile, the full recognition of their mental disorder and associated needs by their immediate caretaker is essential[36,42,100]: "*I guess it would be nice if they'd console me, but all they said was 'take it easy*'"[101]. Downplaying the severity of the mental disorder does not help adolescents make sense of their suffering, adding to their confusion and desperation: *"I cried, and I told my mum that I'm not feeling well and I want to go and see a psychologist. And then she said that I don't have to worry and that I'm not depressed"*[102]. This amplifies inner perceptions of loneliness, embarrassment and shame: *"I did tell my parents that I was hearing voices, and they kept it hidden from school*" *(personal communication)*.

In some instances, adolescents may paradoxically react to this lack of understanding by hiding their mental suffering, in a desperate attempt to protect their unsupportive parents: *"I just did not want to tell [my parents] because I did not want them to worry or to feel guilty or something like that"*[53].

On the other side, parents who acknowledge the presence and severity of a mental disorder but aggressively insist on therapeutic approaches may prompt dehumanization

feelings: "*My parents keep saying this term that I have to be 'fixed' or 'cured', and I hate it because like it makes me feel like I'm not a person, as if I'm almost like an object or a disease*"[103].

Feeling restored by an emotionally supportive family

For many other adolescents, the familial environment may actually represent one of the most supportive settings. The emotional intimacy of a supportive family nurtures vital and positive coping strategies: "*Now I think she [the mother] has begun to understand. It is as if we can walk straight together. I do not feel guilty anymore, and it is easier to be honest when I struggle*"[104].

The feeling of being supported by the family consolidates a warm sense of security that helps adolescents engage with the challenges of living with a mental disorder: "*Whenever I have a problem, they [parents] give me a hand and help me succeed*"[90]. Within a supportive family, they feel able to talk freely and openly about their deepest experiences, thus alleviating their acute suffering and restoring a sense of normality: *"I don't always give in; I turn to my mum; she's like one of my biggest supporters in my life. We're very, very close… I'll go and sit with her and talk to her, and it slowly goes away*"[93].

The parents' perspective

Parents typically experience dramatic changes in their relationship with their unwell kids: "*Where is my daughter gone, because that's not her*"[105]. The onset of a mental disorder forces the parents to redefine their image of their kids[106], "*mourning the child who would have developed normally*"[107].

Parents may express an increasing difficulty in connecting with their kid's inner world, because of severe communication barriers: "*He doesn't talk to me*"[108]; "*He no longer wants to participate in any family things*"[105]. Accordingly, they experience a marked sense of loss[105].

Parents must "*learn how to parent in a completely different way*"[109,110], often negotiating a new balance between maternal and paternal roles[107] and establishing new parental rules[111]. This may include "*letting [the child] get away with things that I wouldn't have before probably*"[108]. It's a hard and unpredictable process of trial and error, frequently leading to frustration and feelings of helplessness: "*I changed the approach and tried to push a bit more and in certain areas, and then that didn't seem to be working and then, I don't know what the best way is*"[105]. Moreover, parents may feel the pressing responsibility to preserve their kids' emotional balance as much as possible[108].

The experience in the school and among peers

Perceiving the school as a magnifier of differences

Adolescents with a mental disorder often perceive the school as a fundamental but precarious environment. When they compare themselves with schoolmates, they feel profoundly different: "*[You] see other people… not being sort of freaked out and anxious or depressed whatever, you feel like 'why can't I be more like that?'*"[112].

Frequently, they feel forced to hide their true feelings from their peers: "*I could not show it to anyone because I never talked to my friends about my feelings*"[53]. This separates them from the surrounding social environment, leading to deep feelings of loneliness and incomprehension: "*You feel quite alone when you're growing up with things like that because there's not really anyone who understands it*"[112].

The vitality and fun that normally characterize the school environment fade away, replaced by feelings of exclusion and defeat: "*Because adolescents are supposed to have fun and hang out with friends at parties, but I kind of never feel like doing anything, and I wish I could enjoy things like before*"[90].

Negative relationships with teachers may further exacerbate the deep experience of loneliness and being different: "*[Teachers] treat me like a cute cat. They treat us like we're not human, like we're less*"[74]. Any teachers' attempt to support the individual can also be experienced as a direct confirmation of their personal ineptitude compared to their peers: "*We are different, that's a fact, but they treat us like we're different. Like we're more different to other people than we actually are*"[74].

Experiencing bullying from peers and teachers

Adolescents with a mental disorder frequently experience severe bullying[113], which further compromises their self-confidence and interpersonal trust: *"They took pleasure in hurting me, in seeing me suffer*"[114]. Because of bullying experiences, they may feel profound shame and embarrassment while at school: "*Me and a bunch of other kids had to go down at lunch to take [Ritalin], and it was kind of embarrassing… people saw me as the kid with ADHD, and they saw it as a bad thing"*[115].

The world of peers becomes a dangerous and unwelcoming place where they must be on guard: *"I'm quite suspicious, at least more than before, always a little apprehensive about who people are, their personality, what they really think*"[114]. The subjective experience of being bullied may be so dramatic that they may feel completely rejected, losing a sense of belonging ("*I felt rejected. No one liked me; none of my teachers liked me*"[90]) and eventually withdrawing

from friendships and social interaction ("*Afraid of my friends sharing what I tell them to other people*", *personal communication*).

At the same time, they still long for vital friendship and social belonging. To overcome this situation, they may resort to a passive acceptance of bullying: "*I wouldn't want to stop being friends with them because I don't have any friends, so I kind of just suffered through it"*[115]. Sometimes, the experience of being bullied is transformed into self-blame, to make sense of the inner confusion and hurt that is elicited by dysfunctional relationships: *"I used to think it was my fault if I was mistreated by friends*"[104]; "*I didn't really try to be friend with anyone because I didn't trust myself to make good friends*"[115].

In other cases, adolescents with a mental disorder may suffer from their teachers' lack of understanding ("*It all comes down to lack of understanding. I felt like teachers did not know how to respond to people experiencing mental disorders", personal communication*), or even bullying (*"One day he [teacher] just told me that I was going to fail and that I was a huge failure and I was never going to amount to anything… in front of the whole class*"[103]).

Experiencing peers as a vital support

For many adolescents with a mental disorder, however, peers may represent an important and positive resource. Feeling accepted by friends is described as destigmatizing, allowing the individual to regain a sense of normality ("*I told them, my close friends. They just said, "So what?" and they just looked at it like a cold, not like a disease"*[116]), and to dissipate feelings of shame and inadequacy (*"They weren't ashamed of it, so I started to not be ashamed of it either*"[116]).

In particular, being with friends who share a mental disorder is perceived as extremely beneficial to overcome the social isolation[117] ("*I'm not the only one going through this", personal communication*), communicate personal experiences ("*My friends and I come together and speak about our experiences", personal communication*), freely express complex emotions ("*We feel liberated; we get all our hatred out, all our anger, it feels good*"[114]), and improve their self-esteem ("*We share a lot of same feelings about things and I'm just able to really be myself*"[115]).

Peers' understanding may also alleviate their subjective suffering: "*When I feel that I am beginning to become anxious in school… then I can tell a friend, 'I do not feel okay at all right now'"*[104].

The experience in the social and cultural context

Feeling inadequate to the social norms and values

Adolescents with a mental disorder may feel inadequate in relation to the norms and values of their sociocultural context. For example, they may feel abnormal and even dangerous because of the beliefs socially attached to mental disorders: "*Like if you have a mental illness, you're not normal, you can't live a normal life… They think that they're going to catch it*"[118].

Others may feel inadequate because they experience their mental disorder as an obstacle to achieving the social standards of a good life: "*I'm wondering a lot about my future, how to manage at school, if I get a good profession and if I reach my dreams instead of leaving them halfway*"[50]. To keep up with external pressures and social expectations, they may adopt a rigid conception of who they should be, silencing their mental health needs: "*As an adolescent, you end up adopting a very narrow view of yourself and the world when academic scores, building a career, and similar external achievements are ranked above mental wellbeing*" *(personal communication)*.

Sometimes, the stress associated with school performance and striving to be socially successful exhausts their already fragile mental reserve: "*I have to be the best in my class. I'm a top athlete – doing sports at the highest level. It's so much pressure and expectations and… I must be ready to go to a party and be together with my friends… it's so much!*"[95].

Feeling stigmatized or supported by social media

Most adolescents with a mental disorder report using social media regularly as a way to interact with their social world: *"[Social media] keep you updated on the day-to-day lives of your friends and celebrities. And popular things that are going on"*[119]. They experience both negative and positive impacts of social media on their mental health.

For example, social media enhance comparisons of their suffering life with the apparently happy and successful accounts of their peers[119,120]: "*One thing that has impacted on my mental health is going on social media when feeling down, and you see all these posts of people living their best life, and you know you are not in that place. I'd wish my life could be like that*" *(personal communication)*.

Another negative experience is the deeply stigmatizing, offensive and insensitive language that they may perceive on social media ("*They will call me crazy*"[51]), particularly if their daily life is exposed: "*Social media are easily accessible. The issue is that you can see it all day, every single day. Think of how many bad experiences and mean comments you'd see*

by scrolling" *(personal communication)*.

A common negative experience related to social media is the pressure to be constantly active online due to fear of "missing out": *"If I didn't have it [social media platform] I just think about all the things that I wouldn't see or know... there's so much pressure to have it and once you get it, you're basically stuck… it feels like you're stuck"*[120]. This is often linked to fears of sharing personal information, losing privacy, and reinforcing negative thoughts[119,120].

However, social media may also be perceived as a supportive resource for restoring some vital social networking and a sense of belonging to a community: "*There are communities of people with mental illness, where people share their experiences… so, on my side, it's been a positive experience*" *(personal communication)*.

Social media may become a way of sharing experiences of being unwell across different communities, thus alleviating the sense of isolation and loneliness: *"It is difficult for me to talk to people, and then, social networks just help me because I'm able to contact certain people that I know will support me in different things, even though they might be far away from me"*[121].

In some cases, social media may actually represent the only positive support received: "*Most of my support system has been from social media*" *(personal communication)*. They may also function as a powerful literacy means, allowing adolescents to get tailored information and empowerment: "*I've learned more about mental health online*" *(personal communication)*.

The parents' perspective

Parents may experience great suffering because of the environmental stigma directed towards their kids: "*That hurt me… when other parents were saying to their child 'don't play with him*"[122]. Parents may feel "*distressed*" by the mental suffering of their kids[108], and at the same time feel helpless[105,106,108] as they do not have "*the right weapons"* to face the mental disorder[123]. Taking care of a kid with a mental disorder is experienced as *"mentally… and physically exhausting*"[105]. Parents frequently perceive themselves as *"alone as no one understands*"[124] and prefer to *"keep all"* to themselves[125,126].

Sometimes, parents report being indirect victims of the bullying experiences suffered by their kids: "*That upsets you as a parent when you know your child is being bullied or criticized*"[122]. They may feel particularly frustrated and guilty because they feel unable to protect their vulnerable kids from being bullied: "*A part of you [is] unable to withstand being with that child*"[122]. At the same time, parents may perceive themselves as a direct target of stigma, being blamed as *"unfit parents*"[122] (''*I always feel like I'm getting judged as a parent… that I'm not doing the right thing, or raising my child the right way*"[122]), or being "*avoided*"[122].

The combination of stigma and bullying experiences may impair their self-esteem and

constantly make them feel judged as bad parents[122]. The bad-parent labelling and stigma may occur not only in the community, but also within the family of origin: "*Close family was saying to me… that I created the problem"*[122].

Whatever the origin, stigma is inevitably perceived as burdensome ("*It made everything harder"*[122]), and parents may end up reducing social contacts ("*I do get asked… by friends, but I try to avoid it, only because I feel I have that stigma that they think I am a bad mum''*[122]). They may feel unwelcome at school, and may withdraw from collaborative and social events: ''*I have opinions, and I want to make a contribution to things [but] I feel like I can't join them because I have a child who is difficult*"[122].

Under these intense pressures, parents may also desperately attempt to *"educate those people"*[122] and *"correct them and their 'ignorance'"*[122], becoming advocates for their kids' needs and, in this way, feeling reassured of being good parents[122]. Moreover, many parents experience an essential supporting role of the family of origin[107], or other families with the same problems, that can help "*to put [the kid's difficulties] in perspective*"[107].

THE LIVED EXPERIENCE OF ADOLESCENTS WITH MENTAL DISORDERS IN RECEIVING MENTAL HEALTH CARE

This section explores the lived experience of receiving mental health care in adolescents with a mental disorder. We describe these subjective experiences through seven overarching narrative themes: a) the experience of being diagnosed with a mental disorder, b) the experience of accessing mental health support, c) the experience of receiving psychopharmacological treatment, d) the experience of receiving psychotherapy, e) the experience of peer support and mental health activism, and f) the subjective experience of recovery. For a) and b), we also cover the parents' perspective.

The experience of receiving a diagnosis of mental disorder

Experiencing a threat to one's identity: surprise, denial, shame and secrecy

For adolescents, receiving a diagnosis of mental disorder is a very sensitive issue during a period in which identity is constantly being defined: *"It [the diagnosis] became the thing that defined me. It was the only thing I saw in myself, and everything was about that"*[127]. They often describe a negative impact on their identity; in particular, a feeling of surprise and disbelief: "*I was surprised and… I think that it made me tense because I had never thought about something like this"*[51]. In several cases, they show a strong rejection and denial: "*No, I can't*

be bipolar. That's just not me. I don't want to be it"[116].

Denial is often accompanied by a desire to be like "normal" young peers: "*I don't want to be bipolar. I want to be normal… I'm sad. Why am I like this? Why did it have to happen to me?"*[116]. An intense feeling of shame often emerges: *"I was ashamed because I don't want to be bipolar. Who does?"*[128]. The intensity of the shame amplifies the uncomfortable feeling of being different: "*I had something [a diagnosis of mental disorder] like something was wrong with me. I was like different. That I was an outcast"*[128]. Shame, in turn, may lead adolescents to conceal their fragile condition: "*I don't like others to know about it. Because it's like none of their business, I just don't want them to know about it"*[116].

Sometimes the denial of the diagnosis leads to a cascade of decisions and behaviors that delay access to mental health care. In this context, the role of health care professionals in adequately and sensitively communicating the diagnosis is of vital importance, as it may otherwise elicit confusion and misunderstanding. For example, many young individuals report a lack of clear information and explanation about the implications of their diagnosis: "*They told me I had schizophrenia… but I didn't know what schizophrenia was; I didn't know that disease"*[106].

Finding a container for personal suffering

In several cases, the diagnosis of a mental disorder is preceded by a long period of difficulties and personal suffering, often tracing back to early childhood. As such, the diagnosis may be welcome as a meaningful container of the presenting problems (*"I took it well because I've always known that there was something different with me", personal communication)*, or as a way to relieve suffering (*"[Getting the diagnosis] was kind of comforting"*[127]).

Acceptance of the diagnosis is facilitated by appropriate and comprehensive communication with health care professionals: "*I got my diagnosis by a psychiatrist. He gave me enough information to understand…, and it was life-changing. It was new information, but he put it in a way that I can understand" (personal communication)*.

The parents' perspective

Parents often experience their kid's diagnosis of mental disorder as "*a shock*"[106], "*an earthquake*"[106], or "*like being punched in the stomach*"[129]. The signs of their kids' difficulties may be "*little strange things*" hard to notice[56]. Sometimes external people (e.g., school personnel) are the first to draw parents' attention to these early problems[108]. In other instances, the parents "*never dreamed it was a medical condition*"[56], attributing the early anomalies to teenage behavior[108]: "*an extension of his personality, just a little bit sort of exaggerated"*[56].

In other cases, parents recognize the problems and feel "*prepared for… the diagnosis*"[129], but wait a long time before turning to professionals: *"You put up with it for a long time, and then there's a point when you break… when you refer yourself to mental health services; you waited till the last minute"*[130]. The diagnosis may be perceived as a relief[129], allowing the parent to make sense of things and "*have a reason for everything*"[109]. Parents may feel comforted by the fact that the professionals' understanding of their kid "*matched what [they] saw*" at home[129], and feel that the information received along with the diagnosis "*has been helpful to explain it to the rest of the family because trying to get it into words yourself and getting them to understand… that's the hardest part*"[129].

Parents may desperately look for external causal factors underlying the diagnosis: "*the dictates of today's society*"[123], "*the social context"*[123], "*our education system*"[105], and the media ("*Television…*, *social media… lead them to see themselves different from the world*"[123]). Alternatively, parents may look for internal causes, either organic or psychological: "*a chemical imbalance*"[123], a hormonal teenage phase[123], "*character*"[123], "*a loss of self-confidence"*[105]*.*

Given the uncertain causal pathways of most mental disorders, parents typically struggle to identify an established cause, and might end up blaming themselves, considering the disorder genetic[123,131] or a consequence of exposure to their behavior[105,108]: "*Is it something I did… when I was pregnant*, *or during the younger years*?"; "*What could I have done to prevent it*?"[122]. A sense of guilt often accompanies the parents' elaboration of the diagnosis ("*I will always blame myself about that*"[122]), leading them to question their parenthood skills[122,132] ("*Maybe because we didn't understand how to raise a child well*"[125]).

Because of these concerns, parents may hide or downplay the diagnosis of mental disorder in their kids: *"He can access services… and people… can make accommodations for him, but… is he going to be treated differently?"*[74]. They may decide to hide it because "*the word mental in our community is very unacceptable*"[131] and to prevent their kids from being "*blackmarked*" at school[74], or even enrolled in special classes for disabled individuals[107,133].

The experience of accessing mental health support

Overcoming emotional barriers

The difficulty in accepting the diagnosis of a mental disorder frequently represents the first barrier to receiving help: *"I didn't accept what I had, and I didn't want any medicine"*[128]. Furthermore, many adolescents, once they have recognized their mental fragility, describe a variety of emotional barriers hindering the start of the treatment process.

The main help-seeking difficulty is related to embarrassment and shame: "*Sometimes I get embarrassed to talk to someone else"*[54]. For some adolescents, sharing their suffering is

like adding to it, because it increases their sense of fragility: "*To share… is difficult because I feel vulnerable, and… kind of naked… feel stupid and embarrassed*"[95].

Some young people report a range of fears, including fear of violation of privacy (*"If people hear things and see things, then they'll discuss it with someone and eventually it will spread"*[134]), of not being understood ("*I don't want people to be like, oh, she wants attention"*[135]), or of being judged ("*I was scared of telling how I felt… because I thought they will judge me"*[135]).

Overcoming structural barriers

Adolescents may also experience access to mental health care as an obstacle race, because of a slow system with long waiting lists (*"I felt that you had to do something to get in here fairly quickly because there's such a demand for these services. Six months waiting list otherwise"*[118]), or an overly complicated care pathway that is difficult to navigate ("*Not knowing what services there are for certain things. It's just you go to one place and then oh no, we don't cover that here, you know, go to this place"*[134]).

Also, access to mental health care is not easily affordable for adolescents in many deprived areas: "*In Kenya, accessing mental health services is quite expensive, so there was that issue of 'am I going to get money, am I going to be able to see a psychiatrist'?*" *(personal communication)*.

Feeling welcome, listened to and encouraged

For many other adolescents, receiving mental health care is a highly positive experience: "*I think here it's great. It's probably the best care I've ever had since my illness started. If I've got a problem, I just phone them and tell them, and they are out instantly. It is brilliant*"[136]. They feel welcome and know that they have a point of reference. This allows them to manage their negative emotions and symptoms better.

Easy access to mental health care enables them to experience that they are not a burden and that they really matter: *"Someone is taking care of me... maybe I am important after all"*[53]. In this context, the relationship with health care professionals may help them to feel that they are not being judged ("*He's easy to talk to, he's not one of those judgy people that I don't like*"[134]); that they are listened to ("*That time the doctor didn't give up but kept on seeing me every day of the week to find a solution. To understand me. He didn't just stick to the protocol for my treatment*"[137]); and that they are encouraged ("*It's nice that somebody says you're doing a good job – it makes you feel a little bit happier"*[129]).

Feeling lost and scared while transitioning from adolescence into adulthood

Adolescents transitioning into adulthood frequently feel lost and alone because of the two-tier split between children and adult mental health systems. A constant experience is the lack of information. Many do not know what to do, and feel lost and frightened: *"I wish someone had told me way sooner, like much more in advance, about what would happen... as opposed to being in the dark until then"*[138].

The lack of information may trigger uncertainty and fear of what would happen: *"I am feeling a lot better, but what happens in a few months if I am not? What can I do? Because I don't know what I should do now if I need someone"*[138]*; "Oh God, what's going to happen?*"[139].

In other cases, adolescents may experience profound feelings of ambivalence towards health care: "*I'm not sure how I feel. I don't really know about [the referral] enough to think much about it*"[138]. Moreover, lack of continuity in care may hinder the development of close and trusting helping relationships with professionals: *"You don't want to have to re-live… Re-living it every time brings back the pain… The fact that there's more than one person that knows about it is even scarier… And, then to have – you know – two or three new counsellors over a few years ends up destroying you"*[134].

The parents' perspective

Parents may also report emotional or structural barriers and negative experiences of mental health care access. They frequently feel that their concerns are dismissed without proper evaluation: *"[Psychiatrist believed that our daughter is] just angry and rebellious at home and not a serious threat to herself*"[140]. They may fear criticism about their parenting skills and express concern that their kids may be taken away from them: *"I was afraid they were going to call the mental health services and [demonstrate that]... I'm not able to take care of my son"*[140]*.* They may feel unaccepted: *"It was like the doctor just didn't seem to hear what I was saying"*[108]*.* They may perceive a lack of information and support: *"We were so frustrated… most of them said just go to an emergency room… that's so traumatizing"*[141].

These negative experiences may be amplified by structural barriers in accessing mental health care services: "*The waiting lists are so long, because there isn't enough staff and the staff are restricted due to funding*"[126]. Complex pathways to care may also be perceived as substantial obstacles: "*It's a lot of paperwork; there's a lot of stuff a person has [to do]… it was a challenge*"[126].

However, there are also positive experiences of accessing mental health care. Some parents feel welcome and fully supported*: "It was nice that someone saw his problems and took him seriously"*[130]*.* They may also report an important reduction in isolation as a result of

the positive and reassuring experiences with mental health care: *"[The doctor] said it's okay, we've seen this before, you're not on your own, there is help. It was really reassuring"*[130].

The experience of receiving psychopharmacological treatment

Experiencing shame and fear of being labelled or different

The experience of receiving medication among adolescents with a mental disorder is highly variable. A range of emotions and feelings may arise, hindering drug treatment to the point of outright rejection: "*I don't want to take them at all*"[142]. Shame is the emotion that most contributes to rejection and poor compliance: "*I mean, it's really difficult... It totally can embarrass you if you have to take it in front of other people"*[116]. In addition to shame, there is also the fear of being judged and labelled, and of what others might say: "*Crazy. Psycho. Nuts. Cause that's what I heard from everyone else"*[116].

These negative emotions are reinforced by the perception of being different when pharmacological treatments are prescribed: "*I give up feeling normal by taking medication. I don't feel like a normal person*"[116]. Feeling different increases the sense of fragility and social isolation, while they desire to be "normal" like everyone else[116,128,143].

Improving social relationships and restoring emotions

On the other hand, adolescents may also describe positive experiences related to psychopharmacological treatment. When they accept medication, they may notice its positive effects on their relationships with family and friends: "*I'm happier. I used to spend all the time in my room, and now I'm upstairs with my family more. I spend more time with them"*[144]. Psychopharmacological agents may also be experienced as essential for restoring their social performance at school: *"In the past... I could not stay in the classroom. I could not even attend a virtual class. I did not want my name to appear there, and I was so anxious. The medicine has been very good for me"*[143].

There may also be a perception that medication improves their emotional reactions: *"I started taking medicine, and I would see a totally different person when I took the medicine. I mean, I wasn't so angry, and I was able to have a good time and laugh and just have fun*"[144]. Adolescents may also report that antipsychotics help to restore their sense of reality and normality: *"It is good because it definitely muted any kind of weirdness"*[145].

The experience of receiving psychotherapy

Experiencing a negative relationship and feeling not understood

Adolescents' experience of psychotherapy is greatly shaped by their relationship with the therapist. Some of them report negative experiences linked to not feeling understood: "*They [doctors] don't dig deep into the problems, what's really the matter with you, they don't do that at all... That's terrible, isn't it? I just felt they didn't really try to understand*"[136]. In some cases, suffering is experienced as being minimized by the therapists: "*[The doctor] thinks my illness is childish and just a way of getting attention, so he treats me like a child*"[136].

Sometimes, adolescents do not feel encouraged to talk about their problems and struggles, and feel that they are simply stuffed with medication: "*[Doctors] just give you medicine all the time whenever you aren't feeling good... they don't try and make you talk enough*"[136].

Feeling closeness and safety

On the other hand, adolescents may also describe positive experiences linked to feelings of closeness and safety with the therapist: *"She was affectionate, she was trustworthy, I would tell her something, and I was sure she would not tell anyone*"[146]. These experiences are especially related to instances in which the psychotherapy is perceived as personalized: "*What he did [the therapist] was something I needed, it surprised me, I thought he was just going to listen… But in reality, he gave me alternatives, things that would not occur to me"*[146].

Adolescents may particularly appreciate psychotherapy when it targets outcomes other than the presenting symptoms, restoring a deep feeling of being human ("*Sometimes you get scared of your feelings… However, when someone else is sitting there and telling you why she would be angry if she experienced that same situation... It is good to know that I am only human"*[104]) and of being a valuable person ("*The psychologist treats me as a person*"[136]).

The experience of peer support and mental health activism

Healing through healing

Adolescents feel that sharing their experiences is a way to help each other and to give new meaning to their fragile condition, overcoming stigma. Many of them describe how helping others affected by similar experiences makes them feel better and promotes a sense of belonging, by reducing feelings of being alone and abandoned: "*Peer support helps young*

people feel belonging, express themselves and improve self-help skills" (personal communication). This shared experience activates a two-way movement of benefits, which is perceived as rewarding: "*I am currently a volunteer at mental health research. It has helped me a lot in interacting with different youths facing different mental health problems, and I am happy I am able to share my experience" (personal communication)*.

Voluntary work is viewed as a highly positive experience. Helping others allows adolescents to feel useful and valued. By spending time in service to others, they can bring structure to their lives and daily routines: "*It helps you get out of bed and also do something productive, so it helps with depression and stuff because you're actually doing something and seeing other people"*[147]. It is also an opportunity to find motivation to go on and push themselves to do something new: "*I'm not the type of person who would just have a conversation with you... I had to talk when I volunteered. I had to push myself out there*"[147].

The subjective experience of achieving recovery

Floating between self-acceptance and the looming shadow of relapse

Recovery may have different meanings for adolescents with a mental disorder. Many of them describe it in terms of learning to accept themselves: *"For me, recovery meant acceptance; accepting everything that I went through, that it is not my fault, being able to go on with my life and being productive, being able to see the sunshine. Being able to be confident and smile again" (personal communication)*; "*Recovery is accepting the things I can't change, and changing the things I can" (personal communication).*

Recovery may also mean separating their identity from the diagnostic label: *"[The diagnosis does not] define me anymore and I have skills that I can use to be the best version of myself"*[127]*.* It may also be described in terms of regaining autonomy and leading a more fulfilling life ("*Recovery to me means being able to live a productive and fulfilling life… socially, being able to interact with my friends, being able to come to work", personal communication)*, and rebuilding a sense of social connectedness (*"I rebuilt another social network and I was doing fine emotionally"*[127]*).*

On the other hand, the recovery experience may fluctuate, including negative emotions, especially the looming shadow and fear of relapse: *"I fear I'm back to square one"*[148]; *"[I fear] that things will deteriorate and I'll end up back here. I'd see that as defeat because you've battled for a long time to get out and then you just end up back; it's like you're starting back from square one"*[148].

DISCUSSION

This study describes the lived experience of adolescents with a mental disorder, covering both their subjective suffering and their positive accounts. The co-designing, co-conducting and co-writing approach adopted by the study has already been detailed in previous publications[21,22]. This approach allows personal experiences of mental disorders to emerge, minimizing exclusion and misrepresentation of the affected persons' perspectives[149]. In this study, we also integrated the parents' and carers' narratives, as applicable.

The study does not address any specific research hypothesis or whether the described experiences adequately represent the relevant mental disorders. We only highlight core (paradigmatic) ways by which adolescents experience their disorder subjectively and within the social context, and their experience of receiving mental health care. We identify common themes and sub-themes holding several implications at clinical, research and societal levels.

A first group of severe mental disorders, i.e. mood and psychotic disorders, are often characterized by experiences of change of one's personal identity, along with overwhelmingly intense emotions, and a distorted perception of the world. Adolescents typically find it difficult to communicate these experiences and, rather than seeking help, tend to conceal them, leading to delayed recognition of their problems. Converging evidence indicates that delayed recognition of mental health difficulties in young people with emerging mood and psychotic disorders is a key driver of missed preventive and early intervention opportunities and, therefore, of poor outcomes in their adulthood[150-153]. We hope that adolescents will recognize their experiences of mood and psychotic disorders in the words spoken by our experts by experience and, by doing so, will be more inclined to seek help and facilitate an early recognition.

Beyond help-seeking behaviors, early recognition of emerging mood and psychotic disorders in adolescents is also limited by the use of suboptimal assessment measures that risk over-pathologizing potentially transient and clinically irrelevant experiences[154,155]. The core experiences of mood and psychotic disorders identified in this study could, therefore, represent innovative research material, which contributes to tailoring the next generation of assessment instruments for emerging mental disorders in adolescents.

A second group of disorders in adolescents (including ADHD and autism spectrum disorders) are largely characterized by experiences revolving around one's neurodiversity. This may be perceived and dealt with in a variety of ways[156], which have been very rarely explored up to now. We think that giving voice to these young people whose minds work differently from others corrects an epistemic injustice[149], while at the same time opening a new research avenue that can potentially expand our perspective of their conditions. Indeed, neurodivergent young people are often unfairly harmed as a social minority[157]: their story is

frequently disvalued, silenced, ignored, distorted or misrepresented[158].

A third group of mental disorders in adolescents share, in different ways, feelings of lack of self-control and high impulsivity, described as experiencing the tsunami of an anxious body, losing control of one's anxious mind, and living in a shrinking and unpredictable box (anxiety disorders); controlling food to control oneself, and desperately searching for an idealized identity (eating disorders); feeling like a bottle full of rage, and feeling misunderstood and rejected (externalizing disorders). These experiences are characterized by a dynamic tension between adolescents' movement toward increased autonomy and their vulnerability to engage in impulsive and out-of-control behavior[159]. This contrast is neurobiologically associated with brain changes in the reward and self-regulating brain networks, that become unbalanced due to pubertal maturation. While pubertal hormones sensitize the brain's reward system, motivating the adolescent toward engaging in more sensation-seeking behaviors, the brain's capacity for self-regulation and inhibitory control matures more gradually over the course of early adulthood[160]. This neurobiological imbalance can also account for the frequent self-harm behaviors reported by adolescents, often described as the need to transform psychic into physical pain to control it, or shouting for help without words.

The latter call for help highlights the importance of exploring the lived experience of adolescents with a mental disorder in the wider society, another neglected research area up to now. Our adolescents described experiences such as suffering a painful lack of understanding within the family; perceiving the school as a magnifier of differences, and experiencing bullying from peers and teachers; feeling inadequate to the social norms and values, and feeling stigmatized by social media. However, they also reported experiences of feeling emotionally restored and supported by the family, perceiving peers as vital support, and feeling supported by social media, indexing the multifaceted and complex nature of each journey.

A dysfunctional parent-child interaction, along with genetic predisposition, has been historically identified as a key mechanism for the familial transmission of mental disorders[161], highlighting that the mental health of adolescents is to a large extent a "family affair"[161,162]. On the other hand, bullying from peers and teachers is a key driver of victimization and perceived stigma[163,164], which was described by our experts by experience as "*having worse consequences than the mental disorders themselves*"[165]. Overall, early traumatic experiences in adolescents emerge as the most robust transdiagnostic risk factor for the development of mental disorders later in adulthood[7,166]. We hope that our findings may thus inform educational approaches; for example, those focusing on parent or teacher training and literacy to improve youth's mental health[167,168], or anti-bullying interventions in the schools[113].

The lived experience of receiving mental health care in adolescents was also highly variable. Receiving a diagnosis of a mental disorder was experienced either as a threat to their

identity – with feelings of surprise, denial, shame and secrecy – or as a useful container for their personal suffering. Accessing mental health support involved overcoming emotional and structural barriers, with frequent feelings of being lost and scared, particularly while transitioning from adolescence into young adulthood. We hope that the latter experience may prompt stakeholders and policy makers to prioritize creating youth-friendly mental health services[169-171]. These services may prevent many adolescents from falling into the cracks of the two-tier health care system split[9].

With respect to the experience of receiving specific treatments, adolescents variably described feelings of shame and fear of being labelled or different, or improved social relationships and restored emotions (when receiving psychopharmacological treatment), and of suffering negative relationships and feeling not understood, or feeling closeness and safety (when receiving psychotherapy). The nature of these experiences was largely influenced by the health care professionals' communication skills and attitudes. Peer support and mental health activism were more consistently associated with positive experiences of healing through healing, restoring networks and a sense of purpose. The adolescents' journey through mental disorders was overall highly variable, and their ultimate experience of recovery was characterized by an unpredictable floating between self-acceptance and the looming shadow of relapse.

It is evident that there is no such thing as a unique experience of the various mental disorders in adolescents, but rather a plurality of individual experiences. This study addressed these lived experiences' variability, complementarity, and even contrasting nature. We considered broad diagnostic groupings, because splitting the lived experiences across specific diagnostic categories would have rendered the analytic task unfeasible. Future studies could better focus on specific sub-diagnostic constructs, for example, by exploring the differential lived experiences of specific autism spectrum disorders such as Asperger's syndrome.

The evidence reviewed here has been critically extracted (although we started with a defined search string, as indicated above). In line with our protocol and with previous publications in this series[21-23], we did not plan to report any quantitative data.

In conclusion, this study is a distillate of the subjective experiences of adolescents from a wide range of backgrounds and cultures, integrated with insights from leading youth mental health academics. We hope that this work will contribute to raising the attention of stakeholders and citizens to the challenge of public youth mental health, because "the neglect of youth mental health is a form of self-harm that society has inflicted on itself"[172,173].

Understanding the lived experience of poor mental health among adolescents can help us address its major consequences in terms of lower educational attainment, increased health care costs, substance abuse, violence, self-harm and suicide[152]. The voices of young experts by experience presented in this study may be instrumental in catalyzing the design and

implementation of a new youth mental health framework to maximize the potential of emerging generations globally[174,175].

We also hope that the themes and sub-themes detailed in this study can be used to train health care professionals and improve the mental health literacy of family members and caregivers, reducing stigma related to seeking help.

We hope that adolescents with mental health problems worldwide can access this study and feel less alone, isolated or stigmatized, by recognizing their own suffering in the words reported by their peers. Ultimately, we hope that this co-designed, co-conducted and co-written journey helps us maintain our commitment to protecting adolescents' fragile mental health, and help them develop into a healthy, fulfilling and contributing adult life.

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