



Understanding the illness representations of young people with anxiety and depression: A qualitative study

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Background. Many young people with anxiety or depression drop out of treatment early, and/or leave treatment without showing measurably improved symptom levels. To enhance treatment engagement and effectiveness, it is critical to better understand how young people's perceptions of the symptoms, causes, consequences, treatability, and course of their anxiety and depression influence engagement.

Aim. This study aimed to provide a qualitative account of illness perceptions among youth with anxiety and depression by applying the Common Sense Model of Self-Regulation (CSM), which was developed in physical health contexts.

Methods. Semi-structured interviews were conducted with 26 young people (aged 16–24, 73% female) with a history of anxiety and/or depression. Interviews were analysed using a combination of theory- and data-driven analysis techniques, consisting primarily of deductive thematic analysis.

Results. The five themes broadly mapped onto the dimensions of the CSM, suggesting parallels in how mental and physical health problems are perceived. Anxiety and depression were viewed as non-linear, relapsing and remitting, but lifelong conditions, with a fluctuating and complex path to recovery and coping. Youth described pervasive negative impacts on their lives, but also described some positive aspects.

Implications. Better understanding of young people's illness beliefs has the potential to open a range of intervention possibilities by prioritizing young people's illness perceptions over the clinician's understanding and the supposed objective condition severity and trajectory. Although this study supported a common structure of illness beliefs, the content of these beliefs was idiosyncratic and specific to anxiety and depression, suggesting the need to develop a valid tool to measure illness perceptions in this group.

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Practitioner points

- Our findings suggest that illness perceptions are complex, highly idiosyncratic, and specific to youth anxiety and depression.
- Given the complexity of these beliefs and the known association with important treatment- and health-related outcomes, it is important that clinical formulation incorporates young people's illness belief models, including their perceptions of symptoms, cause, timeline to recovery, consequences, and personal and treatment control.
- To increase help-seeking, treatment engagement and adaptive coping strategies, therapy should work to a shared understanding of illness beliefs.
- Increasing congruence between the belief models of young people, families, and clinicians may serve to improve treatment benefits and address the unmet mental health needs of young people.

Anxiety and depression are among the most prevalent psychiatric conditions in childhood and adolescence (Bor, Dean, Najman, & Hayatbakhsh, 2014; Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015) and often persist into adulthood, exhibiting high chronicity and recurrence (Beesdo-Baum et al., 2012; Bruce et al., 2005; Dunn & Goodyer, 2006; Neufeld, Jones, & Goodyer, 2017), comorbidity (Cummings, Caporino, & Kendall, 2014), functional impairment (Judd et al., 2000; Olatunji, Cisler, & Tolin, 2007), and increased risk of death by suicide (Gili et al., 2019). The prevalence of youth anxiety and depression is increasing worldwide, which is reflected in rising demand for mental health services (Deighton et al., 2019; Fink et al., 2015; Mojtabai, Olfson, & Han, 2016; Ormel et al., 2015; Pitchforth et al., 2019; Potrebny et al., 2019). However, only approximately 40% of young people who access routine specialist care for anxiety and depression show measurable improvement in symptoms (Bear, Edbrooke-Childs, Norton, Krause, & Wolpert, 2020; Edbrooke-Childs, Wolpert, Zamperoni, Napoleone, & Bear, 2018), and dropout rates are around 50% (de Haan, Boon, de Jong, Hoeve, & Vermeiren, 2013). In order to enhance treatment adherence and effectiveness, it is critical to understand how young people perceive and cognitively represent the course, severity, impact, and treatability of their anxiety and depression, as these representations guide attitudes towards mental health services, help-seeking, coping, self-management and treatment adherence (Baines & Wittkowski, 2013; Law, Tolgyesi, & Howard, 2014; Munson, Floersch, & Townsend, 2009; Munson, Floersch, & Townsend, 2010).

The dominant conceptual model used to investigate cognitive representations of illness and the processes by which individuals respond to perceived health threats is the Common Sense Model of Self-Regulation (CSM) (Leventhal, Meyer, Nerenz, & Rachman, 1980). This model suggests that in the face of health threats (e.g., the symptoms of a specific illness), individuals respond both cognitively and emotionally. The emotional response may involve feelings of fear, worry, or anger. In parallel, individuals actively build cognitive illness representations, which according to the CSM, relate to five dimensions: *Identity* (i.e., the labels used to characterize the illness and its symptoms), *consequences* (i.e., the perceived or expected impact the illness will have on life), *cause* (i.e., perceptions of what caused or sustains the illness), *timeline* (i.e., a sense of how long the illness will last), and *control* (i.e., the perceived chances of recovering from or being able to control the illness, either with the help of treatment [treatment control] or through personal coping [personal control]) (Broadbent, Petrie, Main, & Weinman, 2006; Lau & Hartman, 1983; Leventhal et al., 1980). Individuals then develop coping behaviours to deal with both cognitive and emotional representations (e.g., help-seeking; treatment adherence) and finally proceed to appraising the effectiveness of these coping strategies and their outcomes (e.g., impact on symptom severity). These appraisals, in turn, feed

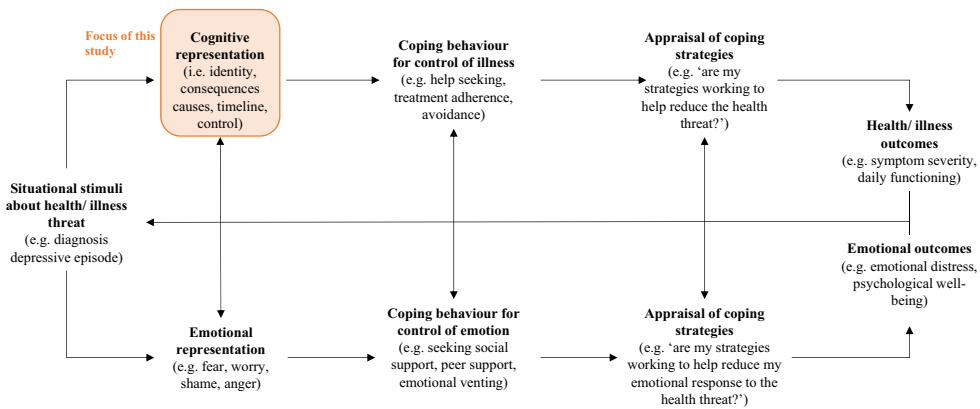


Figure 1. The Common Sense Model of Self-Regulation (CSM) (Leventhal et al., 1980).

back into the formation and reformation of illness representations and coping strategies (see an illustration of the model in Figure 1). Based on the ongoing appraisal of the effectiveness of their chosen coping strategies, individuals iteratively update their coping response and may opt to adapt or modify the coping procedure. The purpose of this dynamic process is that individuals arrive at the coping procedure that produces the greatest success in managing the health threat (Hagger & Orbell, 2021).

In line with the model, research suggests that illness perceptions can motivate self-management and coping behaviours, such as lifestyle changes and treatment seeking and adherence (Dempster, Howell, & McCorry, 2015; Richardson, Schüz, Sanderson, Scott, & Schüz, 2017). An association has been shown between illness perceptions and treatment adherence in adolescents with cystic fibrosis (Bucks et al., 2009), hypertension (Zugelj et al., 2010), and diabetes (Kyngäs, 2007); and between illness perceptions and quality of life in paediatric type 1 diabetes (Terrasson et al., 2018), cancer (Fonseca et al., 2010), and chronic fatigue syndrome (CFS) (Gray & Rutter, 2007). A consistent association has also been found specifically between young people's treatment control beliefs (i.e., perceptions of treatment effectiveness) and their ability to effectively self-manage chronic physical conditions (Law et al., 2014). Psychological determinants of health behaviours are important to consider when designing intervention strategies to improve clinical and functional outcomes (Broadbent, 2010). Several intervention trials have focused on illness representations as a mechanism for improving chronic illness management and reducing the burden of living with these conditions in adults (Humphris & Ozakinci, 2008; Keogh et al., 2011; McAndrew et al., 2008).

While children and young people's representations of physical health conditions are well explored (Law et al., 2014), comparatively little attention has been given to cognitive representations of their mental health problems and how these shape treatment engagement and expectations (Fortune, Barrowclough, & Lobban, 2004; Lobban, Barrowclough, & Jones, 2003, 2005; Pedley, Bee, Wearden, & Berry, 2019). Existing cognitive-behavioural models, including Beck's Cognitive Theory of Depression (Beck, 1987; Beck et al., 1979) postulate that specific cognitive distortions or biases are present in those prone to anxiety or depression, with depressed individuals often interpreting life events through negative schemas of the self, world, and future. Such models are crucial to understanding how youth interpret internal and external experiences and how these interpretations may contribute to the development and maintenance of anxiety and

depression symptoms. However, these models do not typically incorporate individuals' cognitive representations of the condition itself, nor do they examine how these representations influence the way youth understand and manage their condition (Fortune, Barrowclough, et al., 2004). Only a handful of studies have sought to determine the relationship between illness beliefs and outcomes such as attitudes towards mental health services and adherence to both psychotropic medication and mental health appointments among youth with anxiety or depression (Munson et al., 2009, 2010; Wisdom & Green, 2004). Existing studies used diverse methodologies, and no consistent theoretical framework of illness belief models exists (Fox, Buchanan-Barrow, & Barrett, 2010; Georgakakou-Koutsonikou et al., 2019; Midgley et al., 2017; Wisdom & Green, 2004), resulting in a disparate literature that lacks a shared language and common theoretical frame, and from which it is difficult to draw firm conclusions.

The current study

In relation to youth with anxiety and depression, there is a need for a clear, coherent, and complete picture of young people's illness beliefs. This study aimed to address this gap by undertaking a first application of the CSM model in this population, with a focus on cognitive (rather than emotional) illness representations. The primary research question was to examine young people's anxiety and depression-specific illness representations, including perceptions of illness identity (i.e., symptoms), consequences (i.e., life impact), causes and perpetuating factors, timeline, and curability and controllability. We used a qualitative research design to investigate these complex cognitive representations in depth and in young people's own words, and to identify and characterize anxiety and depression-specific illness perception patterns that may go beyond the mechanisms described by the original CSM (Higbed & Fox, 2010; Horowitz, Rein, & Leventhal, 2004; Pedley et al., 2019). This study informed a parallel effort to adapt and validate a quantitative measurement instrument, the Revised Illness Perceptions Questionnaire (IPQ-R) (Bear, Moon, Moon, Edbrooke-Childs, & Wolpert, 2021).

Methods

Design

We used in-depth semi-structured interviews to explore young people's illness perceptions of anxiety and depression. Interviews were conducted between July and October 2018. We chose qualitative methods to provide an in-depth, contextualized understanding of individual illness experiences (Iphofen & Tolich, 2019).

Participant recruitment

Young people with a history of anxiety or depression were recruited from community settings via opportunity sampling. Participants had to be UK residents, be aged between 14 and 24 years old, and self-report experiencing anxiety or depression either currently or in the past. Participants were asked to self-report current or past anxiety or depression based on a definition provided to them in the participant information sheet. Taking this approach meant we avoided discounting the views and experiences of young people who were not experiencing clinically significant levels of anxiety or depression at the time of the interview.

Recruitment happened through a variety of channels, including social media (e.g., Twitter and Facebook), newsletters sent to youth and practitioner networks, outreach to secondary schools across London, third sector organizations and mental health support groups, and advertisements placed on University and charity websites. Recruitment ceased when additional interviews no longer produced new themes or insights (Marshall, 1996). This point of data saturation was reached after conducting 26 interviews, consistent with the saturation points of previous comparable studies (Moon, Moss-Morris, Hunter, & Hughes, 2017; Taylor, O'Neill, Hughes, & Moss-Morris, 2018).

Participants

Interviews were conducted with 26 young people, aged between 16 and 24 years, mean age = 20.3 years, 73% female (see Table 1). Most participants (85%) reported they were experiencing anxiety and/or depression at the time of the interview and all reported having experienced anxiety and/or depression in the past. Twenty-three participants reported a history of both anxiety and depression, one person had experienced only depression, and two had experienced only anxiety.

Procedure

The research team was led by Principal Investigator, MW, Professor of Evidence-Based Practice and Research and Clinical Psychologist by background. JE-C, Associate Professor in Evidence-Based Child and Adolescent Mental Health, provided supervisory input and

Table 1. Participant characteristics

Participant characteristics	Young people (<i>n</i> = 26)
Age (years), mean \pm SD	20.3 \pm 2.53
Gender	
Female, <i>n</i> (%)	19 (73.1)
Male, <i>n</i> (%)	7 (26.9)
Nationality	
British, <i>n</i> (%)	22 (84.6)
Other, <i>n</i> (%)	4 (15.4)
Ethnicity	
White British, <i>n</i> (%)	17 (65.4)
Other, <i>n</i> (%)	9 (34.6)
Currently in paid employment, <i>n</i> (%)	11 (42.3)
Currently in full-time education, <i>n</i> (%)	17 (65.4)
Highest level of education completed, <i>n</i> (%)	
Secondary education (e.g., GCSE/O-Level/A-Level)	8 (30.8)
Further education (e.g., Higher National Certificate and Diploma)	6 (23.1)
Higher education (e.g., Bachelor's, Master's, Doctoral degree)	12 (46.1)
Currently experiencing anxiety and/or depression, <i>n</i> (%)	22 (84.6)
Experienced anxiety and/or depression in the past, <i>n</i> (%)	26 (100)
Long-term mental or physical health condition other than anxiety and/or depression, <i>n</i> (%)	13 (50)
Currently receiving help or treatment for anxiety and/or depression, <i>n</i> (%)	18 (69.2)
Received help or treatment for anxiety and/or depression in the past, <i>n</i> (%)	23 (88.5)

guidance as a leading expert in the field of child and adolescent mental health research. Researchers HAB and KRK were PhD students at the time the research was conducted, both of whom have several years of experience conducting qualitative research with young people and expertise in analysing qualitative data. The authors had no relationship with any of the participants.

Interviews followed a semi-structured schedule based on the domains of the CSM (Table 2). Topics included symptomatic experience, perceived causational attributions, chronicity, and impact on life. Interviews were conducted by first author, HAB, in person or by telephone and lasted approximately 45 minutes. Participants also provided demographic information and answered structured questions about use of mental health services and comorbid mental and physical health conditions. With prior consent, all but three interviews were audio-recorded. In the remaining cases, the researcher took verbatim notes. All participants were reimbursed for their time with a £10 Amazon voucher.

Ethical considerations

Ethical approval was granted by the University College London Research Ethics Committee (9777/003) on 4 July 2018. All research was performed in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All participants provided informed consent after receiving written information and an oral

Table 2. Semi-structured interview topic guide

CSM domain	Key question and follow-up question(s)
Identity	What symptoms or side effects have you experienced that you believe are associated with your anxiety or depression? What term/language do you prefer when referring to your anxiety or depression? (i.e., condition, illness, problems)
Cause	What do you believe may have caused your anxiety or depression?
Timeline	How long do you believe your anxiety or depression will last? Do you view it as being chronic or acute or relapse-remitting? Note: By acute we mean that the signs and symptoms of a condition came on quickly, yet only last a short duration. It may be severe and impair normal functioning (i.e., appendicitis or a broken leg). By chronic we mean a condition which persists and lasts a long time (i.e., dementia or cystic fibrosis). By relapse-remitting we mean a condition where the symptoms are at times worse (relapse) and other times are improved or gone (remitting) (i.e., asthma or multiple sclerosis)
Consequence	Do you think there are any potential consequences of having anxiety or depression for either now or in the future?
Cure/Control	Do you think treatments are effective in treating your anxiety or depression? (This could be treatments you have had/are currently having or treatments more generally). What term do you think is preferable when referring to cure? Does this term make sense to you in relation to anxiety and depression? How much control do you have over your anxiety or depression? Both in general and in relation to treatment

CSM = Common Sense Model of Self-Regulation.

briefing about the study scope and protocol. Care was taken to conduct the interviews in private, quiet spaces, and in a warm and reassuring manner to ensure participants felt comfortable and safe. It was hoped this would help reduce any potential researcher-participant power imbalance.

Analytic strategy

Interviews were transcribed verbatim by the first author (HAB), and the transcripts were anonymized by assigning a unique pseudonym to each participant. Hereafter, participants are identified by their pseudonyms and without indication of their age to provide the highest-possible level of confidentiality. Data analysis was conducted by the first author using NVivo11 (Bazeley & Jackson, 2013).

The interviews were analysed using a combination of theory- and data-driven analysis techniques, consisting primarily of deductive, theory-driven thematic analysis (Braun & Clarke, 2006), with elements of inductive and content analysis (Shelley & Krippendorff, 1984; Stemler, 2001). We combined elements of deductive and inductive coding to elicit a coherent and comprehensive picture of young people's illness belief models based on the original dimensions of the CSM, while also allowing for the identification of new patterns not described in the original CSM, which were coded inductively. Content analysis (Stemler, 2001) was used to compress young people's idiosyncratic descriptions of symptoms, causal attributions, and consequences of anxiety and depression into a smaller set of categories, and to quantify their occurrence.

Initial familiarization with the data was achieved through the transcription process and iterative re-reading of the interviews. Analysis was carried out through a recursive process of open coding, when concepts were named and their properties and dimensions identified, followed by axial coding, when links and associations were drawn between codes. Codes were based on language used by the young people and were applied to each new unit of meaning. Data extracts were multiply coded when appropriate, as were contradictory and minority features of the data. The data set was iteratively reviewed, and codes were systematically applied to the whole dataset until a finalized coding manual was established. Codes were organized into potential themes using thematic maps and tables. The development of the coding manual was iteratively reviewed and refined through discussion with all authors throughout the analysis process to ensure the reliability and rigour of the process and results.

Approach to inquiry

Analysis was conducted from a critical realist perspective (Ellaway, Kehoe, & Illing, 2020). This position assumes that although participants' accounts provide important insights about the real world, these accounts are not objective and represent an interpretation of reality (Willig, 2012). These data require interpretation by the researcher, who also has their own perspectives on the world, to better understand the underlying mechanisms and processes.

Results

Across the 26 interviews, we identified following five themes: (1) Differential symptomatic experience, (2) Multidimensional explanations of causation, (3) Coping

with a lifelong condition, (4) Pervasive impact with a silver lining, and (5) Outcomes are unique to the individual. These five themes broadly mapped onto the five dimensions of the CSM (see Table 3). Each theme is described in the following.

Theme 1. Differential symptomatic experience

With regard to the *identity* domain of the CSM, young people described a diverse range of symptoms associated with anxiety and/or depression. While there was great variation between individuals, symptoms were commonly described as markedly debilitating and enmeshed with the youth's sense of self and daily life. Most participants were able to distinguish between their anxiety and depression symptoms, however, some spoke more generally about their mental health symptoms and did not separate the two.

Young people described a total of 58 different anxiety symptoms. The most common symptoms included overthinking and having irrational thoughts, catastrophizing, difficulty leaving the house, problems sleeping, self-harm, isolation, panic attacks, loneliness, difficulty attending school or university, nausea, palpitations, difficulty breathing, sweating, shaking, and low self-esteem. Less commonly mentioned symptoms (experienced by only one or two people) included headaches, restlessness, self-doubt, feeling empty/a void, and imposter syndrome.

A total of 41 symptoms were mentioned for depression, the most common of which were self-harm, low mood, problems sleeping, difficulty leaving the house, social withdrawal, lack of interest and desire, difficulty attending school or university, negative thinking, lethargy, suicidal thoughts, low self-esteem, worthlessness, poor eating habits, lack of motivation, isolation, loneliness, dysphoria, and poor personal care. Less commonly mentioned symptoms included feeling heavy, lack of emotion, hair loss, skin and nail picking, and being quick-tempered.

It was notable that each young person's experience of anxiety and depression was distinct and unique to them. For some, symptoms were more physical in nature (e.g., nausea, palpitations, difficulty in breathing, sweating); for others anxiety and depression manifested primarily in reduced social interaction and isolation.

Table 3. Themes identified in the data and their mapping across the CSM domains

Theme	Relevant CSM illness perception domain				
	Identity	Cause	Timeline	Consequence	Control
Theme 1. Differential symptomatic experience	✓				
Theme 2. Multidimensional explanations of causation		✓			
Theme 3. Coping with a lifelong condition			✓		✓ Personal control ✓ Treatment control
Theme 4. Pervasive impact				✓	
Theme 5. Outcomes are unique to the individual					✓ Treatment control

CSM = Common Sense Model of Self-Regulation.

I sometimes feel like strange, like nauseous and I can't breathe and um dry heaving like tingling in my whole body. I don't know how to explain it. Like really numb and tingly. (Anita, Female)

I think agitation. Yes, agitation definitely for both anxiety and depression. The sort of fidgetiness and not being able to concentrate. Then low mood and not being able to do anything. . . because worrying about everything then leads to me not wanting to do it. (Ellie, Female)

Theme 2. Multidimensional explanations of causation

With regard to the CSM dimension of *cause*, young people provided multidimensional explanations for their anxiety and depression, often describing more than one cause. The most mentioned causes were adverse childhood experiences ($n = 13$), having always been that way/personality ($n = 8$), the illness or death of a close friend or family member ($n = 7$), family problems ($n = 7$), family history of mental health problems or genetics ($n = 7$), physical illness or injury ($n = 5$), a gradual build-up of things ($n = 4$), thinking style ($n = 3$), and upbringing ($n = 3$). Only one young person mentioned chemical imbalances and hormones, respectively. One participant spoke about having an innate predisposition to mental ill health but also acknowledged that environmental factors such as upbringing could have played a role: 'I've always had it in me—I've always been someone who can get really low mood. I'm bad at dealing with change. I had a very bad year, with nothing picking me up. I just kept getting lower and lower. It's my personality and how I deal with things. It could be genetic or my surroundings and how I was brought up. It didn't come as a surprise—there were indications about how I reacted to things.' (Emma, Female)

Around a third of young people said they did not know what had caused their anxiety and depression.

For me, I'm not sure. It just came about. But I've had it for a long time since primary school. I don't think I'm able to identify why. (Nina, Female)

Theme 3. Coping with a lifelong condition

In touching upon the CSM dimensions of *timeline* and *personal control*, most young people believed that their anxiety and depression followed a relapse-remitting but lifelong, chronic course. They described their symptoms getting better and worse in cycles but that the condition(s) were always there in the background. Youth thought the exact course of anxiety and depression very much depended on the individual, with no 'one size fits all' timeline.

My symptoms come and go but they are always there. Even when relaxed they will come back at some point. It can be intermittent but will be in the background for the rest of my life. I don't speak about it and that much so that makes it much worse. (Keira, Female)

It's ingrained into the way I think, work and process things. So, in that sense I think it is chronic. I have to learn how to manage it in a way that it doesn't affect my life. (Anita, Female)

In line with the perceived chronicity of these conditions, many young people emphasized the importance of learning to cope with ongoing symptoms and distress. Many felt that their self-management skills had already become better with time, and that

although their anxiety or depression might always be present in the background, their improved ability to manage their symptoms meant they felt less impacted.

People learn how to live alongside it and learn to live with their symptoms. They learn how to deal with it and cope better. There's always the potential for it to come back. It's always there somewhere. (Olivia, Female)

Yet, young people had varied perceptions about how much personal control they had over their anxiety and depression. Some young people had a strong internal locus of control and felt they had agency in dealing with their mental health problems, while others felt these problems were primarily caused by their environment, leaving them with little control over them. Some young people described that a sense of personal control had developed over time.

I don't think I have that much control. Most of what causes my problems is caused by things around me. What's making me upset, for want of a better word, is out of my control. So therefore, my mental health problems are out of my control. (Benjamin, Male)

Things were more difficult for me until I reached the point where I wanted to help myself. Before that I felt less in control but when I realised that I felt more in control, it was in my hands. Recognising that didn't mean things were instantly better but helped me to help manage my symptoms. (Olivia, Female)

Several young people spoke about how their expectations of treatment and recovery changed during the course of their condition(s). One young person discussed how, following a series of different treatments, his expectations for his own outcomes changed with time, from a recovery-orientated view, to one which was less optimistic, viewing his mental health problems as something that is more long-term. Aaron also discussed that his shift in optimism may in fact be a feature of his depression, which is hard for him to discern.

It's so individual. It's now starting to feel that it's more of an indefinite, coping and managing thing. As opposed to initially, when I thought that it was 'how will I get better and cured?' and that was for my parents as well. Now, given the amount of different treatments I've tried, I don't think I will be cured. But it's also possible that the depression is making me feel less optimistic about that. It's like an endless loop—do I feel like I won't get better because that's what it is or is it because of the condition that I won't. Hard to unpick that. (Aaron, Male)

Benjamin used a bank loan analogy to express how he believed treatment would be effective but that it was a process that would take time.

With treatment, what I've got will get better. Although I'm speaking to people, effectively what they're doing is clearing the interest. Depression is like clearing a bank loan. Every week it's accruing interest. Counselling for me clears the interest, it doesn't clear the debt capital . . . talking to people at the moment isn't doing anything. But it often takes longer to get out of debt than it took to get into it. (Benjamin, Male)

Theme 4. Pervasive impact with a silver lining

With regard to the CSM dimension of *consequences*, young people described a catalogue of profound and wide-ranging negative impacts that having anxiety and depression had

had on various aspects of their life, including on relationships with others ($n = 12$), their ability to work and/or attend school ($n = 11$), or to socialize with friends and family ($n = 9$). They described experiencing stigma ($n = 6$), feeling their life had been put on hold ($n = 5$), missing opportunities ($n = 5$), a lack of understanding from others ($n = 4$), limited capacity and functioning ($n = 4$), and the predictive belief that anxiety and depression would be life-limiting ($n = 3$).

The impact magnifies as I grow up. When I was younger it was more bullying and peer issues. It was a constant struggle to stay in school and college. In the future I see it as being more about my relationships and ability to hold down jobs. My social life is difficult. It isolates me. (Clara, Female)

However, many young people also described a 'silver lining' and spoke about a comforting or hopeful aspect that had come out of challenging circumstances and which offset some of the negative aspects. For instance, in addition to being able to cope and manage better, some felt they were now more open-minded, resilient, empathetic, introspective, and self-aware. Experiential benefits were also mentioned, including meeting new people, and shaping career choices.

It makes it harder to process information and to meet new people, but it makes me more empathetic to other people as you know how awful it feels first-hand. Experience generates the greatest amount of empathy. (Ajay, Male)

There are some good points about it [...] It allows me to feel things deeply often. Not everyone does that. (Anita, Female)

It was hard at the time, but it has led me to where I am now. I wouldn't change it even though it was horrible and hard. If I had the opportunity to go back and change it—I wouldn't. (Olivia, Female)

Theme 5. Outcomes are unique to the individual

Theme 5 relates to the person-specific nature of treatment effectiveness, and hence to the CSM dimensions of *treatment control*. Young people had diverse beliefs and expectations about the chances that treatment could help control and reduce anxiety and/or depression effectively. Several were optimistic, while others were not confident about the prospects of a positive treatment outcome. Most spoke about how treatment effectiveness depended both on the person (e.g., their treatment engagement or their readiness for change) and on the type of treatment. Participants had received a variety of different treatments with varying degrees of success, and they tended to draw on these experiences when making prognostic predictions. They also considered the experiences of friends and family and how well treatments had worked for them.

I think it probably depends on the person. I know one of my friends went to group therapy and she said it wasn't that effective. Her mum has anxiety and depression and went to a similar thing and she found it really helpful. I think it's about the mind-set you're in as well. If you want to be helped or you're ready to be helped. (Keira, Female)

I went two years without any help, then I had twelve weeks of CBT with CAMHS. It didn't help at all, it was pointless. A waste of time. I knew it all and wasted twelve weeks. (Georgia, Female)

Discussion

Summary of findings

To the best of our knowledge, this was the first study to apply the CSM of physical illness to improve understandings of young people's cognitive illness representations about their anxiety and depression. Anxiety and depression were perceived as being highly symptomatic, long-lasting conditions, present throughout life but coming and going in waves and having a pervasive and wide-ranging impact on life both now and in the future. The themes identified were broadly consistent with the illness perceptions domains outlined in the original CSM. This suggests that models of illness representation share a common conceptual structure between paediatric physical and mental health conditions and that there are structural parallels in how young people perceive illness identity, cause, consequences, control/curability, and timeline.

Although this study supported a common structure of illness beliefs, the content of these beliefs was complex, idiosyncratic, and specific to youth anxiety and depression. First, there was a widely held belief that anxiety and depression followed a relapse-remitting, yet lifelong trajectory and youth expected to live with these conditions for some time. In line with this, a prominent theme was the fluctuating nature of treatment, recovery, coping, and locus of control (Theme 3). Recovery and learning to cope were viewed as a non-linear, complex journey, which took time to achieve. Several young people spoke of a gradual change in mindset, which shifted from a predominantly recovery-orientated view in which the causes and cures to anxiety or depression were seen as external to them and recovery from symptoms appeared achievable; to a view which focused more on long-term self-management and internal locus of control, with several young people describing that their agency and ability to manage the symptoms had improved over time. This finding is consistent with the adult and youth recovery literature that describes recovery as an active, individual, and unique non-linear process (Ballesteros-Urpi, Slade, Manley, & Pardo-Hernandez, 2019; Higbed & Fox, 2010; Lavik, Veseth, Frøysa, Binder, & Moltu, 2018; Law et al., 2020). Yet, the complex and non-linear nature of the recovery process and the building of resilience strategies over time are largely absent from studies using the CSM in physical health contexts.

Second, the negative illness impact described was pervasive and far-reaching, often affecting relationships, the ability to work and/or attend school, or to socialize with friends and family (Theme 4). This finding is largely consistent with studies across physical and mental health contexts that also often describe important negative consequences (Higbed & Fox, 2010; Hunter & Riordan, 2014). However, many young people in this study also described the sense of a *silver lining*, identifying positive consequences of having experienced anxiety and/or depression, such as being more open-minded, resilient, empathetic, and self-aware. There is now a large and growing literature across conditions that documents the notion of benefit finding, or experiences of positive outcomes when faced with illness (Danoff-Burg & Revenson, 2005; Helgeson, Reynolds, & Tomich, 2006; Mattsson, Ringnér, Ljungman, & von Essen, 2007; Tomich & Helgeson, 2004; Wicks & Mitchell, 2010; Woodgate, 2005). Research indicates that adolescents who have survived cancer describe their illness resulting in personal growth and development (Mattsson et al., 2007; Woodgate, 2005), for example, by enabling a more positive attitude towards life, improved relationships, becoming more mature and enhanced self-esteem (Hokkanen, Eriksson, Ahonen, & Salanterä, 2004; Mattsson et al., 2007; McCaffrey, 2006). However, benefit finding has yet to be included in the CSM. It is currently not measured in quantitative studies of illness perceptions and has not been commonly explored in illness

perceptions research. Future studies should aim to incorporate these constructs, especially in relation to youth anxiety and depression.

Third, youth had variable expectations around treatment effectiveness, suggesting that *outcomes are unique to the individual*, with no single treatment working for everyone and positive outcomes being highly dependent on the individual, their problems, their engagement with treatment, and the type of treatment they receive (Theme 5). The literature suggests that such expectancies are not fixed, but are subject to change with exposure to information and experiences (Schulte, 2008), and tend to evolve as treatment progresses.

One finding that is consistent with the illness perceptions literature is that illness perceptions are shaped by a person's knowledge and experience and the discourse of those close to them, and therefore tend to vary between individuals, as well as fluctuate over time and with new information (e.g., new diagnostic information) and experiences (Higbed & Fox, 2010; Moon et al., 2017; Pedley et al., 2019; Taylor et al., 2018). In this study, we specifically found differences between young people in terms of their symptoms, causal beliefs, and control beliefs. For some, symptoms were more physical in nature (e.g., nausea, palpitations, difficulty breathing, sweating), whereas for others anxiety and depression manifested in reduced social interaction, isolation, and cognitive symptoms such as low self-esteem and self-worth. The heterogeneity of symptom experience, causal, and control beliefs is important as these representations are known to be associated with help-seeking, engagement, and treatment acceptability in other health contexts including depression treatment uptake in primary care (Brown et al., 2001; Elwy, Yeh, Worcester, & Eisen, 2011). It was not within scope to explore these associations using the data gathered for this study; however, current findings suggest that this is an important avenue for future research.

Implications for clinical practice

There is a growing body of work designing and evaluating interventions that aim to modify adult patients' illness perceptions in order to increase the congruence between the patient's model of illness and the treatment plan, to improve self-management, and to reduce the burden of living with the condition (Humphris & Ozakinci, 2008; Keogh et al., 2011; McAndrew et al., 2008). Such efforts include, for example, providing patients with end-stage renal disease with concrete illustrations of how phosphate-binding medication works in order to improve their medication adherence (Karamanidou, Weinman, & Horne, 2008). Illness perception interventions have also been successfully developed to enhance clinical care for myocardial infarction (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009); diabetes (Keogh et al., 2011) and psoriasis (Fortune, Richards, & Griffiths, 2004). In child and adolescent mental health, young people's views of their illness or symptoms are rarely asked about or indeed incorporated into clinical decision-making in current practice. This is problematic given that individuals tend not to spontaneously report their illness beliefs without prompting or may even not be attuned to what their beliefs are (Petrie & Weinman, 2006).

Clinical psychology currently works to a formulation-based model, whereby practitioners formulate a treatment plan based on a young person's precipitating, presenting and perpetuating factors. This formulation should be inclusive of the young person's illness models, including their own perceptions of identity, cause, timeline to recovery, consequences, and personal and treatment control. Therapy should be working to a shared understanding of illness beliefs and notice should be taken if there is incongruence.

Increased congruence between the belief models of young people, families, clinicians, and the reality of outcomes may improve treatment outcomes.

Our findings suggest youth have a long-term view of their anxiety and depression, which is associated with a desire to improve their ability to manage symptoms over the life course. To prevent young people disengaging from treatments they find unhelpful and to better meet the needs of those with longer-term anxiety and depression, services and clinicians should ensure to incorporate young people's outcome priorities into shared decision-making about treatment, and consider placing a greater focus on providing the skills young people need to cope and self-manage their anxiety and depression successfully in the longer term without continued reliance on intensive specialist care.

Our findings indicate a need to carefully manage young people's treatment expectations in routine care. Many young people in this study believed that treatment was necessary to recover from anxiety and depression, which can create heightened treatment expectations so that youth regard professional support as the 'expert solution' to solving their mental health problems (Armstrong et al., 2019; Ronzoni & Dogra, 2012). However, adjustment to a chronic illness typically also requires effective coping and self-management behaviours, as well as mental health and social care systems that are set-up to provide longer-term support. Clinicians should elicit and manage young people's expectations about likely response patterns and timelines prior to starting treatment. Best practice should involve refraining from promising an unrealistic degree or speed of change, yet being hopeful about prospective outcomes, addressing expectations explicitly prior to commencing treatment, particularly regarding what to expect in terms of response patterns, provide patients up front with an approximate length of treatment, and regularly checking on patients' outcome expectations and responding accordingly (Bear, Dalzell, et al., 2021; Constantino, Arnkoff, Glass, Ametrano, & Smith, 2011; Constantino, Ametrano, & Greenberg, 2012). This can be achieved using tools, such as the Outcome Expectancy Scale (OES) (Ogrodniczuk & Sochting, 2010), and/or through discussions with the young person. By setting realistic expectations, clinicians may avoid early frustration and disengagement, and hence possibly prevent drop out (O'Keeffe, Martin, Target, & Midgley, 2019).

Implications for research

Using quantitative methods, future research should aim to investigate the extent to which illness perceptions are associated with important treatment-related outcomes, including help-seeking, treatment engagement, coping, self-management, symptom change and outcome expectations among youth with anxiety and depression. Depending on the results, illness perceptions in youth anxiety and depression may represent a useful target for intervention. Cognitive behavioural therapy (CBT) could be harnessed to create more adaptive illness belief models with the aim of improving self-management. This may include tapping into a young person's personal control beliefs and increasing their self-efficacy and internal locus of control. It is also important to capture young people's symptomatic experience (e.g., physical, emotional, cognitive) and ascertain what beliefs young people hold about the cause(s) of their difficulties (e.g., hormonal imbalance, problems with family, thinking style) to ensure that these are congruent with the treatment, or combination of treatments, being offered (medication, family therapy, cognitive therapy, respectively) (Bhui & Bhugra, 2002; Nunstedt, Nilsson, Skärsäter, & Kylén, 2012).

To achieve this aim, a validated tool of illness perceptions for youth anxiety and depression is needed. Illness representations are measured using the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), which assesses the five cognitive dimensions of identity, cause, timeline, consequences, curability/controllability, as well as coherence and emotional representations. The IPQ-R is a well-established measure with sound psychometric properties across populations (Hagger & Orbell, 2005; Moss-Morris & Chalder, 2003). Yet, a limitation of the IPQ-R is that it is a generic measure of illness perceptions and lacks specificity to individual health conditions (French & Weinman, 2008). To address this, we are currently finalizing a parallel study focused on developing and validating anxiety- and depression-specific versions of the IPQ-R for youth populations (Bear, Moon, et al., 2021). If beliefs can be measured in a reproducible way using a quantitative format, relationships between beliefs, adherence and outcome can be assessed.

Our findings, whereby youth place a strong emphasis on learning to cope with anxiety and depression, are in line with existing qualitative research about young people's treatment outcome priorities suggesting that youth assign similar levels of importance to learning to cope and self-manage, as they do to symptom reduction (Krause, Edbrooke-Childs, Edbrooke-Childs, Bear, Calderón, & Wolpert, 2020; Krause, Midgley, Midgley, Edbrooke-Childs, & Wolpert, 2020b). Yet, learning to cope is rarely an outcome of interest in treatment trials for youth depression (Krause, Bear, Edbrooke-Childs, & Wolpert, 2019) and anxiety. Treatment trials tend to conceive of symptoms as acute rather than long-term problems, and focus on achieving symptom remission (i.e., restoration of normative symptom levels by the end of treatment) as a marker of treatment success (Courtney et al., 2020). Our findings suggest a discrepancy between this focus on acute symptom management and young people's long-term view of their condition. If treatment trials are to identify interventions that can be delivered within person-centred care frameworks and deliver outcomes that are meaningful to youth, the current oversight of coping and self-management outcomes should be reviewed.

Limitations

This study is subject to several methodological limitations. Foremost, the sample was recruited using a self-selected, opportunity sample of young people. It is likely that those who participated only represent a subsample of anxious and depressed youth, and the views expressed may not be representative of the views of all young people. The sample for this study comprised young people who were mostly white females, with a mean age of 20, approximately 50% of whom had completed higher education. This study used semi-structured interviews, which provided a rich account of the participants' experiences of treatment and perceptions of illness, yet there may be bias in what was reported. The data used in this study were based on what the participants were able to remember, willing to share, and aware of. It is possible that there may have been other aspects of their treatment that the young person was not aware of or had forgotten by the time they were interviewed.

As previously noted by others, results may be subject to further bias in that findings could be led by more articulate young people, while it is more difficult to hear the voices of those who are less articulate (Midgley et al., 2017). Most young people had experienced various forms of treatment at the time of interview. Therefore, it was not possible to compare the pre- and post-treatment expectations of young people. Re-sampling based on this characteristic was beyond the scope of this study; however, future research may wish

to address this. Finally, practical constraints meant it was not possible to formally assess the inter-rater reliability of the coding manual using independent coders. However, steps were taken to ensure the reliability and rigour of the analysis process and results through a series of discussions with the wider research team.

Conclusion

This study used qualitative methods to explore young people's beliefs about their anxiety and depression, assessed across five illness perception dimensions outlined in the CSM of Self-Regulation (Leventhal et al., 1980). Themes broadly mapped onto the dimensions of the CSM, suggesting that there are parallels in the ways that young people with mental and physical health problems perceive illness *identity* (i.e., symptoms), *cause*, *consequences*, *control/cure*, and *timeline*. However, within these dimensions, we identified beliefs and experiences that are specific to anxiety and depression. Anxiety and depression were seen to have a non-linear relapse and remitting, but lifelong course, and youth strongly emphasized the importance to learn coping and self-management skills. While youth described pervasive negative impacts of these conditions on their lives, they also frequently described benefits or positive aspects (e.g., relating to personal growth). Finally, there was strong diversity in young people's expectations about treatment effectiveness, highlighting the need to monitor and discuss these in clinical practice. Although this study supported a common structure of illness beliefs, the condition-specific content of these beliefs suggests the need to develop a valid and reliable tool to measure illness perceptions in this group. Better understanding of young people's beliefs about their anxiety and depression has the potential to open up a range of possibilities for intervention by incorporating the young person's illness belief models in treatment formulation, above other factors such as the clinician's understanding and the supposed objective condition severity and trajectory.

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Conflicts of interest

KRK reports personal fees from the International Consortium for Health Outcomes Measurement (ICHOM), outside the submitted work: From October 2018 through March

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Author contributions

Holly Alice Bear, PhD (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing)
 Karolin Rose Krause, PhD (Data curation; Formal analysis; Writing – review & editing)
 Julian Edbrooke-Childs, PhD (Formal analysis; Supervision; Writing – review & editing)
 Miranda Wolpert, DCLinPsy (Formal analysis; Supervision; Writing – review & editing).

Data Availability Statement

Due to the confidential and sensitive nature of the interview transcripts, data will not be made available.

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