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The experience of young people with depression: a qualitative study

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Accessible summary

- Young people struggle to come to terms with depression.
- They may withdraw from friends, fearful of stigma and to preserve friendships in the longer term, but withdrawing from friends can have paradoxical consequences.
- They may respond in self-protective, harmful and sometimes life-threatening ways to their depression.

Abstract

People who develop depression experience a maelstrom of emotions as they struggle to understand what is happening to them. While the experience has been comparatively well documented in older adults, much less is known about the depression experience and responses of young people. In this study, we aimed to explore the experience of young people diagnosed with depression. Twenty-six young people were recruited from a youth mental health service. A qualitative interpretative design was used, incorporating semi-structured, audio-recorded interviews. Results provided four overlapping themes, reflecting the young people's difficulties in coming to terms with, and responding in self-protective, harmful and at times life-threatening ways to their depression: (1) struggling to make sense of their situation; (2) spiralling down; (3) withdrawing; and (4) contemplating self-harm or suicide. Study conclusions are that young people faced considerable difficulties coming to terms with, and responding to, depression. Improving young people's understanding of depression and its treatment, reducing community stigma and providing accessible and youth-focused services remain important targets for intervention. It is also important to improve mental health literacy in the community to increase awareness of depression and how mental health professionals, including nurses, respond effectively to the young person.

Introduction

More than one in four young Australians (16–24 years) experience a mental disorder, giving this age group a higher prevalence of mental disorder than any other (Australian Bureau of Statistics 2008). In particular, depressive disorders, which commence frequently in adolescence or in early adult years (Kessler *et al*. 2005), have a prevalence rate of 5.7% in adolescents, with a higher rate in girls (5.9%) than boys (4.6%) (Costello *et al*. 2006). Lutz & Warren (2007) present similar figures for the prevalence of adolescent depression in the USA.

There have been comparatively few studies of adolescent depression despite its impact on morbidity and mortality. Most studies focus on adults (Lutz & Warren 2007) and fail to consider the developmental considerations that differentiate depression occurring in adolescence from its manifestation in adulthood (Farmer 2002). For example,

anger and aggression are typical features of adolescent depression, yet these are not included in diagnostic manuals such as diagnostic and statistical manual of mental disorders (DSM-IV-TR) (Farmer 2002).

For young people living with a mental illness, such as depression, impairments caused by the illness may be exacerbated by associated social consequences. They are often stigmatized (Larson & Corrigan 2008) and shunned, leading to increasing social isolation as they are excluded from everyday activities (Schulze & Angermeyer 2003, Hinshaw 2007). Stigma of depression in youth presents a particular burden for young people (Perry *et al*. 2007). People with depressive illnesses are less likely to be stigmatized than those with psychosis (Crisp *et al*. 2005, Jorm & Griffiths 2009), yet the effort of getting out and building social networks can be considerable for young people with depression.

Depression can have a significant impact on adolescents as they prepare for their transition to adult life. Farmer (2002) identified the problem of unremitting fatigue, often accompanied by physical malaise, leading to poor academic performance, loss of self-esteem and potential disharmony at home. Dundon (2006) undertook a metasynthesis of qualitative studies describing the experience of depression in adolescents. Six themes emerged, characterizing the pattern of the illness, including 'beyond the blues', where adolescents realized they were experiencing something more than normal teenage mood swings; 'spiralling down and within', the growing social isolation as the effort of maintaining and building social relationships became too great; and 'breaking points', times of despair if parents or significant others failed to accept that the illness is real.

Young people with depression sometimes engage in a range of maladaptive behaviours in an effort to cope with the symptoms of the illness. In a powerful autobiographical account, Deitz (2004) described her battles with depression and anxiety that started when she was 6 years old. Her responses included suicide attempts, self-harm, and misuse of alcohol, prescription and illicit drugs, highlighting the need for greater mental health literacy in the community to prevent, recognize and respond appropriately to young people in this situation (Jorm *et al*. 1997). Deitz's response pattern is not unusual. Baker *et al*. (2007) described the co-occurrence of affective disorders and substance use disorders in adolescence and noted that this led to higher levels of psychopathology and psychosocial problems, and poorer quality of life. While, in general, strong social support networks help protect against mental illness, such as depression, young people with the dual diagnosis of mental illness and substance use disorders sometimes draw their principal social support from others who are similarly affected and hence lack appropriate support in managing their conditions. These peer attachments may need to be broken and replaced by networks of non-users as part of recovery (MacDonald *et al*. 2004).

Understanding the lived experience is essential in informing the development of appropriate early intervention services for young people with depression. Limited research has been conducted in this regard despite considerable research documenting the symptomatology and treatment of depression in adults and, to a lesser extent, young people. In particular, few studies have adopted a qualitative approach, despite the value of such methodology for providing a deep and rich understanding of young people's experiences of depression.

In this study, we aimed to examine the lived experience of young people diagnosed with depression.

Method

Interpretative phenomenological analysis, a hermeneutic or interpretative method based primarily on the Heideggerian perspective of phenomenology, informed data collection and analysis. Interpretative phenomenological analysis is informed by the social constructionist perspective that historical, social and contextual factors have a central influence on how individuals experience and perceive their lives (Eatough & Smith 2008). Interpretative phenomenological analysis is especially useful where the issue is new or underresearched, where problems are many-sided or obscure, and where the researcher seeks to understand process and change (Smith & Osborn 2004).

Participants

Young people were recruited via clinicians of a Headspace service located in a large Australian city. Headspace (national) was established in 2006, funded mainly by the Australian government under the Youth Mental Health Initiative Program (Muir *et al*. 2009). The service was established as an enhanced primary care service for providing mental health support, information and services to young people (aged 12–25 years) and their families. At present, there are 30 Headspace services at various locations throughout Australia.

Criterion or purposive sampling was used to guide data collection (Parahoo 2006). Inclusion criteria were: (1) young person with depression as a primary diagnosis, and (2) aged 16–25 years. Exclusion criteria were: (1) history of psychosis, or (2) currently expressing suicidal plans.

Thirty-two young people were invited to take part in the study, and, of these, 26 agreed to participate (none withdrew from the study). The mean age of those who took

Table 1
Socio-demographic information about young people

Variables	*n* = 26 *n* (%)
Gender	
Female	16 (61.5)
Male	10 (38.5)
Marital status	
Single	19 (73.1)
Married/de facto	4 (15.4)
Boyfriend/girlfriend	2 (7.6)
Missing data	1 (3.8)
Living circumstances	
Reside with one or both parents	15 (57.7)
Reside with spouse/partner	1 (3.8)
Reside with boyfriend/girlfriend	1 (3.8)
Reside with other relatives	2 (7.7)
Alone in non-supported accommodation	2 (7.7)
Alone in supported accommodation	1 (3.8)
Homeless	1 (3.8)
Other[1]	3 (11.5)
Highest level of education completed	
High school (Year 10)	12 (46.2)
High school (Year 12)	7 (26.9)
High school (continuing)[2]	6 (23.1)
University	1 (3.8)
Country of birth	
Australia	21 (80.8)
Asia–Pacific countries	4 (15.2)
African countries	1 (3.8)
Primary language/s spoken at home	
English	24 (92.3)
Other	2 (7.7)
Main reason/s for attending Headspace	
Depression	7 (26.9)
Depression and anxiety	13 (50)
Depression and substance use	1 (3.8)
Depression, anxiety and substance abuse	3 (11.5)
Missing data	2 (7.7)
Age	Mean 18 ± 1.78 years (range 16–22 years)
Duration of treatment with Headspace	Median 4.5 ± 5.05 months (range 0–24 months)

[1]Living with foster parent, parents and partner, stepfather.
[2]Still attending high school.

part was 18 years (SD = 1.78 years) (Table 1). Sixteen were female, most were single, and 15 resided in the same household as one or both parents. The most common completed levels of education were Years 10 and 12 high school. Their median duration of treatment at Headspace was 4.5 months. In most instances their primary diagnosis was depression and anxiety, followed by depression and then depression and comorbid substance use (mainly alcohol, cannabis and amphetamines).

Data collection

Data collection took place in a private room at Headspace. Semi-structured, in-depth, audio-recorded interviews were carried out, each lasting from 30 to 60 min. The purpose of the interviews was to enable the researcher to ask a range of in-depth questions, so the young people could describe their experience of having mental health problems in *their own* narrative (Patton 2002). Examples of the interview prompts are listed in Table 2. At the end of each key section of the interview, the researcher summarized the content to ensure the participant's perspective was correctly stated and comprehended, a verification process that strengthened the credibility of the study (Guba & Lincoln 2005).

Table 2
Sample of interview prompts relating to the young people's experience with mental health problems

- Can you tell me what it is like to be a young person with depression?
- Can you tell me the good things, if any, about your experience with depression?
- Can you tell me the 'bad' things, if any, about your experience with depression?

Ethical considerations

Ethical approval was obtained from a university and a health service research and ethics committee. In particular, written consent was obtained, including written parental/guardian consent for those under 18 years.

Data analysis

Smith & Osborn's (2008) method was used to inform data analysis. First, transcribed data were read and reread in order to obtain a broad understanding of the young people's experience of living with depression. Second, transcripts were scrutinized closely, coding was undertaken, and initial codes were grouped into conceptual themes, which depicted the meaning of the participants' experience. Third, themes were grouped together chronologically into clusters of themes. Concurrently, data reduction took place with provisional themes insufficiently grounded in the data being excluded. Fourth, a more intense analytical and theoretical arranging of themes occurred. Finally, another researcher carried out an independent audit of the process (Smith & Osborn 2008).

Results

Four overlapping themes were identified in the data, reflecting the young people's difficulties in coming to terms with, and responding to, depression: (1) struggling to make sense of their situation; (2) spiralling down; (3) withdrawing; and (4) contemplating self-harm or suicide.

Struggling to make sense of their situation

In attempting to comprehend their situation, sometimes the young people engaged in questioning themselves about why they were different, and why they could not be the same as other individuals in their age group.

> Well sometimes you get like thoughts of, why can't I be like other people, but you can't really change it, so it's just kind of negative to think about it. (Interviewee 5)

At some point in their predicament, they tried to make sense of their depression and the effect it had on their lives. They struggled to comprehend what was happening to them, to try to make the confusing understandable. It also involved trying to work things out, to find a way forward.

> It's kind of confusing. You know that something's wrong and you try and progress on things, but it's kind of hard when you know there is something going on in your mind or wherever else, and you try and figure it out or fix it, and it's just kind of hard sometimes and confusing. (Interviewee 1)

Another aspect of struggling to comprehend their situation was an acknowledgement that the circumstances were unique to each individual. For some, the severity, duration and consequences of their depression were considerable, whereas for others they were more manageable.

> Everything's just harder to get through, and you want to isolate yourself and you don't actually want to be a part of all the normal things. (Interviewee 9)

> I think it's different for each person, because I don't believe that I have, like, depression and anxiety to a full extent, only have like a tiny bit. (Interviewee 2)

Spiralling down

As the depression became more prominent in their lives, the young people felt that their quality of life was spiralling down. There were several aspects to this process: they felt they were deteriorating mentally to the extent that they were uncertain how to reverse the situation; their confidence and self-esteem was decreasing; they experienced physical and mental fatigue; the depression was dominating their lives; and they had difficulty concentrating and doing the taken-for-granted things in their daily lives.

The young people felt they were deteriorating mentally to such a depth that they were unsure how to return their lives to the state they were in mentally before becoming depressed.

> . . . with the depression spiral you just keep going down and down, and it's horrible. You get into a pit where you just can't get out anymore and you don't know how to dig your way out. (Interviewee 14)

Other aspects of spiralling down were a decrease in confidence and self-esteem, coupled with physical and mental fatigue.

> Well, it lowers your confidence. It doesn't give you the confidence to do the things you want. Like, it makes you more fatigued. You don't have that, the energy; you feel more restless; stuff like that. I don't know how to explain it. (Interviewee 13)

Their depression and associated problems were also becoming self-consuming, dominating their lives and making it difficult to concentrate on and become motivated to accomplish the taken-for-granted aspects of daily life.

> I feel like it's a condition that is really self consuming. It's really exhausting. And like I feel like it's hard to accomplish things or to see myself accomplish things. (Interviewee 22)

Withdrawing

One consequence of spiralling down is that sometimes the young people withdrew from those around them, such as family and friends. While some disclosed their depression to friends, others withdrew, fearful of the perceived stigma and loss of status from being labelled as having mental illness. In some instances, withdrawal was prompted by the desire to preserve existing friendships, fearful that if friends became aware of their situation they would relinquish their friendship permanently. In order to protect themselves and preserve friendships, young people responded by being secretive and not disclosing their situation to others beyond their immediate family.

> I think the bad things would be the stigma associated with it, because it's not something that you'd want to go and tell any of your friends that you have it, because you'd be perceived differently. (Interview 2)

Withdrawing was also be influenced by their desire to refrain from talking to others about their circumstance, to give themselves space and time to reflect on their situation, to try to work things out. However, retreating from others contributed to their loneliness and isolation.

> I've been suffering since I was 14. Yeah, like everything's just harder to get through, and you want to isolate yourself and you don't actually want to be a part of all the normal things. (Interviewee 9)

Contemplating self-harm or suicide

Another consequence of spiralling down was that some young people contemplated or attempted self-harm or suicide. This was attributable to a combination of the suffering brought on by their depression and perceptions about the way others may react to their situation. At one

level, in response to their depression and related problems, some engaged in various forms of self-harm, such as sexually promiscuous behaviour, drug and/or alcohol abuse, as a way of coping with their depression.

> . . . because of being depressed I have made really stupid choices, and done some stuff that's given me a really bad reputation. I started having sex with heaps [lots] of different people, and drugs and alcohol were even worse. And then the depression came . . . at the start of this year, I hit rock bottom . . . (Interviewee 23)

At another level, some responded by contemplating or attempting suicide, an act that could have brought an abrupt and dramatic end to their suffering.

> Suicide attempts, to like the point where I cracked my skull when I . . . [ended up in] a rehabilitation unit to learn to walk and talk again for . . . [number] months. . . . I had . . . [number of suicide attempts] attempted suicides and they all [resulted in] hospitalization since I was . . . [number] years old. (Interviewee 9)

Discussion

This exploratory study provides an understanding of the experience of young people with depression, a research topic that has received little attention to date. The results presented four overlapping themes that depicted their difficulties comprehending and responding to their circumstances.

First, the young people had difficulty coming to terms with their depression, while at the same time it cast an increasing shadow over many aspects of their lives, as reflected in the theme struggling to make sense of their situation. This indicates that the experience was difficult, demanding and unpredictable for some participants, and led to uncertainty about their present and future. However, overlapping with these feelings was a desire to try to work things out, to recover. Implicit in this situation was an acknowledgement that something was wrong in their lives, similar to Dundon's (2006) meta-synthesis of young people's experience of depression where they recognized that what they were encountering was 'beyond the blues', a situation that was much more challenging than a short-term period of unhappiness that most individuals encountered in their lives. There was also recognition in this study of the difficulty they had in trying to work things out, to make the confusing comprehensible. At the same time, the uniqueness of the experience for individuals was evident. For some, the severity, duration and consequences of their depression were considerable; for others depression was troublesome but manageable. This parallels, somewhat, the findings of MacDonald *et al*.'s (2005) study of young people recovering from first-episode psychosis, where the authors stated there is uncertainty about whether it is the stigmatizing nature of the illness or its severity, including symptomatology, that contributed more to the adverse experience. In the present study, it seems that the stigmatizing nature and the severity of the depressive illness both contributed to the experience.

Second, overlapping with the difficulty in coming to terms with their situation was the increasing prominence of depression in the young people's lives. Most felt they were losing control or spiralling down, with the problems affecting adversely their physical, psychological and social well-being. As a result, they were uncertain how to reverse their unfavourable situation. This was also apparent in Dundon's (2006) meta-synthesis, where the struggle to maintain existing relationships and roles became overwhelming and, as a consequence, their social isolation increased.

Third, a consequence of struggling to make sense of their depression and associated problems and spiralling down was that some young people responded in self-protective and reflective ways to their predicament, and these were reflected in the theme withdrawing. They did this in order to protect themselves from unwarranted stigma and, in some circumstances, to preserve existing friendships. Withdrawing also gave them an opportunity to reflect on their situation and try to resolve their problems.

There were paradoxical consequences, however, of withdrawing. In the short term, it helped protect the young person from stigma, by reducing the possibility of differences being detected by others (Hinshaw 2007). Indeed, withdrawing was considered justifiable in view of the marked differences in the public's attitude towards those with physical and mental illnesses (Angermeyer *et al*. 2003). However, withdrawing prevented the young people from having contact with and obtaining support from others, and increased their social isolation and alienation from friends (Schulze & Angermeyer 2003, Gonzalez-Torres *et al*. 2007). Farmer (2002) found a similar paradox; the young people chose solitude even though they were feeling alone and wanted friendship. Another implication is that with some young people withdrawing contributes to delays in help-seeking from primary care or mental health services (Crisp *et al*. 2005). It is recognized that the longer the duration of untreated illness, the worse the outcome for the young people's depression (Altamura *et al*. 2010).

Fourth, another repercussion of struggling to comprehend their situation, spiralling down and withdrawing was that some young people contemplated or attempted self-harm or suicide. At one level, this resulted in them engaging in a range of maladaptive behaviours in order to cope with their depression and associated problems, such as misusing alcohol and illicit drug use (Deitz 2004, Baker *et al*. 2007)

and engaging in risky sexual behaviours (Hallfors *et al*. 2005). At another level, this contributed to some attempting or committing suicide (Deitz 2004). Indeed, a considerable proportion of young people who commit suicide may have undiagnosed or under-treated mental illness, and the strongest risk factor for suicide in this age group is mental illness (Agerbo *et al*. 2002).

Limitation

The main limitation of the study is that recruitment through key clinicians might have produced an atypical sample of engaged young people with depression who had different experiences than those who were not engaged with the service.

Conclusion

Depression in young people gives rise to several adverse, potentially life-threatening experiences and these events are interrelated. These experiences undermine directly the well-being of the young person. Our findings have three key implications for communities, primary care practitioners and mental health professionals, including nurses. First, there is a need to improve community mental health literacy, so that families, friends and those whose work brings them into contact with young people are more aware of the signs of depression and how to respond appropriately with them. Mental health professionals also need to appreciate the differences between depression in adolescents and adults. Second, government funding is needed to counteract stigma and improve community understanding of, and support for, young people with depression and other mental health problems. Primary care practitioners and mental health professionals, including nurses, play a key role in providing timely access to care and strengthening young people's ability to counteract stigma by promoting their self-empowerment. Third, in light of the detrimental effects of depression and the increased duration of untreated illness, including the likelihood of self-harm and suicide, it is important that effective interventions are readily accessible to young people. Understanding the experiences of those who are not engaged with services is an important area of future research, as well as developing and evaluating initiatives that improve young people's help-seeking.

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