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Listen and learn: engaging young people, their families and schools in early intervention research

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ABSTRACT

Recent policy guidelines highlight the importance of increasing the identification of young people at risk of developing mental health problems in order to prevent their transition to long-term problems, avoid crisis and remove the need for care through specialist mental health services or hospitalisation. Early awareness of the often insidious behavioural and cognitive changes associated with deteriorating mental well-being. however, is difficult, but it is vital if young people, their families and those who work with them are to be fully equipped with the skills to aid early help-seeking. Our early intervention research continues to highlight the necessity of engaging with and listening to the voices of young people, families and those who work with children and young people, in developing greater understanding of why some young people may be more at risk in terms of their mental health, and to provide children and young people with the best mental health support we can. Collaborative working with young people, their families and those who work with them has been an essential dimension of our youth mental health research in Birmingham, UK, enabling us to listen to the personal narratives of those with lived experience and to work alongside them. This paper highlights some of our key studies and how we have endeavoured to make intra-agency working successful at each stage of the research process through increasing use of digital and youth-informed resources to engage young people: a methodology which continues to inform, guide and develop our early intervention research and implementation.

INTRODUCTION

Intervening during the early stages of a young person's mental health problems may help prevent transition to long-term issues, avoid crisis and remove the need for care through specialist mental health services or hospitalisation. The work of the CLAHRC-WM (Collaboration for Leadership in Applied Health Research and Care, West Midlands) Youth Mental Health theme focuses specifically on early identification and intervention for young people with regard to their mental health. The Five-Year Forward View (2014), published by NHS England, emphasised the need to design and deliver new models of healthcare to better meet the needs of patients. In particular, the report highlighted the necessity for greater engagement with patients, carers and communities in order to improve care pathways, promote well-being and prevent ill health.2 This paper highlights some of the key research of the CLAHRC-WM team and illustrates the importance of greater engagement and consultation with young people with regard to their mental health.

TALKING ABOUT FIRST-EPISODE PSYCHOSIS

Understanding who may be at risk of developing mental health problems and providing the opportunity to intervene before things reach crisis point is, however, problematic. Young people, their relatives or carers and those who work with young people may experience difficulties in recognising the need for help and also struggle with how, when and where they can access mental health support. This situation can leave many young people in a highly vulnerable state, experiencing untreated mental health difficulties for inordinate amounts of time prior to reaching specialist treatment.

This challenging state of affairs was highlighted in our recent exploration of the care pathways of young people with first-episode psychosis (FEP), specifically focusing on those who experienced a long time between the onset of their psychotic symptoms and accessing specialist treatment (referred to as DUP (duration of untreated psychosis)),³ which has significant consequences for ongoing mental health and treatment outcomes.⁴ ⁵

Early intervention teams (EIT) are specialised services for young people between the ages of 14 and 35 who are experiencing the symptoms of FEP. EIT are accessed via referral from primary care, for example, a general practitioner (GP), or from within secondary mental healthcare teams, such as a community mental health team (CMHT) or child and adolescent mental health services (CAMHS). These teams offer multidisciplinary, multiagency assessment, treatment and care for those with a wide range of mental health problems.

Our exploration of the care pathways of a group of young people who had been accepted to an EIT in Birmingham, but who had experienced a long DUP (>6 months)³ revealed that long DUP was often due to young people and their families not seeking help for symptoms during the early stages of their illness. This was typically due to poor knowledge and awareness of the early warning signs of psychosis and stigmatic attitudes regarding mental health; knowledge and awareness often informed by negative media representation of mental ill health; and adverse familial experiences of mental health service provision. However, even when early help was sought, many young people went on to experience further delays within mental health services themselves, most commonly with delayed referrals from secondary CMHTs to specialist EIT due to under-recognition of psychotic symptoms by staff, poor disclosure or disengagement from services.



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This work described analysed care pathway documents and medical notes to paint the picture of a typical care pathway of someone with long DUP. While informative, this methodology was, nevertheless, restricted by the quality of accessible clinical documentation. In order to fully understand the subjective experience of a young person with FEP, we felt it essential to take time to engage with them and listen to their voices and the voices of those who care for them. The importance of engagement and consultation with young people regarding their welfare was highlighted by Article 12 of the United Nations Convention on the Rights of the Child almost 30 years ago.⁶ Signed by the UK in 1991, this document stressed the need to explore and consider the views of young people and children with regard to their well-being, to fully appreciate their needs and improve child and adolescent service provision. Following further recommendations from the Health Advisory Service in 1995, there has been a growing focus on the engagement of young people;8 9 a survey by Young Minds, 'Stressed Out and Struggling' (SOS) Project (2006), concluded that young people 'want to be consulted and to be involved in the development of services, and commissioners will find that this involvement will help shape and guide improvement'. 10 Yet, despite the WHO estimation that, globally, around 20% of young people will experience a mental health disorder in any given year, 11 with one in ten requiring ongoing support or treatment for severe or persistent issues such as depression or anxiety, successful engagement and partnership working with young people to inform and shape youth mental health services is still a relatively new process and not standard practice. In light of such findings, we enhanced our psychosis care pathway analysis with an in-depth exploration of the personal narratives of young people who had experienced a very long DUP (>12 months) and their families. 12 Fourteen complete 'family' dyads (a young person and their primary carer) consented to be interviewed about their experiences of emerging psychosis. All were interviewed individually in their own homes or another, previously agreed, setting. The stories they shared exposed the complexity of the help-seeking process, the tremendous difficulties they had faced in recognising the early warning signs of mental ill health, the stigma they experienced and the challenges they encountered knowing how, when and where to seek help. Inability for young people to fully comprehend the seriousness of their symptoms. to determine and source what help was needed, and to be able to communicate these needs to family members and mental health professionals, were common.

Being able to distinguish between the usual emotional unrest and turmoil typically associated with adolescence and what may be a serious mental health problem is notoriously difficult, and many carers told us how they had mistakenly interpreted the early signs of their relatives' illness as part of a 'teenage phase' which they hoped would pass and which had prevented them from early help-seeking. Even when help was sought from health professionals, however, tales of poor engagement with secondary mental health services had further impacted on the young person's swift and timely referral to EIT. While we acknowledge that the factors associated with poor help-seeking are often complex and idiosyncratic, our findings highlighted how the poisonous combination of delays in help-seeking *along-side* delays within secondary mental health services was responsible for long DUP in Birmingham.

CHANGING THE CARE PATHWAYS OF THOSE WITH FEP

In response to these significant findings, we were keen to explore the ways in which we might be able to reduce the DUP

of young people with FEP, by directly targeting the delays identified by our interviews, improving understanding and awareness of the early warning signs of psychosis and ways to seek help, and developing better connections and engagement with mental health services. The successful TIPS study ('Tidlig oppdagelse og behandling av psykoser'-early detection and treatment of psychosis)¹³ used such an approach in an attempt to reduce DUP in Norway. Their trial introduced an early detection team for psychosis in a specified area of Norway but cleverly combined it with a youth-appropriate public health campaign aimed at improving awareness and knowledge of the early warning signs of psychosis, and was successful in reducing DUP in their context. Inspired by their results, we launched a proof-of-principle public health trial to explore whether adopting a similar approach to reducing DUP could be successful in our particular setting. 14 Our trial had two clear aims, directly driven by our previous findings: (1) to reduce the delays within secondary mental health services, through the introduction of a direct referral youth-friendly mental health service for FEP, providing seamless transfer to EIT and removing the need for further assessment by secondary mental health services, and (2) to improve knowledge, awareness and help-seeking by young people and their families, through the design, development and implementation of a youth-friendly 'psychosis awareness' public health campaign which would provide a range of resources to increase the knowledge, awareness and engagement of the wider community with regard to youth mental health.

The new youth access pathway ('YouthSpace') was launched in July 2011. This service promoted within local GP surgeries in the locality and was embedded within two large CMHTs located in a specified area in the south of Birmingham and provided direct access to EIT, with prompt clinical assessment in a youth-appropriate setting for young people with FEP.

The central information and communication hub for the public health dimension of our trial, however, was our youth mental health website, http://www.vouthspace.me. Carefully designed through consultation with young people, the website was our primary source of engagement with the community, providing young people, their families and those who work with them with youth-friendly, engaging, easily accessible and trusted online sources of mental health information, to improve their knowledge, promote discussion and raise awareness of FEP and, thereby, help improve help-seeking behaviour for psychosis. The public health campaign was informed using the 'Precede-Proceed' public health model framework¹⁵ and emphasised the use of youth-friendly images, text and content informed by ongoing consultation with our advisory board of young people with experience of mental health problems ('YouthBoard') and their families. Throughout the campaign, these groups provided great insight and expertise in the design and development of the website and campaign resources, including the use of the strapline 'Don't turn your back on the symptoms of psychosis' which featured on all campaign merchandise. The YouthBoard also produced a host of photographs and films about youth mental health and inspiring blogs which described their own experiences of psychosis and engaging with mental health services. These resources were available via the website and displayed at a variety of community events in the area. This extensive methodology enabled ongoing assessment of context and setting which evolved throughout the campaign to ensure a responsive, stratified 'knowledge-transfer' approach to our public health campaign.

While the website functioned as the central information and communication hub of the public health dimension of the

Original article

campaign, we were very aware of the importance of embracing wider social media in engaging young people. Facebook and Twitter links, therefore, featured on all campaign materials (see figures 1 and 2) and gave us further opportunities to open a range of channels of communication with young people and their families, and the wider community, including schools and third sector organisations, to discuss youth mental health, learn about the benefits of early help-seeking and to 'spread the news' about the early warning signs of psychosis.

This targeted and youth-focused approach was effective in reducing DUP from median of 71 to 39 days. Delays within mental health services and help-seeking behaviour were also reduced. Our successful trial is the first UK study to reduce the DUP in young people with FEP. 16

SCHOOLSPACE

While experiencing a serious mental health problem, such as psychosis, can result in lower educational attainment and increase the likelihood of participation in smoking, drug and alcohol abuse, and risky sexual behaviour, ¹⁷ it can also have long-term consequences for a young person's mental well-being

as they transition into adulthood. With half of lifetime mental health problems occurring *before* the age of 14,¹⁸ the design and development of feasible, youth-appropriate and acceptable strategies to help improve recognition and avoid young people falling into crisis and requiring specialist mental health services is essential.¹⁹ Failure to do so may cost lives and also have serious economic consequences.²⁰

Teachers and school nursing staff have great potential to be the instigators and communicators of early detection strategies to first identify and then work with vulnerable young people who may not have reached the threshold for diagnosis, or who are deemed at high risk. The Royal College of Nursing report on school nursing in 2012²¹ cites the government's public health white paper from 2004 'Choosing health: making health choices easier'²² ²³ which recognised the essential role that school nurses play in improving outcomes for children and young people and committed to providing schools with 'at least one full-time, year round, qualified school nurse for each secondary school and its cluster of primary schools'.

Research indicates that mental health awareness and education programmes, embedded within the school curriculum and

Figure 1 Campaign poster.





Figure 2 The YouthSpace branding on campaign materials.

delivered within schools can be extremely beneficial for young people,²⁴ especially when using a 'whole school' approach whereby positive mental health and well-being is integrated into the ethos of the school. School nurses, however, are often overstretched;²¹ safeguarding and child protection work and national immunisation campaigns can take precedence over additional health-promoting activities. The role of educating young people about mental health, identifying and supporting those at risk, therefore, increasingly falls to teaching staff who may struggle to deliver consistent, youth-friendly mental health programmes, due to an increasingly packed curriculum with a primary focus on academic concerns and lack of expertise in the subject having received little or inadequate training. Recent reports from the Department of Health emphasise the importance of providing robust mental health training for teachers in order for them to offer appropriate education and support for their students. 25 26 While many schools in the UK provide excellent programmes and support for their students, it is acknowledged that many do not, with mental health failing to be treated as a priority. Youth mental health is often only alluded to during initial teacher training in relation to safeguarding policies and is not necessarily included as part of continuing professional development, despite the increasing expectations put upon teachers to provide support for young people presenting with mental health issues. Acknowledgement of this shortfall has led to increased calls for child development and mental health to become essential components of the teacher training programme, enabling trainee teachers, in particular, to become proficient in supporting young people with their mental health.

It was through our contact with schools during the psychosis awareness public health trial that teachers revealed to us their concerns about their increasing role in supporting students with their mental health. Many questioned their capacity to access and deliver reliable youth-appropriate educational material and expressed further frustration at the difficulties faced when trying

to secure professional help for a young person in their care. To explore these issues further, we conducted an online survey with teachers in Birmingham.²⁷ One hundred and sixty secondary schools in the Birmingham Local Education Authority (LEA) were approached in November 2010. A total of 320 teaching staff responded to the survey over a 3 month period (58% female and 39% male, of predominantly white British heritage (87%); 72% between the ages of 26 and 55 years). Teachers confirmed that, they do feel ill-prepared to support young people with their mental health, and that they themselves suffered from increasingly high levels of stress, dealing with their own mental health difficulties often preventing them from effectively supporting their students. Those who had experienced problems with their own mental health felt that lack of support and understanding of mental health from senior management teams had sometimes led them to hide their needs for fear of being regarded as unprofessional and unable to cope. Through this survey, it became evident to us that despite teachers being expected to support increasing numbers of young people with mental health problems such as depression, anxiety, eating disorders (EDs) and self-harm, they are themselves at risk and ill-prepared for the role.

These findings prompted the development of the 'SchoolSpace' network, a group of schools in Birmingham, UK, committed to working in collaboration with us in our early detection and intervention research. This collaboration aims to improve mental health education in schools, engage with young people and support teachers in their role as mental health advisors with a range of specially designed resources for themselves and their students to use. The network is also an opportunity for teaching staff and students to participate in our youth mental health research and play an integral part in the future design and development of evidence-based interventions, suitable for use within the school environment.

EDS—THE SCHOOLSPACE STUDY

In order to develop evidence-based interventions for young people and to help prevent crisis, it is necessary to clearly understand the risk factors that are associated with the development of mental health difficulties. Approximately 80 000 children and young people are estimated to suffer from depression and anxiety in Great Britain. ²⁸ ²⁹ Such problems can often feature as early warning signs of other adolescent mental health problems, such as EDs and self-harm, ³⁰ ³¹ both of which can result in serious physical and mental consequences.

Anorexia nervosa (AN) is suggested to have risen threefold during the past 40 years³² and is predicted to rise further, and it is estimated that up to 40% adolescents have engaged in selfharm at some point in their lives, with the average age of onset 12–14 years.³³ Early identification of young people at risk, however, remains a neglected area of research,³⁴ and population studies to recognise early risk factors prior to full emergence of the illness are few.³⁵ As with all mental health problems, paying greater attention to the risk factors before a clinical diagnosis of ED is reached, however, it may be possible to prevent many young people from requiring hospitalisation and long-term care. Primary risk factors for ED often focus on the physical characteristics of a young person such as perceived body size and weight. Emerging literature suggests, however, that nonweight factors, such as perfectionism, depression and anxiety, may be more helpful in determining those at risk and understanding the function that disordered eating behaviour may serve for individuals, such as emotional regulation.³⁶ This was recently highlighted in qualitative explorations with young people.³⁷ Studies in this area often focus on exploring young people's concepts of dieting and thinness,³⁸ but a longitudinal cohort study in 1999 revealed that, while dieting was an important predictor of EDs in young women, it was psychiatric morbidity, such as pre-existing depression and anxiety, that increased their vulnerability during the early stages of their disordered eating behaviour and put them at an almost sevenfold increased risk of going on to develop a full-blown ED.³⁵

Even just one discussion about eating behaviour, weight or shape concerns during a consultation with a young person in a primary care setting can be a strong predictor of the subsequent development of an ED.³⁹ Indeed, in the 5 years preceding their ED diagnosis, girls with early onset AN have been observed to visit their GP more frequently to discuss issues involving eating, weight and shape, compared with girls with other mental health problems and healthy controls.³⁷ Despite this knowledge, however, 50% of children under the age of 13 diagnosed with childhood onset ED are so unwell by the time they have accessed secondary care that they require immediate hospitalisation.

Universal interventions to prevent the development of ED in children and young people focus on providing all young people with useful strategies and knowledge, rather than specifically targeting those deemed 'at risk'. Universal interventions are typically implemented within a school setting and aim to raise general awareness of ED, exploring a wide range of attitudes and behaviours associated with disordered eating behaviour, improving media literacy and increasing their sense of advocacy in relation to body image and representation. While such interventions are often less stigmatising for young people and offer wide application, they are often generic, offering insufficient evidence to suggest they are effective for those deemed at risk.⁴⁰ Targeted interventions produce the largest treatment effects, make the best use of limited resources and increase understanding of the wide range of risk and maintenance factors⁴¹ in the ED 'at-risk' population.

In an attempt to add to the literature regarding risk and resilience factors associated with the development of ED in adolescence, we recently conducted an online early detection ED study with the schools and students in our 'SchoolSpace' network via http://www.youthspace.me . Overall, 784 young people (male and female, aged 13-16 years) completed a survey at least once during the 24-month period (September 2014— March 2016). The study was approved by the Research Ethics Committee at the University of Birmingham. Great care was taken in designing the survey to be attractive and meaningful to young people to help ensure high levels of engagement and participation given the potentially difficult subject matter. Students completed measures recording their eating behaviour, levels of depression and anxiety, incidents of self-harm, any difficulties with emotional regulation, levels of self-esteem, body esteem, adherence to food rules and dieting behaviour. Preliminary analysis of the data from the first two surveys has revealed that around 8% of young people reported some disordered eating behaviour. These were predominantly female and also reported greater levels of dieting behaviour, adherence to food rules, lower body esteem, difficulties with emotional regulation, greater levels of depression and anxiety and low self-esteem. Outcomes from this study will help us to develop a greater understanding of the risk and maintenance factors associated with the development of disordered eating behaviours during early adolescence and to work towards codesign and development of youth-informed screening tools and evidence-based interventions for use in schools in order to prevent ED. The importance of such evidence-based interventions and screening tools was recently highlighted by the Mental Health Commission of the think tank CentreForum stating that '65 per cent of schools do not use screening tools to differentiate between severity of mental health need (mild, moderate or severe). Yet, in schools where these tools are used, 85 per cent of head teachers reported they were effective'. 42

CONCLUSION

An estimated 10%-20% of children and young people worldwide are affected by mental health issues, 43 approximately 15%–25% of these psychiatric disorders believed to emerge during adolescence.⁴⁴ Half of lifetime cases of psychiatric illness have had their onset by the age of 14, with around threequarters by the age of 24; 18 78% of cases 18-26 years old with mental health problems have been diagnosed before the age of 18, and 58% before age 15.45 Multiple prospective assessments, such as The Great Smoky Mountain Study¹⁸ and The Dunedin Study, 46 have revealed the extent and cumulative rates of mental health disorders during adolescence, concluding that lifetime prevalence of such problems during adolescence is around 40%. However, for those aged between the ages of 9 and 21 years, the figure has been argued to be more like 60%, rising to 80% if diagnoses 'not otherwise specified' are taken into account, a diagnosis given to many young people presenting with low level or comorbid mental health problems which are unable to be captured using traditional DSM diagnoses.⁴

Many of the mental health problems experienced by young people will usually resolve themselves, without the need for specialist treatment or hospitalisation. It is the *duration of an untreated episode* which is likely to determine recurrence.⁴⁸ This highlights the urgent need for greater understanding of the early warning signs of mental distress in young people. Listening to their personal experiences, engaging them in the design and development of preventative mental health strategies and encouraging them to become

Original article

active participants in the research process are essential if we are to be able to provide truly effective early intervention.

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