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Conditional Disclosure on Pathways to Care: Coping Preferences of Young People at Risk of Psychosis

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Abstract

The interrelationship between stigma and help-seeking is under-researched amongst children and adolescents. This study explored stigma in relation to pathways to care amongst young people putatively in an early stage of increased risk of developing psychotic disorders. ‘Pathways to care’ was defined as help-seeking and support from informal and formal resources, and increased risk was determined though the presence of persistent psychotic-like experiences and internalizing/externalizing psychopathology. Twenty-nine qualitative interviews were analyzed using thematic analysis. We defined the super-ordinate theme in these data as “conditional disclosure”; a concept reflecting the rules and prerequisites that influenced how/whether participants sought help. Through parallels between these findings and established stigma theory, we examined how these conditions could be interpreted as influenced by stigma. Our findings demonstrate the influence of stigma on young people's perceptions of a range of pre-clinical symptoms, and on how they seek support for these symptoms.

Key words: Adolescents, Youth, Young Adults, At Risk; Adolescents, Youth, Young Adults, Mental Health and Illness; Children, Illness and Disease; Community and Public Health; Social Support; Confidentiality, Privacy, Disclosure; Health, Health Promotion; Health Care, Access to; Psychology, Psychological Issues; Stigma; Illness and Disease; Prevention; Western Europe, Britain**;** Research Strategies, Interviews; Research Strategies, Thematic Analysis

Mental health problems are estimated to affect around one in ten children and adolescents (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). These early difficulties can develop into longstanding issues; indeed, the origins of most adult mental disorders can be tracked back to early life, with onset for around half of lifetime cases occurring before the age of fifteen years, and three-quarters by the mid-twenties (Kessler et al., 2007). Early difficulties are also associated with disrupted social functioning, compromised educational attainment, and negative impacts on, for example, adulthood relationships and marriage stability, parenting, physical health, and socio-economic outcomes (A. Goodman, Joyce, & Smith, 2011; Riglin, Petrides, Frederickson, & Rice, 2014). These early difficulties remain untreated for many, and this under-treatment of mental disorders amongst children and adolescents is recognized as a public health concern around the world (Polanczyk et al., 2015). For example, in Great Britain, only 24% of children aged 5-16 years with a diagnosable mental disorder had received treatment from specialist mental health services within the previous year (Green, McGinnity, Meltzer, Ford, & Goodman, 2005). An improved understanding of the mechanisms, stages and patterns underlying young people's help-seeking and service use, and the potential barriers to these processes, could inform strategies aiming to reduce this treatment gap.

One potential barrier to receiving care is mental-health related stigma. Stigma has been defined as the situation of a person disqualified from social acceptance due to possessing a deeply discredited attribute, which reduces the stigmatized individual from a whole and usual person to a tainted and discounted one (Goffman, 1963). This definition outlines that, in the case of mental illness, this attribute reflects a blemish on the individual character. Stigma has been conceptualized in many ways. For example, one frequently cited conceptual framework outlines stigma in terms of six interrelated processes: distinguishing and labelling differences, stereotyping, separating people into in- and out-groups based on these differences/stereotypes, emotional reactions following these processes, status loss and discrimination amongst those labelled, and these processes taking place within a power context favoring the stigmatizers (Link & Phelan, 2001; Link, Yang, Phelan, & Collins, 2004). It is proposed

(Pescosolido & Martin, 2015) that stigma can be categorized, for example, based on how it is experienced (perceived, endorsed, anticipated, received, or enacted) or in terms of who (or what) gives or receives the stigma (e.g., public stigma, endorsed by the general population; structural stigma, enacted through laws, policies, and constitutional practices; courtesy stigma, acquired through a connection with a stigmatized group/person; and self-stigma, legitimizing and applying of publicly held stigmatizing attitudes to oneself).

Receiving a psychiatric diagnosis, or contact with mental health services, can initiate the labelling process and the development of a stigmatized identity (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Subsequently, publicly endorsed stigmatizing views can impact on a person with mental illness (Corrigan, Kerr, & Knudsen, 2005), a person might anticipate or experience stigmatizing responses and discriminatory behaviors from others (Lasalvia et al., 2013; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009), or apply stigmatized stereotypes to themselves and experience self-stigma reactions such as reduced self-esteem (Corrigan, Larson, & Rüsch, 2009). Stigma is reported to potentially significantly reduce people's help-seeking choices (Savage et al., 2016). To avoid stigma-related outcomes, people have been reported to, for example, delay help-seeking or minimize service contact (Thornicroft, 2008). Such influences of stigma remain under-researched amongst children and adolescents, and to our knowledge no review has specifically examined stigma and help-seeking/service contact amongst young people. However, the findings of two systematic reviews with a broader focus have highlighted the importance of these dynamics. The first focused on barriers and facilitators to mental health help-seeking amongst young people (primarily student populations), and identified stigma as the most important barrier to help-seeking (Gulliver, Griffiths, & Christensen, 2010). The other review examined stigma and help-seeking across a range of populations (both in terms of age and mental health status), and subgroup analyses revealed that help-seeking amongst people under the age of 18 years was disproportionately affected by the influence of stigma, compared to adults (Clement et al., 2015).

The influence of stigma on pathways to care might be particularly pertinent for young people at risk of developing psychotic disorders. Namely, psychosis is a highly stigmatized condition (Angermeyer & Matschinger, 2003; Thornicroft et al., 2009), and stigma-related barriers to care have been reported following the initial onset of psychosis (Franz et al., 2010). While it is recognized that stigma-related concerns might be present already in at-risk stages of psychotic disorders, research in this area is sparse and has focused primarily on the impact of labelling through clinically defined high risk statuses or following interventions targeting prodromal symptoms (Nieman & McGorry, 2015). In addition to stigma related to at-risk labels and treatment, it has been reported that also the symptoms and behaviors associated with the prodromal stage of illness (i.e., the symptomatic stage that immediately precedes psychosis onset) can elicit stigmatizing attitudes (Anglin, Greenspoon, Lighty, Corcoran, & Yang, 2014). Another study concluded that both the at-risk label and risk symptoms were associated with stigma, but more stigma was described in relation to the symptoms (Yang et al., 2015). Overall, however, research examining stigma in relation to at-risk (premorbid) stages of psychotic disorders is sparse. Furthermore, explorations of how stigma might impact on initial coping preferences and pathways to care (i.e., help-seeking from both informal and formal sources of support, and possible service contact) amongst individuals in at-risk stages are even less common. It is thus not clear how early stigma-related concerns might manifest amongst people at increased risk of developing psychosis, and how they might influence the early stages of their pathways to care.

It is suggested that the presence of psychotic-like experiences (PLEs) can be used to assess early stages of increased risk of developing psychotic disorders, before the illness proceeds to a stage where prodromal symptom criteria are met (Keshavan, DeLisi, & Seidman, 2011; Laurens & Cullen, 2016). PLEs reflect attenuated psychotic symptoms below the threshold of frank psychosis. They are common in the population, and generally transient in nature (Keshavan et al., 2011; van Os & Linscott, 2012). However, PLEs are considered clinically significant given their association with increased risk for developing psychotic disorders (Linscott & van Os, 2013), and the continuum perspective of psychosis considers PLEs reflective of the softest expression of an extended psychosis phenotype (Van Nierop et al., 2012). Persistent PLEs, or PLEs that occur comorbidly with social, emotional, or behavioral problems might be particularly indicative of increased risk for psychosis (Laurens & Cullen, 2016). Early, proactive and preventative interventions targeting early distress and psychotic-like symptomatology could ameliorate the impairment and persistence associated with PLEs, potentially reducing future risk for those with putative vulnerability for developing psychosis (Dimitrakopoulos, Kollias, Stefanis, & Kontaxakis, 2015; Maddox et al., 2013). Such efforts could be facilitated by an increased understanding of preferences and processes underpinning pathways to care during these early sub-diagnostic symptomatic stages. One factor to consider is the stigma associated with mental health, and how stigma-related concerns might influence help-seeking preferences and access to appropriate support. PLEs have been linked to stigma. For example, perceived public stigma was positively correlated with the experience of PLEs in a non-clinical sample (Lien et al., 2015), and stigma due to unusual experiences and mental health difficulties was reported by children experiencing PLEs and emotional distress (Maddox et al., 2013). However, to our knowledge, no study has examined possible stigma-related influences on pathways to care amongst young people, whose problem presentation is characterized by PLEs.

Thus, this study aimed to explore stigma and discrimination in relation to initial pathways to care from the perspective of young people putatively in an early stage of increased risk of developing psychotic disorders. ‘Pathways to care’ was defined as help-seeking and support from informal (e.g., family, friends) and formal (e.g., primary care, school-based support, specialist services) sources, and increased risk of developing psychosis by virtue of experiencing persistent psychotic-like experiences (PLEs) and comorbid internalizing/externalizing difficulties. This exploration built on first obtaining an understanding of the coping preferences and processes along pathways to care amongst young people characterized by this early symptom profile, and subsequently, examining how these could be considered as stigma-related processes. Specifically, we examined our findings in relation to the conceptual framework of stigma developed by Link and colleagues (Link & Phelan, 2001; Link et al., 2004), to assess how influences and experiences in participants' accounts could be understood as reflective of stigma.

Methods

Ethical permission for the study was granted by King's College London (reference PNM/12/13-68).

Twenty-nine individual semi-structured interviews were conducted (between April and October 2013) to examine stigma in relation to pathways to care amongst young people putatively at increased risk of developing psychotic disorders. Individual interviews were used to generate descriptions and interpretations of people's lived experiences, subjective social worlds, and the meanings assigned to these. Such subjective accounts are well suited to understanding how young people's help-seeking and service use are experienced and negotiated, and potential barriers encountered in this process (Boydell, Gladstone, & Volpe, 2006).

Recruitment and Sampling

Participants were recruited from families involved in the London Child Health and Development Study (CHADS); an ongoing prospective investigation of children recruited via population screening conducted in primary schools in Greater London, United Kingdom, between 2005 and 2010 when aged 9 to 11 years, over-representing families from deprived, ethnically-diverse inner-city areas (Laurens & Cullen, 2016). Young people from a subsample of the CHADS longitudinal community cohort (n=407; as reported in (Gronholm et al., 2015)) who met the following two criteria were eligible to participate in the present study: (1) at least one child-reported "certainly true" response among nine items assessing psychotic-like experiences (PLEs) (Laurens et al., 2007) at the CHADS screening assessment, and at least one "certainly true" or "somewhat true" response at follow-up data collection (on average two years later; see (Downs, Cullen, Barragan, & Laurens, 2013)); (2) internalizing or externalizing problems in the clinical (abnormal) range (approximately top 10% on population norms) as measured by child-reported

Emotional Symptoms, and/or caregiver-reported Conduct Problems, Hyperactivity-Inattention, and/or Peer Relationship Problems on the Strengths and Difficulties Questionnaire (SDQ) (R. Goodman, 1997) at CHADS screening, and at clinical or borderline range (approximately top 20% on population norms) at follow-up. Further, purposive sampling was used to achieve a balanced sample amongst those who met inclusion criteria in terms of the following individual and family-characteristics: gender, age, ethnicity, and caregivers' reports of stigma. Data on the first three characteristics were collected during the initial screening assessment (2005-2010), and data on caregivers' intended stigmatizing behaviors were collected using the Reported and Intended Behaviour Scale (Evans-Lacko et al., 2011) during subsequent data collection (2011-2012) (Gronholm et al., 2015).

Invitation letters were sent to individuals who met study inclusion criteria and had consented to further contact. These letters were followed up with a telephone call, and participation arranged for those interested. Participants aged 16 years or over provided written informed consent, and participants under 16 years of age provided written assent and their caregivers written consent indicating their agreement with the young persons' study participation. Participants received a £20 gift voucher as a thank-you for their time.

Study sample size was guided by thematic saturation; the final sample consisted of twenty-nine participants. Thirty-seven young people were approached during recruitment; amongst them, one could not be reached and seven declined participation. Reasons for non-participation included lack of time and/or interest in research involvement, and preference for questionnaire-based assessments. There were no statistically significant differences between those who participated and those who declined participation based on age (under vs. over age 16 years), gender, ethnicity ("white" vs. "other"), or caregivers' stigma (low vs. high scores; based on a mean split of the intended stigmatizing behaviors score). The mean age of the participants at interview was 15.7 years (*SD*=1.6, range 12.2-18.6 years). Table 1 characterizes the sample in terms of individual- and family-level characteristics used to define the target participant group.

INSERT TABLE 1 ABOUT HERE

Data Collection

Interviews were conducted on university premises or in the participant's home, during April to October 2013. All interviews were conducted by Petra Gronholm during doctoral research. Having previously worked as a researcher on the CHADS study Petra Gronholm was familiar with the families' research involvement, which facilitated rapport building during participants' interview assessments. To address potential power-imbalance between the researcher and participants, it was emphasized that the aim of the interview was to engage the young person in an interview as an expert in their own experiences, in which there were no "right or wrong responses" to interview prompts. Additionally, a process of exchanging participants' study consent forms for documents outlining their "rights" during the interview was implemented, as a symbolic gesture emphasizing the researcher's and participant's equal status. During the interviews, participants also completed psychopathology screening questionnaires (re-assessing SDQ and PLEs) to provide a break from talking, and a point of reflection that could elicit prompts on experienced difficulties during the interview. Interviews lasted between 50-82 minutes, were digitally recorded, and transcribed verbatim. Additional reflective notes were kept for each interview.

Topic guide development. A topic guide (see Table 2) was used during interviews. This was developed in three stages. First, a preliminary guide was structured around concepts identified as critical for young people's pathways to care: understanding early symptoms, coping strategies, disclosure, and help-seeking from various sources of support. Second, a focus group process refined this guide. The focus group was advertised to the Young People's Advisory Panel within Time to Change, England's biggest programme to challenge mental health stigma and discrimination (Henderson & Thornicroft, 2009). The invitation was limited to individuals able to reflect on personal experiences of early psychopathology; six young people took part (all female, aged 17-24 years). The focus group was used to identify potential problems with the intended interview procedure, and to learn how respondents talked about the phenomena of interest (see appendix for further details on the focus group process). Finally, six pilot interviews were conducted with colleagues knowledgeable regarding child and adolescent mental health, to test the feasibility and flexibility of the topic guide.

Overall, during the interviews participants were encouraged to reflect on coping with emotional/behavioral difficulties that they identified as most salient. That is, although the sample was defined by the experience of persisting PLEs, the interviews were not structured to explicitly explore PLE-related difficulties. The decision to not overtly ask participants about PLEs specifically was taken on ethical grounds, to ensure no alarm or concern was caused through alluding to putative early risk of developing psychotic disorders (McGlashan et al., 2007). Additionally, overall, a line of inquiry focused on PLE-related experiences only might not be useful for understanding pathways to care amongst people at increased risk of developing psychosis. Namely, help-seeking for PLEs specifically is not common (Gale, Wells, McGee, & Browne, 2011). Even amongst people at clinically defined ultra-high risk of psychosis, prodromal psychosis symptoms are not generally the main reason for service contact. Rather, people in these high-risk groups are reported to present at services primarily due to affective symptoms (Falkenberg et al., 2015), and seek help for problems linked to bullying, peer relationships, self-harm, anxiety and depression, rather than subclinical psychotic symptoms per se (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013). Thus, our study’s focus on coping in relation to personally meaningful emotional and/or behavioral difficulties was considered an ethically and clinically appropriate approach for exploring pathways to care amongst young people characterized by persisting PLEs; a problem profile reflecting an early stage of putative increased risk of developing psychotic disorders.

INSERT TABLE 2 ABOUT HERE

Data Analysis

NVivo 10 software facilitated analysis of the interview data.

Thematic analysis (Braun & Clarke, 2006) was inductively grounded in themes emerging from the participants' accounts. The analysis process involved: familiarization with the data; generating initial open codes and arranging these within an initial primarily descriptive coding frame; identifying themes amongst these codes, creating a thematic framework, and indexing and sorting data according to this framework (i.e., axial coding; reflecting implicit processes and relationships within the data); reviewing coded data extracts for coherence, and further refinement of the framework; and summarizing data and displaying the final model. The process commenced with coding by Petra Gronholm. A subset of interviews were independently coded by a Sara Evans-Lacko and another colleague, both experienced qualitative researchers. These codes were compared until consensus regarding an early coding frame was achieved. After this, Petra Gronholm proceeded with the analysis, and the process was periodically discussed with Sara Evans-Lacko and a third colleague familiar with the data, to increase rigor and validate the emerging thematic framework. A constant comparative approach was used; for example, initial themes were identified through an iterative process of drawing links between transcripts, and emerging themes were validated through comparisons of data coded within these. Disconfirming quotes were purposefully sought to validate the emerging thematic model through revising, broadening and confirming themes arising from the data. Themes were iteratively restructured within an overall model until a central, higher order concept emerged. To examine how these inductively derived themes might be understood as reflective of stigma, parallels were drawn between these and Link and colleagues' model of stigma (Link & Phelan, 2001; Link et al., 2004).

Results

We identified "conditional disclosure" as a super-ordinate theme, reflecting that although disclosure was the central element of young people's narratives about dealing with emotional and behavioral difficulties, it was dependent on rules and restrictions. Namely, the young people in this study discussed disclosure as a key factor influencing pathways to care, both in terms of opening up to seek help from informal sources of support (family and friends), and at times in terms of talking to formal service providers (general practitioners, school-based support, and specialist mental health services). Main themes reflected the conditions for disclosure; that is, the thoughts and processes on which it was dependent: (1) why is disclosure conditional; (2) who do young people disclose to; (3) how is conditional disclosure maintained, and; (4) the impact of conditional disclosure on pathways to care. These themes (illustrated in Figure 1) are discussed next, alongside selected supporting anonymized quotes (presented with participants' gender and age). Additional supporting and disconfirming quotes (where identified), are provided as an appendix.

INSERT FIGURE 1 ABOUT HERE

Why is Disclosure Conditional?

This theme described reasons young people reported for their conditional disclosure. Key features were anticipated or experienced reactions from others in response to disclosing their mental health related concerns – specifically, perceived risks of disclosure – and contextual and interpersonal factors which influenced expectations regarding these risks.

Others' reactions and risks of disclosure. Weighing up others' reactions along a risk-benefit axis appeared a core determinant of young people's disclosure decisions; most participants discussed opening up to others in terms of whether their reactions were expected to be helpful and understanding, or negative and unsupportive. Overall, when reflecting on possible outcomes of disclosure, "risks" of opening up were described in much more detail than potential benefits. Thus, others' anticipated unhelpful, negative and unwanted reactions seemed a key consideration based on which young people made disclosure-decisions.

A key feature of these perceived risks of disclosure was being viewed differently and subsequently judged negatively by others if a person's difficulties were known. Most participants described being scared and/or worried about changes to their public image, from healthy and "normal" to something “different”. This perceived change was expected to involve others’ negative judgements, such as being thought of as stupid, attention seeking and other stigmatizing and unwanted labelling.

> People judge you different ways (...) some people do think I'm a bit stupid fo- or silly, even. . . . They thought that I wasn't ... I wasn't quite as good or I wasn't... like… I wasn't as n-normal as everyone else. (Girl, over 16 years)
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> Probably some of them [friends] might be thinking like, I don’t know like, like judging and saying “Oh she’s just doing this for attention.” or whatever. Yeah. (Girl, under 16 years)
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> I thought, you know if I say something, people are going to think I’m mad. (Boy, over 16 years)

Some participants also expressed concerns regarding overt negative and discriminatory actions, such as bullying or name-calling, if their difficulties were known. In particular difficulties of a “psychological or mental” nature seemed to lead to such reactions.

> People started teasing me . . . It was more that I had an issue, it was more that I wasn't... normal. That there was actually something wrong with me and it wasn't like physical but it was... I don't know, psychological or mental, something wrong within my brain rather than something that they could see. (Girl, over 16 years)
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> In the dining hall, cos of the knives, cos they knew I cut they would be like “Oh, do you want a

> knife? Do you want a knife? You need to cut, you don't look well.". . . . Then we were doing in Maths, about like grams and like weight and that. And people kept asking, kept saying comments like "Oh how much blood would you have to lose before you die? How many pills would it take to kill yourself?". . . . They would have that little smug smile on their face and that look in their eye when you know they are aiming it at us. (Girl, under 16 years)

Many participants also discussed disclosure risks in terms of gossip and malicious rumors, which might "completely spiral out of proportion" (girl, over 16 years) and lead to "everyone talking about it" (girl, over 16 years). Consequently, control regarding disclosure was lost and it was no longer limited in the preferred "conditional" manner.

Some young people also discussed risks of disclosure in terms of a negative impact on peer relationships; that is, if their difficulties became known, others would not want to get to know them, or existing friendships would be lost.

Some participants also discussed a sense of being inadvertently treated differently through others' well-intended efforts to be supportive. Although these reactions were not purposefully malicious, they were nevertheless unwanted as they could seem condescending, or reinforced a sense of difference, non-normalcy, or being treated as less capable than others.

Factors influencing expected risks of disclosure. Judgmental social environments shaped participants' expectations regarding others' negative reactions. For example, participants described the school context as highly judgmental, and some had witnessed peers being treated badly due to their emotional/behavioral problems. Consequently, participants anticipated comparable negative reactions toward themselves if their difficulties were known. Stigmatizing media portrayals of mental health issues had also contributed to expectations of judgmental reactions from others.

> Cos like you see like on that, movies and people went to therapy . . . I thought I was going kinda cuckoo. . . . I thought they [friends] would have called me crazy. (Girl, under 16 years)

Additionally, some participants discussed perceived social norms around talking about personal thoughts and feelings as discouraging openness.

> We don't really talk about . . . It feels like very much taboo subject, how people are feeling. Um... and most things, things like growing up, changes... we just don't really talk about it. (Girl, over 16 years)

A further feature of contextual influences on disclosure was a sense that no blame was placed on those displaying judgmental attitudes. For example, one participant felt uncomfortable about opening up to her peers who were “quite ready to judge and like assume things”, but she also commented that “it’s not like they are bad people, ‘cos they like judge you” (girl, under 16 years). That judgmental tendencies remained unchallenged, even by those disadvantaged by them, illustrates the strength of the negative societal attitudes regarding emotional/behavioral difficulties.

Also participants’ personal beliefs and perspectives could limit disclosure. For example, some young people seemed reluctant to disclose their difficulties as they perceived that this would indicate that they accepted or admitted to being different from others. Also, disclosure was limited due to young people feeling embarrassed, weak or inferior due to their difficulties. Some participants also contrasted emotional and behavioral problems to physical issues. Subsequently, it was discussed how disclosure of the former specifically was restricted, as others’ reactions were expected to be more negative if a problem was “mental”, rather than if a person “like actually had a disease” and was “physically” unwell (girl, over 16 years).

> Like if you broke your leg, people wouldn't assume you did it for attention. . . . But if you like cut yourself, people would assume it [that this is done for attention]. (Girl, under 16 years)

Who Do Young People Disclose To?

Although concerns around negative reactions to disclosure were common, many young people also reported feeling comfortable about discussing their difficulties with others. These contradictory expectations illustrate that disclosure was not inevitably "risky", and under certain circumstances participants also felt able to open up and seek help for their difficulties. This theme reflected rationales regarding the "right people" to whom disclosure was considered appropriate.

Core characteristics for disclosure: close relationship, trust, ability to relate. Certain characteristics were discussed as critical for disclosure, as they were thought to lessen the likelihood of a potential confidante reacting negatively. First, a close relationship was important; knowing someone well helped anticipate their reactions, and disclosure could be restricted to those expected to respond in a caring and helpful manner. Second, a sense of trust within the interpersonal relationship was thought to ensure the conversation remained confidential, thus limiting risks of gossip and subsequent loss of control regarding disclosure. A final characteristic was the other person's ability to relate to the situation. This was likewise thought to ensure an understanding, rather than judgmental, reaction to the disclosed matter. A person's ability to relate was often judged by being of a similar age, or having experienced similar difficulties

> I'd rather avoid talking to people that maybe I don't know really well, because then I wouldn't be able to like read their reactions as easily. (Girl, over 16 years)
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> I think as I started really opening up, we were really close and then... I had trust in her and I knew she wouldn't tell anybody else. (Girl, over 16 years)

Relevant for informal and formal disclosure. Participants discussed core characteristics primarily in relation identifying the “right people” for disclosure amongst family and friends. However, similar considerations seemed important also when considering disclosure of difficulties within formal settings. Thus, whether young people felt comfortable to discuss problems with formal service providers seemed, to an extent, also dependent on whether disclosure-easing interpersonal characteristics were identified.

> The [school counsellor] said like how it would be confidential . . . And I felt like "Oh this is a person I can trust.". And that I can tell everything. (Girl, under 16 years)

How is Conditional Disclosure Maintained?

This theme described the practical activities and strategies participants discussed in relation to managing their disclosure.

Selective disclosure and concealment strategies. Nearly all participants described a preference for selective disclosure, both in relation to who they spoke with and how much was said. This was linked to the preference to only speak with people considered to possess the core characteristics for disclosure, as outlined in the previous theme. A number of concealment strategies were discussed in relation to achieving this selectivity. These included pretending to be happy or “acting normal”, evading questions and conversation by insisting everything was fine, making up excuses to conceal activities such as leaving class to attend counselling, and social withdrawal to make problems less noticeable.

> Get out of bed, put a smile on, just so people wouldn’t ask you questions like “Are you ok?”. . . . When you wanna cry [on the] outside, you just gotta put a fake smile on just act like everything's ok just to save the awkward questions. (Girl, under 16 years)

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> I used to go to CAMHS… when I got back I used to just say I went to the dentist. And I had to alternate between “Oh I went to the dentist”, “Oh I went to the doctor”. And then next time it happened, [I would say] “I went to the dentist.”. [Friends responded] “Again? It hasn't been six months?” and I'm like “Oh yeah, er my teeth were really bad I need an emergency check-up”. (Boy, under 16 years)

Impact on Pathways To Care

For most participants in this study the continuous process of assessing and managing risks of disclosure primarily constituted a layer of complexity that was navigated when determining appropriate coping options and actions, rather than a barrier that prevented progression along pathways to care. However, for some, disclosure-related concerns had resulted in noticeable help-seeking delays or reluctance to engage with sources of support. This theme captured these experiences.

Delayed disclosure to family and friends. The sense of fear or unease associated with the perceived risks of disclosure meant some participants had delayed opening up to family or close friends, at times until reaching a near-breaking point. Reflecting back on these periods of not seeking help, participants felt they would have benefited from opening up to others earlier.

> Uh, I held it in for about half a year, six months or so. So I was kind of trying to act normal but finally I just couldn’t do it anymore, I needed someone there. (Girl, under 16 years)

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> I think I made matters worse cos I, I could have, if I had spoken about it, I could have definitely got the right help, earlier. (Boy, over 16 years)

Rejecting formal services. Some participants anticipated particularly negative and judgmental reactions to situations where formal help was involved, with mental health-related stigma seemingly influencing these expectations. Additionally, formal services were considered inappropriate as this kind of support was thought relevant for severe issues only, and young people were reluctant to consider their difficulties in such terms.

> Some people at school knew I had counselling, but it just made it more awkward cos they were like “Oh so you need counselling now, are you that mental?”. . . . I didn’t really wanna do it [attend counselling], cos I felt like oh I’m gonna get people like constantly judging me, like labels put on me and stuff like that. (Girl, under 16 years)

Reluctance to engage with support was evident particularly in school-settings, where service contact was often noticeable to others.

> I'm allowed to ask if I can leave the classroom [when anxiety rises]. But um... I don't want to draw attention to myself. . . . I don't think I would even do it [utilize opportunity to leave classroom]. . . . They [the teachers] don’t understand how I feel and what I need. They just say "You can stand outside". (Girl, under 16 years)
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> It's a bit weird for people to go [to school counselling]... miss the first fifteen minutes of a lesson, fifteen, twenty, twenty-five minutes of a lesson, then come back in for the rest. . . . they'll

> [friends] be like “Oh where have you been?”. . . . Cos of the pattern... er so... this lesson I'm in. This lesson I'm in. Every lesson I'm in. And then suddenly in out in in, in in in out. (Boy, under 16 years)

Conditional Disclosure and Stigma

We next examined how the processes linked with conditional disclosure identified across the four main themes above could be understood as reflective of stigma. Table 3 outlines how participants’ experiences, coping preferences and rationales correspond with Link and colleagues’ model of stigma (Link & Phelan, 2001; Link et al., 2004). A number of parallels were evident, illustrating how stigma and discrimination were reflected in these young people’s accounts, specifically relating to thoughts around perceived risks of disclosure. For example, the stigma components of labelling, stereotyping and separating manifested through fears of being seen as different and being judged due to experiencing emotional and/or behavioral problems.

INSERT TABLE 3 ABOUT HERE

Discussion

This study explored stigma in relation to experiences of and preferences for obtaining appropriate care amongst young people putatively in an early stage of increased risk of developing psychotic disorders (i.e., experienced persistent PLEs and comorbid internalizing/externalizing difficulties). The superordinate theme within these data reflected “conditional disclosure”. That is, although disclosure was a core feature of how young people coped with their emotional and behavioral difficulties, there were many rules and contingencies governing disclosure-decisions, largely in terms of assessing and managing perceived risks of disclosure. When comparing the rationales and processes underpinning conditional disclosure with Link and colleagues’ stigma conceptualization (Link & Phelan, 2001; Link et al., 2004), it was possible to interpret processes in relation to perceived risks of disclosure as reflective of stigma.

Thus, the findings of this study illustrate the nature of stigma-related influences on initial pathways to care amongst this sample of young people.

The correspondence between our findings and existing stigma theory (Link & Phelan, 2001; Link et al., 2004) indicates that stigma-related influences and concerns can be anticipated and experienced in a somewhat comparable manner in relation to diagnosed illnesses and contact with specialist mental health services (Corrigan et al., 2005, 2009; Lasalvia et al., 2013; Link et al., 1989; Thornicroft et al., 2009), and subclinical (premorbid) symptom presentations and associated help-seeking (often from informal resources) as explored in this study. Additionally, these concerns influenced coping preferences and decisions around disclosure, similarly to what has been reported about stigma-related barriers to care in relation to diagnosable mental health problems and contact with mental health services (Clement et al., 2015; Gulliver et al., 2010; Savage et al., 2016; Thornicroft, 2008). Thus, these findings indicate that even early symptoms can give rise to stigma-related concerns and barriers to help-seeking, well before clinical high-risk definitions or services targeting these are relevant.

These findings also extend previous understanding of how stigma manifests and operates amongst young people putatively in an early stage of increased risk of developing psychotic disorders. Namely, our findings regarding stigma-related concerns amongst people with a problem profile characterized by PLEs correspond with previous reports that the symptoms and behaviors associated with early prodromal risk-stages of psychotic disorder can be stigmatizing in themselves, notwithstanding possible at-risk illness labels (Anglin et al., 2014; Yang et al., 2015). Furthermore, these findings contribute to the initial evidence base regarding stigma in relation to PLEs that has been reported previously (Lien et al., 2015; Maddox et al., 2013).

A further parallel was evident between the current findings and past literature in terms of stigma contributing toward delays on pathways to care. Namely, in the current study, participants' stigma-related anticipated and/or experienced risk of disclosure contributed to delays in opening up about difficulties, whether to informal or formal sources of support. This mirrors stigma-related delayed symptom disclosure and help-seeking reported amongst samples of people at clinical high-risk of developing a psychotic disorder, or experiencing first-episode psychosis (Byrne & Morrison, 2010; Franz et al., 2010).

Our findings are also comparable to past reports of stigma-related perceived risks of disclosure amongst adolescents, both in terms of accessing informal and formal support (Best, Gil-Rodriguez, Manktelow, & Taylor, 2016; Buchholz, Aylward, McKenzie, & Corrigan, 2015). In a further parallel with previous literature considering clinical samples, the participants in the current study described coping with perceived risks of disclosure in a comparable manner to what has been reported amongst populations with established mental health difficulties; namely, strategies like secrecy, selective disclosure and withdrawal (Ilic et al., 2011). A further coping-related comparison between the current sample and previous reports from clinical samples can be made in terms of stigma stress; that is, the cognitive appraisal of mental illness stigma as a harmful stressor exceeding personal coping resources. Amongst people at clinical high-risk of psychosis, stigma stress has been linked to suicidality, risks of transitioning to schizophrenia, as well as help-seeking attitudes (Rüsch et al., 2015; Xu, Müller, Heekeren, Theodoridou, Dvorsky, et al., 2016; Xu, Müller, Heekeren, Theodoridou, Metzler, et al., 2016). The present findings indicate that stigma stress might be a relevant concept already during earlier stages of increased risk of developing psychotic disorders. Namely, although risks of disclosure were discussed by all, the extent to which these compromised help-seeking appeared linked to whether participants had access to the “right people” to whom they might open up. Access to appropriate disclosure targets could thus mitigate early stigma stress, and its negative consequences. This interpretation corresponds with reports that the association between distress from subthreshold psychotic symptoms and self-stigma was stronger for people with lower peer social support (Denenny, Thompson, Pitts, Dixon, & Schiffman, 2015).

Overall, the concordance between the findings of this study and previous literature indicate that experiences of stigma can, to some extent, be comparable between symptomatic young people reflecting on initial difficulties with no psychosis-related mental illness labels, and populations in clinical at-risk stages or with diagnoses of psychosis or other psychiatric illnesses. These similarities also give an indication of how early stigma-related concerns can influence coping preferences and people's pathways to care.

Strengths and Limitations

This study is, to our knowledge, the first that examines the presence of stigma and its influence on pathways to care amongst a sample defined by the experience of PLEs. A number of parallels were observed between the findings of the current study and past research conducted amongst clinical samples, which enabled tracing back the presence and influence of stigma to putative risk stages of developing psychotic disorders, contributing toward an advanced understanding of the pervasive nature of these influences.

These findings must, however, be considered in view of certain limitations. One researcher, Petra Gronholm, conducted the majority of work for this study, which might have introduced bias in study processes. However, joint analysis and interpretation strategies were employed to limit the risk of the findings being unduly influenced by a single researcher's perspective. Also, although the findings reflect experiences of young people with a PLE-focused problem profile, during the interviews participants reflected on coping in relation to difficulties they identified as most salient, not PLEs specifically. Most participants described distress associated with periods of low mood or anxiety, and some described difficulties around self-harm and disordered eating. Some experienced distress due to peer-conflict, family issues, school transitions, and exam stress. Participants were not asked about mental illness diagnoses, but one person mentioned a diagnosis of depression, one had a diagnosis of attention-deficit hyperactivity disorder, and two discussed Asperger's syndrome. It is thus not clear to which extent these findings apply to coping with attenuated psychotic symptoms specifically. However, understanding coping preferences in relation to the problem profiles the participants reported still provides a useful point of comparison with pathways to care amongst people at clinical high-risk of psychosis. Namely, it is reported that also amongst these groups service use is generally not related to subclinical psychotic symptoms specifically, but a broader set of difficulties (Boydell et al., 2013; Falkenberg et al., 2015). Finally, as with any qualitative study, it cannot be assumed that the findings are generalizable to populations and contexts beyond the current study sample. Such transferability judgements are, however, facilitated by a description of the study sample, research context and process, multiple quotations illustrating the results, and a discussion of how the findings correspond with previous literature.

Implications

This study provides insights regarding the mechanisms through which stigma can operate amongst young people putatively in early stages of heightened risk of developing psychotic disorders. An increased awareness of what constitutes stigma within this population can inform efforts to assess and target stigma amongst young people and at-risk groups. For example, these findings indicate that difficulties of a "psychological or mental" nature can elicit stigma already at the level of early symptoms, rather than diagnosable illnesses. Consequently, educational efforts and anti-stigma strategies could aim to place emotional and behavioral difficulties along a continuum-perspective of mental health and wellbeing (Schomerus et al., 2016). This could support mental health promotion and prevention efforts through facilitating an understanding of symptoms and issues preceding diagnosable mental health difficulties, and what could constitute appropriate support prior to the need to access specialist services. A continuum perspective could also help reframe young people's perspective on mental health by blurring the sharp divide that currently appears to separate anything associated with mental health or related difficulties and "normalcy", and subsequently reduce resulting stigma and barriers to recognize and act on emerging difficulties.

The findings can also inform strategies to alleviate stigma-related concerns in relation to help-seeking. For example, in view of the characteristics which facilitated disclosure, young people might feel more comfortable to approach services if confidentiality is emphasized and ensured, and it is made clear that service providers can relate to their difficulties. For example, one participant explained how the content of a pre-counselling screening questionnaire helped her understand that the counsellor had encountered problems similar to hers before and would be able to help, which subsequently facilitated disclosure.

Also, our findings regarding reluctance to engage with services in school-settings indicate that if service contact is noticeable to others, uptake might remain low amongst young people despite service availability. These barriers could be mitigated through offering support in an appropriate manner, addressing concerns regarding unwanted disclosure and its possible stigmatizing consequences. For example, procedures facilitating more discreet means of obtaining support in school-settings could make young people more likely to utilize this type of help.

Our findings indicate that stigma-related concerns can be involved in decisions underpinning help-seeking and service contact already at an early stage, where no official at-risk labels or other diagnoses have necessarily been applied to the young people’s difficulties. These insights can contribute to the current debate regarding clinical high-risk characterizations, and whether their utility in terms of, for example, treatment access is outweighed by potential stigma-related consequences of at-risk labelling (Corcoran, First, & Cornblatt, 2010). The present findings indicate that a comprehensive evaluation of the potential drawbacks of risk labels might require a better understanding of stigma-related experiences associated with symptoms alone, so that this influence can be factored in when weighing up the risks of early labelling and treatment against the benefits of such early intervention.

Understanding the rationale underpinning conditional disclosure could also facilitate the development of decision-making tools, aiming to support young people with gathering their thoughts in relation to the circumstances of their help-seeking and assessing when and how disclosure could be appropriate. Encouraging young people to consider their help-seeking resources, and benefits and risks associated with these options, could facilitate timely help-seeking through empowering young people, making them feel more aware and in control of their help-seeking options.

Conclusions

Conditional disclosure processes, which could be interpreted in terms of stigma-related concerns regarding risks of disclosure, underpinned help-seeking preferences amongst young people putatively in an early stage of increased risk of developing psychotic disorders. This finding contributes research evidence that has been lacking in relation to help-seeking processes amongst young people experiencing early psychotic-like symptoms, and generally in terms of stigma as a potential barrier on initial pathways to care.

Conditional disclosure provides a framework within which young people's help-seeking processes – and related influences of stigma – can be understood. Subsequent insights regarding under what conditions young people felt able to disclose their difficulties could inform strategies to facilitate young people's pathways to care. For example, considering how services are provided and how young people are supported to understand and access available help and support could help reduce the service underuse and high levels of untreated difficulties currently observed amongst this population.

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Conditional Disclosure on Pathways To Care: Coping Preferences of Young People at Risk of Psychosis

Figure caption:

Figure 1: Overview of the themes that emerged from the analysis

Figure 1

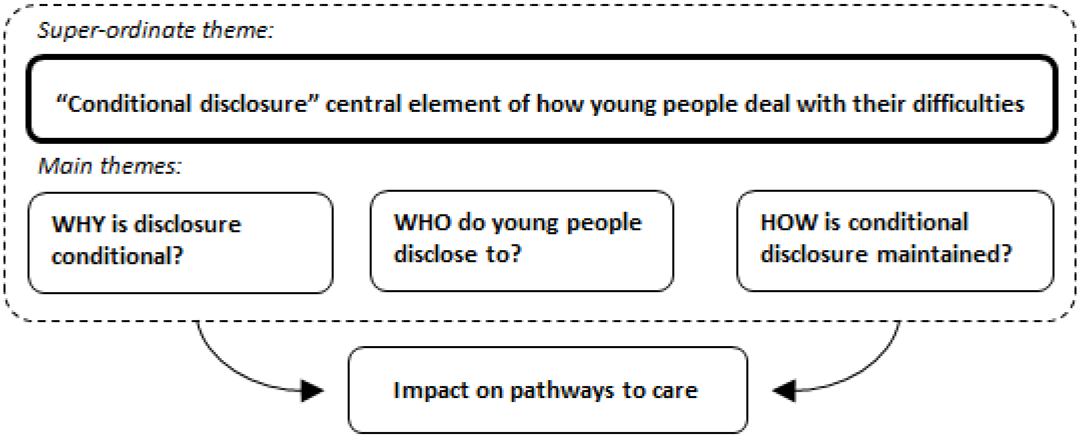

Table 1

Table 1 Individual and family-level characteristics of study sample (n=29).

Characteristic	***n* (%)**
Age (under vs. over 16 years)	*14* (48.3) under 16 years
	15 (51.7) over 16 years
Gender (female vs. male)	*19* (65.5) female
Ethnicity	*19* (65.5) White
	9 (31.0) Black
	1 (3.4) Asian
Caregivers' intended stigmatising behaviours score (lower vs. higher)*	*17* (58.6) higher scores

*Based on mean split of the Reported and Intended Behaviours total score; higher scores reflect fewer intended stigmatizing behaviours toward people with mental illness.

Table 2

Table 2 Overview of topic guide.

- Health; concept of “emotions and behaviours” within health, personal health
- Salient experiences, personal difficulties, consequences of these
- Coping preferences
- Use of informal (family/friends) and formal (service contact) support
- Summarising discussion, debriefing

Table 3

Table 3 Stigma components* reflected in conditional disclosure processes.

Stigma	**Conditional disclosure**
Labelling	Being viewed differently due to difficulties; emotional/behavioural problems different from physical issues.
Stereotyping	Others' anticipated negative judgements; personal sense of being weak or inferior.
Separating	Changes in public image following disclosure; unwillingness to accept/admit difference or that difficulties warrant formal support.
Emotional reactions	Anticipated negative reactions; sense of embarrassment/weakness; feeling uncomfortable/concerned/fearful that others would find out about difficulties; selecting confidantes based on sense of comfort.
Status loss and discrimination	Others' discriminatory actions; negative impact on peer relationships, well-intended actions experienced as condescending/ generating a sense of difference/non-normalcy; personal sense of weakness/inferiority.
Power	Feeling weak/inferior; social norms influencing disclosure; no blame placed on judgemental peers.

*(Link & Phelan, 2001; Link et al., 2004)

Appendix A: Focus group process

Developing topic guide through focus group process. In a focus group, data and insights are generated through the process of group interaction. Through listening and responding to other group members, participants' are triggered to reflect on their own standpoint, resulting in a deeper and more considered discussion (Ritchie & Lewis, 2003).

Participants and recruitment. The focus group was advertised to the Young People's Advisory Panel operating within Time to Change, England's biggest programme to challenge mental health stigma and discrimination (Henderson & Thornicroft, 2009). Information regarding the focus group was distributed to the young people's panel via the Youth Involvement Officer overseeing the activity of the group, approximately a month prior to the next panel meeting.

The invitation to participate in the focus group discussion was limited to young people who identified as having personal experience of mental health problems. This was to generate a sample where participants were able to reflect on their own experiences of early psychopathology, and from this perspective offer insights and feedback on intended interview procedures. Six participants (all female, aged 17-24 years) took part in the focus group discussion.

Procedure. The focus group discussion took place in a private, quiet room at the premises of the Young People's Panel. The researcher re-introduced the purposes of the discussion to the group, re-distributed study information sheets, and all participants provided written consent to participate. The discussion was audio-recorded, and lasted approximately one hour. Following the discussion, each participant received a voucher (value £10) as a thank-you for their time.

The discussion focused on the preliminary topic guide developed for the individual research interviews. Participants were invited to comment on the intended topics to be covered by the interview guide, as well as provide perspectives on how to approach the topic of mental-health related problems during interviews, and strategies which could be drawn on if interviews became upsetting or unpleasant for the participant.

Outcomes. In line with suggested appropriate uses of focus group data (Stewart & Shamdasani, 1990), insights gained from group discussion were used to comment on potential problems with the intended interview procedure and to better understand what language would be best to use around the interview topics.

(a) Generate impressions and diagnose potential problems with objects of interest. It was discussed how some young people could find talking about personal difficulties challenging, and some might also feel cautious regarding sharing such personal information. The focus group provided feedback on the intended interview topics and how these could be introduced to the participants, which aided efforts to create an environment where young people would feel more comfortable and able to discuss their personal experiences. In particular, the group highlighted the importance of being clear regarding the confidential nature of the interviews, and also highlighting under which conditions there could be exceptions to this (i.e., if a participant under the age of 16 years discloses that they have been placed at risk either by their or someone else's actions).

The focus group consultation also suggested that the power balance between the researcher and interviewee could be skewed due to participants' past experiences of interviews and being asked questions (e.g., during admissions interviews or in a classroom environment, where the person asking the questions holds an expert position). Strategies to re-address the balance were discussed, and based on this a process of "exchanging contracts" prior to the interview was devised. This involved the researcher reading through a sheet of "promises" to the participant before the interview. Written in lay-language, these re-iterated the conditions for confidentiality and clarified the boundaries of the interview (these matters had already also been outlined in the study information sheet). Furthermore, these also emphasized the participant's position as an expert in their own experiences, that there were no right or wrong answers, and that the interview would be conducted on the participants' terms (e.g., that they could stop the interview at any stage, and also that they did not have to talk about anything they did not want to disclose). Once these "promises" had been explained, the researcher signed the document and it was handed over to the participant in exchange for their signed consent form. This symbolic event of the researcher and participant signing and exchanging forms prior to the interview was intended to explicitly empower the participant and highlight and validate their expert position in the interview, in order to even the power between the two interview parties.

(b) Learn how respondents talked about the phenomenon of interest. The focus group discussion informed the approach to the language used in relation to psychopathology, help-seeking and stigma and discrimination during the interviews, in an attempt to make this acceptable and appropriate for the participants. In particular, the focus group discussion highlighted how the word "help", for instance in terms of "help-seeking", could be experienced as off-putting as for some it might imply personal weakness, or indicate a high degree of severity of difficulties. The word "support" was suggested as a more acceptable and less negatively charged term, and this phrasing was thus used throughout the interview process.

References

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Appendix B: additional supporting and disconfirming quotes

Why is disclosure conditional?

Others’ reactions and risks of disclosure

(Others’ reactions core determinant of disclosure decisions)

No. It's- I wouldn't really want them to know. . . . Unless I knew their reaction. To me it's sort of, it's, it's about all, it's all about like how someone's reaction would be. Whether it'd be “Yeah, cool, whatever”. Or it'd be “Why? What are you doing that for?”. (boy, over 16 years)

I know the response that I'll get from the certain people. . . . They [people she does not feel close to] don't know you they don't... particularly know th- what's going on. So they might be a bit judgemental. But then with the people that you're really close to, they already know like, they'll probably already know what the situation is. (girl, over 16 years)

I think about whether they could help me for a start. So I think about er who would I approach. . . . I just think, what would they do. Would they help me or would they just say like “Oh I don't know, um... I wanna go talk to my friends now.”. And um I just sort of decide will it be worthwhile actually me telling them my problem.. (boy, under 16 years)

(Risks of disclosure)

Being viewed differently and subsequently judged negatively

If I spoke to someone ... it could like be me seen as being different cos I would never have shown me that side before. So they could see it in like a new light, in like a different way. . . . Like differently from like how I normally act or like come across to them. (girl, over 16 years)

I think it's just that worry of people seeing all these different sides of me. (girl, over 16 years)

I think just because you never know how other people would react, you'd have to like think about it. There might be a certain like stigma about something and then it would be like, oh like, they'd judge you differently based on that I think. (girl, over 16 years)

Because I don't ... I don't like people calling me a person who has an eating disorder. I don't like being labelled that. I don't like... people... saying that to me I don't like people thinking that. (girl, over 16 years)

Overt negative and discriminatory actions

If you, er if you were a soldier, er and you gave a grenade to the opposite team they're just gonna throw it straight back at you. And um... whereas that's the sort of same with a problem. If you tell someone and they pass it on to someone else, they're gonna come back to you ... and maybe take the mick or ... er laugh about it with other people. (boy, under 16 years)

Probably cos I acted weird. . . . I acted eccentrically, I believe. Cos um because of the Asperger's it affected me in a way that . . . And therefore that might seem weird to a few people and therefore that's a reason to be picked on. To some people, yeah. (boy, over 16 years)

[Once peers at school found out about her difficulties] (they) just kinda went off and started calling us names and then were just kinda like, ok then, you know that we're not nor...we don't feel ourselves and you'll still do that.

INTERVIEWER: So that's your friends and they know you and they are calling you names?

Yeah, that hurt so much. . . . People started calling, they called me an Emo sket and I was just like, that's nice. They started calling us mental, psychopaths, I was just like, great, thanks for that. (girl, under 16 years)

I'm not sure, he probably saw it, he probably saw it as a weakness. I'm not entirely sure. I think he realised calling me a retard would push my buttons and start getting me annoyed, so he started doing that a lot. (boy, under 16 years)

Gossip and malicious rumors

I think... they'd pass it on. Then person would pass it on. And then gradually I'd get ... first of all I'd get one person coming up to me "Oh is it true that you did this?". And then the next person. "Oh is it true..." And then it would get... more and more regular. And then I'd be like - er I finally have to admit it, cos I can't deny it to everyone. (boy, under 16 years)

It would spread like wildfire around our school and then by the end of the day, everyone in the school would know.

And you would just be sitting there by the end of the day, everywhere you go, with eyes just casually watching you and you'll just be like, "What's going on?". And then someone would come and finally say it to you and you'll just be like well that's none of your business. But, oh well, you kinda know now. (girl, under 16 years)

When you're upset, you don't really wanna tell anyone. But then for the whole school to know it's like, ooh. That's even worse. So yeah. (girl, over 16 years)

They started talking "Oh, we hardly ever see you eat.". And then, that's how it started. And then people were talking about it and then people went "Oh, you have an eating disorder there's something wrong with you.". And then, spread around the school and school drama started and ... All of that. (girl, over 16 years)

Negative impact on peer relationships

So I would do sort of things that wouldn't want them to-, like they wouldn't wanna be friends with me. . . . They probably say to theirself, "Oh he thinks too much, don't really wanna know him.". (boy, over 16 years)

If they suddenly sort of ... don't want to be friends with me, because they see another side of me. (girl, over 16 years)

Like risk losing friends because of it. Cos people might take the mick out of my friend cos he's friends with someone... that... er... might go to these places [CAMHS services]. . . . So they wouldn't be friends with me, because other people that are friends with my friend... er would take the mick out of my friend too because he's friends with er someone that goes to like CAMHS and counselling. . . . And then because, cos they're being, er taken the mick out of cos they're friends with me, then I would lose that friend. And then, then gradually they'd all do it. And I'm left by myself. (boy, under 16 years)

Being inadvertently treated differently

Other people that just acted a certain way around me, like I was disabled. . . . So... Yeah. A few people started to- weird and I guess they tried to be ... thoughtful but ... I don't think it came across like that. It came across as if, as ... You're too stupid to know whether you should eat or not. I think that's more how it came across. That we have to talk to you about it, for you to know. You know. (girl, over 16 years)

I'm kinda glad that they don't really know cos then they kinda like, not being over nice but it's like kinda like, they *talk to me like a child and then it's like not really like that great. Yeah. (girl, under 16 years)*

I think most of my friends would probably like, just like support me I guess . . . I'd just prefer if it was like normal to be honest. . . . I'd just want them to treat me normally. (girl, under 16 years)

They [friends and teachers] were kinda checking up on me . . . Some of them, even though I had told them I was ok, they kept coming back and forward, um that caused me stress cos people kept constantly looking and whispering. (girl, under 16 years)

- **Factors influencing expected risks of disclosure**

Judgemental social environments

(Seeing others treated badly)

In my secondary school there were a lot of people I guess going through the same thing I was going through. Like some were bulimic and some were anorexic and stuff like that. And they got severely bullied and had to leave secondary school so... stuff like that. I didn't wanna be one of those children. I didn't wanna be one of the children who got bullied and had to leave secondary school. (girl, over 16 years)

Yeah, cos um, one girl um, she had like loads of different problems and everyone was like, "Why is, why is she? She has no reason to.". I guess, I wouldn't want people to be like, "She has no reason.". I don't know, I just wouldn't want people to think like and assume things about me. . . . I don't want people to like, yeah I wouldn't want people to do that for me. (girl, under 16 years)

(Media influence)

Have you heard of a film called Rain Man? (yeah) Cos I think sh...all she knew about me from that film so she instantly assumed that I was sort of [a] dumb kid that was in a world of his own. . . . People with wrong views have usually watched a film or something and they'll instantly assume you're always of the worst type. (boy, under 16 years)

(Media influence – disconfirming)

I think I'm thinking about it more cos a lot of people that are around me are going through things, then I think about them, so, yeah. (...) And like watch, like, and I'm like ex...ex...I'm kinda exposed to it more, cos like, on books like on books and on the computer and on TV, it's talked about and I didn't really take any notice of that kind of thing when I was younger. (girl, under 16 years)

(Social norms)

I don't really go shouting, go shouting it about [diagnosis of Asperger's syndrome]. . . . General attitude seems to be it's not the sort of thing you shout about. . . . Cos once my teacher a while back he was a bit shocked when he found out and asked me not to reveal it to the rest of the class like it was some sort of disease. (boy, under 16 years)

I like to think that me being open about it has actually helped some of my friends be more open about it if they are feeling like that. Because it's like I guess we all- there's like a stigma about it. I have noticed more people talking about like the way they are feeling, but I don't know if that's just to me or in general. (girl, over 16 years)

Personal beliefs and perspectives

(Not wanting to admit/accept "difference")

You feel like your reaction to something isn't normal. . . . You feel like ... you should be dealing with it in a different way. . . . You're just thinking ... I, I shouldn't be thinking about this in this way, in reaction to that, i-it's not normal because ... you don't, I don't know why you, you don't, you tell yourself it's not normal. . . . I think a lot of people worry a lot of teenagers worry i-if their reactions or the way they're behaving... is ... normal. So they won't say anything. . . . Even if people considered going to their GP [general practitioner] they would might have to face up to the fact that, about their worries, that they weren't normal. And wouldn't want to be told or... feel like they weren't normal. (girl, over 16 years)

I didn't think there was anything wrong with myself cos I just thought it was the norm. . . . I don't... don't like people calling me a person who has an eating disorder. I don't like being labelled that. . . . I didn't believe I needed to get... professional help because I've never thought of myself as a person who has an eating disorder because I've always *said I don't have eating disorder. The doctor has it wrong I don't have eating disorder. There's nothing wrong with me. . . . I don't think I have an eating disorder I think I'm a normal person. . . . I would have rejected help. Um... yeah. I would have rejected the help. I don't need help, there's nothing wrong with me, I'm completely fine. (girl, over 16 years)*

INTERVIEWER: You said you were a bit worried and you didn't wanna tell other people [that she attended counselling]. What was it that you were worried about?

Maybe that they would... um... the first one I found that ... um... in my school they had counselling I thought that how counselling was like for people with ... like kind of... prob- um health problems, mental problems maybe. Like problems in life that how ... they're... really miserable and didn't live a happy life. And I didn't really want people to think, think that of me. I... I wanted them to think that how I was living a normal life like them. (girl, under 16 years)

Actually thinking about the way I was feeling, I think it would have just completely thrown me to... for everyone else to know, cos I thought I was crazy. (girl, over 16 years)

(Feeling embarrassed)

You know it's quite hard to be you know sixteen and still crying at something really small. Because often it is, often it's not ... a massive thing and it does, it is slightly embarrassing. . . . I just- yeah it was really embarrassing and I think that was part of it was it would show that I was really struggling. Um... and I think... um... ... (exhales) I think that was just a struggle. . . . I didn't want people to know how bad it was. (girl, over 16 years)

[Reflecting on attending school counselling] Er I think it's cos... I don't... them- it's a bit embarrassing that I just go there. (boy, under 16 years)

If you've been upset about for too long... it's quite embarrassing to um... to carry on talking about it. (girl, over 16 years)

(Feeling weak and/or inferior)

People wouldn't wanna tell people what they're going through emotionally because it might make them feel like weak and that.

INTERVIEWER: Did you ever feel like anything like that was going on for you?

Yeah I did, I did at first... Of course, I felt weak, yeah. (boy, over 16 years)

I rather sit there than get help cos, I don't- I feel dumb when I get help. ... I don't like getting help when they ask to help me I don't want help. So I say no. (girl, under 16 years)

(Feeling weak – <u>disconfirming</u>)

I think because I knew I was diagnosed . . . I kinda let that run me for my childhood cos I thought, OK whatever I do it's just the Asperger's. I can use that as an excuse. . . . Now I know it's just a mild form of the syndrome. Which um I think, <u>I treat it like a super-power</u> now, so yeah, that's kinda fun. . . . . . . It gives a mild lack of empathy which makes me deal with terrible situations easier. Because then I can talk the voice of reason. (boy, over 16 years)

(Emotional/ behavioral difficulties different from physical problems)

I think it's different cos ... I could er go to ... my friend with a hurting wrist. . . . Say "Oh I've got a hurting wrist, would you know what to do.". Er and they would tell me. But if I went to them with a [emotional] problem they'd pass it on and stuff. (boy, under 16 years)

And because it's not like you've got, like you've broken your arm and you can see it, like it's all...cos it was all internal, I just I was going...I just thought I was going mad. . . . ...Cos I mean if I was ill, like actually had like a disease, then like it would be different cos they [friends] would be like "Oh well she's really ill today she's like throwing up so she can't physically come out.". But because it's mental and they don't see anything wrong, then there's no way of them... it's not like acceptable. So, I don't know, cos they don't really see as being on the same level whereas I guess being incredibly depressed and suicidal then it's kind of, in some ways worse than having a cold and not being going out, so yeah. I just don't think they understand, so yeah. (girl, over 16 years)

Like you kinda feel more awkward talking about it somehow than if it was something physical. I don't... cos you think that people might think like there's something... like oh... like something like wrong with you. . . . Would be much more straight-forward for something physical than something like more emotional, people might be... a bit more like wary about kind of telling everyone. (girl, over 16 years)

Who do young people disclose to?

- ***Core characteristics for disclosure: close relationship, trust, ability to relate***

(Close relationship)

INTERVIEWER: So finding someone that you're close with? Someone who knows you, that's an important thing?

Yeah, someone who won't judge you I think in the same way that other people might, so yeah. (boy, under 16 years)

If it's like someone you know quite, know quite well then it's ... there's nothing wrong with it. But if, if it's someone you don't know really very well... then... you... I wouldn't personally do it. Just in case they find something they could, they could try and exploit out of you. (boy, under 16 years)

I know my friends, even if you know thousands and thousands of people ask "What was wrong with (name) [refers to self] today?", they wouldn't, they wouldn't tell. They would keep it private. But then other people I wouldn't know, whether they would or they would just spread it around. (girl, over 16 years)

(Closeness – disconfirming)

It's really I'll find it easier to talk to a total stranger about everything that's happened, because sometimes I feel like I'm never going to see this person again, I might as well tell them everything. Cos it saves the awkwardness of next time when I do see them. (girl, under 16 years)

It was you know just someone else to talk to who just didn't know anything about anything . . . It's just difficult to kind of talk to family about something like that because you're kind of, cos they know you . . . It's quite easy to end up it being argumentative because you… end up sounding like you're blaming them for the way that you're feeling . . . I think the reason that therapy helped was because I was like a blank canvas. They didn't know me . . . It was easier to admit that I was as ill as I was to people I didn't know than to people I did know? Because they... because I was putting on a front for them [people she knew] and I didn't have to put on a front when I went to therapy. (girl, over 16 years)

(Trust)

Cos they know me very well. And then I trust them. ... And I only have like a small circle of friends cos I don't trust a lot of people. So I'll speak to them, but... yeah. ... Nah I think it's just about trust. (girl, over 16 years)

Sometimes like I'll tell my friends and stuff. Or, the friends I can trust. Cos I've got... eight best friends. And like they wouldn't tell anyone anything. Um like so I will tell them like the really bad stuff that's like gotten me down. (girl, under 16 years)

(Ability to relate)

INTERVIEWER: And what to you makes the difference, what makes it easier to talk to some people than to others?

If they have problems too. ... Say someone that, I don't know, had dyslexia. Then... and their friend had it as well, you're more likely to tell someone with dyslexia than without. Cos that people might think they're dumb and that, they've got dyslexia. (girl, under 16 years)

There's no point talking to people who don't relate to it. . . . No I thought there's no way I'm going to talk to anyone that doesn't relate to this at all because what advice can they give me if the experience is not shared. (boy, over 16 years)

Cos if they'd have similar experiences then they'd probably also share the ways they'd deal, dealt with it. Erm, with you. And then that might help you. (boy, under 16 years)

They people my age, they probably been through as well what I've been- what I'm going through now. And maybe older people like... my parents maybe... they maybe they did but they won't have, they won't remember so they wouldn't be able to tell me much of how to deal with these things. (girl, under 16 years)

- **Relevant for informal and formal disclosure**

INTERVIEWER: How would you feel about talking to your GP?

Awkward...cos he doesn't really know me... so ... it would be weird. (girl, under 16 years)

How is conditional disclosure maintained?
- ***Cover-up efforts: selective disclosure and concealment strategies***
(Selective disclosure; to whom and what) *I only told [friend] about it cos I thought that, I knew that she would kinda understand better. But I wouldn't ever like tell some people. (girl, under 16 years)*
Um I only tell them [friends] a little bit, and then they might give me a bit of an advice or something, and that's pretty much it. But when it's my mum I tell her everything. And... yeah, and she'll talk to me and help me through what I'm going through. (girl, over 16 years)
Um I'm still going there [counselling] now but I find it still awkward to open up to them. . . . Some of my friends go to it as well and we all have the same problem trying to open up to them. Cos we're scared of saying too much in case they freak out. . . . But I kinda opened up a bit ... but I still haven't really told them everything. Because I think if I do, just, will get too much really. (girl, under 16 years)
(Concealment strategies) *I'd act if everything was fine at school like I'd act like nothing cos I wouldn't want to make my parents or my sister worry. And so I'd just act normal. . . . Like pretend that it's just not going on. Like... Um... when I come home I'd just... act like nothing. (girl, under 16 years)*
Oh I'll just be like "I'm fine.". Just like getting them away from me, be like "Yeah I'm fine.". And they'll be like "No you're not.", and I'm like "No no no I am, I'm fine, see!". (girl, under 16 years)
Hiding away from certain people and when certain things get mentioned, I'd like step back from it, withdraw from it, sort of hide away from it. (boy, over 16 years)
(Concealment strategies – disconfirming) *And then I believe as I got a bit older then I realised that ah... I can't be bothered to go on with this... act no more. Might as well just... be who I am. . . . When people asked me about it I'd be "Ok let's talk about it.". And I'd talk to*

you about it cos it would make me feel better about myself. (girl, over 16 years)
Impact on pathways to care
• ***Delayed disclosure to family and friends***
Whereas you know I didn't open up as a kid. . . . Yeah at the time I thought I, at the time I felt I needed to talk to someone but I just can't. . . . If I told someone there's always a fear, it's a cliché fear, um textbook that I would understand that if I told someone that the kid who was picking on me would find out and then he would want to target me more for singling him out. . . . I thought ok, there's no reason to talk of this with him [dad] or my mum. . . . So I thought ok, no cause to tell them. [Parents would ask] "Had a good day at school, (name) [referring to self]?" [he would reply] "Yeah.". "Anything happen?" "No." Every day. For two years. (boy, over 16 years)
Just feeling crap all the time and then the amount of panic attacks I was having. I ended up, I was having like quite a few a week and kind of often in like difficult places, like at school and just like not being able to kind of talk about it. . . . I had a panic attack and it lasted like... it was probably the worst thing I've ever happened, like I blacked out and I fainted because it was so bad. And I think that's when I realised that this wasn't normal, like that's not something that people cope with everyday. That's not something that I should be coping with, like I'm meant to be like 16, 17 [years old] trying to like do stuff and do my GCSEs [General Certificate of Secondary Education qualification] and whatever. . . . Then, I just realised... I think I just woke up and realised that I needed to talk [to someone] about it because it wasn't normal. (girl, over 16 years)
(Reflections on opening up earlier) *I was scared. Didn't know how people were going to react. I thought, you know if I say something, people are going to think I'm mad. But now I feel I should have said something earlier then I could've you know, could've been sorted out earlier. . . . I feel like an idiot for not telling them [parents].* (boy, over 16 years)
Yeah talking to family and friends were the hardest thing. But it, I wish I had spoke to them sooner because the sooner I started speaking to people the more people I found out who had the same problems and we could help each other, so. I wish I had spoke out sooner. . . . Yeah, I thought that their reaction was going to be the complete

opposite, but it turned out that they were fine with it. They knew how to deal with the situation, so. (girl, under 16 years)

- ***Rejecting formal services***

(Negative reactions when formal help is involved)

If they'd [classmates] known that I was there [school counsellor], it might have been like "Oh you've got, you've got ... you <u>have</u> got issues then.". Cos I used to just say "Oh no, um I just can't control it that well [his temper]. . . . Er but it's not anger management.". Um ... and then... if they knew I was going to a <u>counsellor</u> . . . [They'd] take the mick out of me . . ..

INTERVIEWER: So in those people's eyes, if there was something you spoke to a counsellor about, it made the problem something else?

Yeah.

INTERVIEWER: So you could be going through the exact same stuff, but if you were seeing a counsellor about it, it would be somehow different in their eyes?

Yeah. (boy, under 16 years)

(Formal help appropriate only for severe issues)

I would have thought any kids that go to that [help groups] they must have had serious problems like compared to mine. Mine's nothing compared to whatever they've been through. . . . So I thought ... at the time, no no reason to bother. . . . I've never had any problems that were that severe. I, I thought if I was going to go to a psychiatrist or a GP for anything it would be for something so terrible and for, yeah I feel like I've had a generally, yeah really good life. (boy, over 16 years)

I just... didn't think there was anything wrong. I just thought... this is how... life normally is for me. . . . I don't think there's anything wrong as I don't think I <u>need</u> any help I don't think I was entitled to any help. Think... I, I would've thought that ... um somebody else who would have a far worse situation should be getting the help that... this person would have been giving to me. I shouldn't be entitled to this sort of help, somebody else should get it. Who was in a *far worse situation, who was not dealing with it as well as I would've dealt with it. (girl, over 16 years)*

INTERVIEWER: When you had this counsellor to talk to, how did you feel about that?

Um... I was quite like annoyed. . . . I just... never really thought that um... there was any point of talking about it. Um... I never thought it was that serious. Cos like I've heard worse stories than mine and I'm just like “Blergh it's nothing to be talking about.” like it's big. . . . I realised I've been crying more, when I go to bed. Or... if I'm alone or something like that. So yeah. . . . [but] like after I finished crying I would be like “Oh why am I crying so much, blergh just leave it, just forget about it, it's not even big, it's just... Uh me being silly or something.”. (girl, over 16 years)

Like my mum was like “Oh, you've got this thing for a term.”. Ok. She's like “It's just therapy.”. And I was like “What did I do?”. . . . I thought I was going insane. Cos like you see like on that, movies and people went to therapy... But um when I first went, I thought “Well this is fine, nothing, she's not giving me pills or anything.” so it was fine. Cos it was just drawing. . . . It wasn't really counselling, I just went into this room with this really nice lady and then she'd tell me “Draw anything!” and I'd draw, for the whole thing. And then each week she, she'd kinda try to analyse it and see why I drew it. . . . [But] when my mum first told me I was like “I don't wanna go! I don't wanna go to a therapist!”. (girl, under 16 years)

(Difficult to hide support in school settings)

[Attending school counselling] was also quite stressful. Because I didn't want to tell anyone. Um. But it meant that it was during lessons and I sort of had to slip away and so it was hard to um hard to get that. . . . It was um- but it was quite hard because um... I told her [counsellor] you know I um... When she was like “Why weren't you here last week?” and I was like “Because I couldn't get away from my friends.”, and it was quite hard. And she interpreted that, interpreted that to mean that um when I got the slips [for attending appointment] in the morning she ... I didn't want anyone to notice that I was getting these slips. So she put it in an envelope, and I told her “No that's not what I mean.”. But I still ended up getting in the envelopes. And I was like “You're clearly not listening to me.”. And that was part of the reason why I also left. (girl, over 16 years)