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How does psychiatric diagnosis affect young people's self-concept and social identity? A systematic review and synthesis of the qualitative literature

Abstract

Receiving a psychiatric diagnosis in childhood or adolescence can have numerous social, emotional and practical repercussions. Among the most important of these are the implications for a young person's self-concept and social identity. To ensure diagnoses are communicated and managed in a way that optimally benefits mental health trajectories, understanding young people's first-hand experience of living with a diagnosis is paramount. This systematic review collates, evaluates and synthesises the qualitative research that has explored how psychiatric diagnosis interacts with young people's self-concept and social identity. A search of 10 electronic databases identified 3,892 citations, 38 of which met inclusion criteria. The 38 studies were generally evaluated as moderate-to-high quality research. Thematic synthesis of their findings highlighted the multifaceted ways diagnosis affects young people's self-concept and social identity. Diagnosis can sometimes threaten and devalue young people's self-concept, but can also facilitate self-understanding, self-legitimation and self-enhancement. A diagnosis can lead to social alienation, invalidation and stigmatisation, yet can also promote social identification and acceptance. Further research is needed to clarify which self and identity outcomes can be expected in a given set of circumstances, and to establish how self and identity effects interact with diagnoses' other clinical, practical, social and emotional consequences.

Keywords

Psychiatric diagnosis; mental illness; children; young people; self; identity; qualitative; systematic review

Introduction

Diagnosis is an important step in the everyday practice of mental healthcare, shaping clinical decisions regarding which treatment pathways and explanatory frameworks are appropriate. For the recipient, a psychiatric diagnosis can have profound practical, social and emotional implications (Jutel, 2009; Perkins et al., 2018). Diagnosis' effects may be particularly pronounced in childhood and adolescence, which are critical periods in the development of self and identity. To ensure diagnoses are communicated and managed in a way that optimally benefits mental health trajectories, understanding young people's first-hand experience of receiving and living with a diagnosis is paramount.

A diagnosis serves many functions for mental health service-users. At a practical level, a diagnosis can explain symptoms and facilitate access to resources, treatment and prognosis (Jutel, 2009). Research suggests ascribing appropriate diagnostic labels to psychological symptoms positively affects help-seeking and symptom management decisions (Wright et al., 2007). Service-users may further benefit from the 'common language' that diagnoses provide, which streamline communication between the different services and clinicians involved in their care. However, diagnoses can also have negative consequences for mental healthcare provision. Diagnoses may exclude people from certain services: for example, some child and adolescent mental health clinics do not accept clients with a primary diagnosis of Autistic Spectrum Disorder (ASD), and persons with a dual diagnosis of substance misuse and mental illness can fall between the cracks of different services' admission policies (Schulte and

Holland, 2008). Diagnoses with poor prognoses (such as personality disorders) can also lead to fatalism among service-providers and consequent restriction of treatment options (Nehls, 1999; Newton-Howes et al., 2008; Ramon et al., 2001; Stalker et al., 2005).

These practical implications of psychiatric diagnosis must be considered alongside diagnoses' social and psychological effects, which are complex and diverse (Callard et al., 2013; Jutel, 2015; Perkins et al., 2018). Particularly important are implications for the *self-concept*, defined as an individual's set of beliefs about herself/himself (Baumeister, 1999), and *social identity*, defined as the portion of the self-concept that derives from membership of social groups (Tajfel, 1981). Previous research suggests diagnostic classification can affect a person's self-concept and social identity in both positive and negative ways.

On the positive side, diagnosis can provide a sense of relief and self-understanding by implying symptoms result from a 'real', independent disease entity (Hayne, 2003; Horn et al., 2007). For people whose difficulties were previously dismissed as imaginary or self-inflicted, a diagnosis can be welcomed as validating their authenticity and severity (Dinos et al., 2004; Hayne, 2003; Punshon et al., 2009). Diagnosis can also protect self-image by apparently lessening personal culpability for undesirable behaviour and externalising the disorder from a person's 'true' self (Bilderbeck et al., 2014; Pitt et al., 2009). Within everyday social settings, disclosing a diagnosis can prompt more lenient treatment by facilitating access to the 'sick role' (Parsons, 1975) that relieves a person of usual responsibilities. Furthermore, diagnosis can introduce service-users to a community of similar others and serve as a rallying-point around which people assemble to gain social support and advocate for services (Brownlow and O'Dell, 2006; McNamara and Parsons, 2016; Tan, 2018). Emerging research provides strong support for the importance of such social identity processes in promoting and maintaining mental health (Jetten et al., 2014). Diagnosis can thus have numerous positive implications for a person's social identity and personal self-concept.

However, a diagnosis also carries risks for self-concept and social relations. Psychiatric diagnosis can provoke grief and despair (Horn et al., 2007; Knight et al., 2003; Pitt et al., 2009; Ramon et al., 2001), particularly if it is associated with poor prognosis and treatment options. Some may struggle to reconcile a diagnosis with their previous self-image, and dislike feeling marked as ‘abnormal’ or ‘different’ (Hayne, 2003; Knight et al., 2003; Schulze and Angermeyer, 2003; Stalker et al., 2005). Another risk, often articulated under the rubric of labelling theory (Scheff, 1974), relates to the proposition that diagnoses function as self-fulfilling prophecies, i.e. that the disclosure of a diagnosis establishes expectations of certain behaviours, which influence how the person is treated and therefore makes those behaviours more likely. While some research has produced evidence supporting this proposal, particularly regarding diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in childhood (Harris et al., 1992; Sayal et al., 2010), recent longitudinal research finds no evidence prosocial behaviour worsened following a diagnosis of ASD (Russell et al., 2012).

A further concern is that disclosure of a diagnosis might exacerbate the stigma that symptoms of mental illness already attract (Ben-Zeev et al., 2010; Corrigan, 2007). People with direct experience of mental illness report that diagnostic disclosure leads to disadvantage in a range of interpersonal, employment, educational, health and social welfare settings (Dinos et al., 2004; Schulze and Angermeyer, 2003). Numerous studies have experimentally investigated the social effects of diagnosis by comparing people’s attitudes to hypothetical characters with and without a diagnostic label. This literature contains mixed effects, with some reporting a diagnostic label increases prejudice (Batzle et al., 2010; Harris et al., 1992; Ohan et al., 2013) and others that it does not (Jorm and Griffiths, 2008; Law et al., 2007; Thompson and Lefler, 2016). Certain diagnostic labels are more stigmatising than others, e.g. young people with ADHD are perceived more negatively than those with depression (O’Driscoll et al., 2012). Schizophrenia, eating disorders and substance abuse are among the most stigmatised of

common mental illnesses (Angermeyer and Dietrich, 2006). Moreover, mental illness stigma is intersectional with socio-demographic categories: an eating disorder diagnosis, for example, is more stigmatising for males than females (Jones and Morgan, 2010).

Thus, receiving a psychiatric diagnosis can involve both positive and negative social, psychological and practical effects. This ambiguity can be reflected in service-users' attitudes towards receiving a diagnosis (Hayne, 2003; Pitt et al., 2009; Voorhees et al., 2005). For instance, a study of adaptation to a diagnosis of bipolar disorder found that people maintained ambivalent attitudes towards the diagnosis, with attitudes constantly in-flux across time, contextual circumstances, and symptomatic cycles (Inder et al., 2010). In real clinical contexts, individuals' responses to a given diagnosis are not determined purely by its scientific validity or clinical benefit; also important are the ways the diagnosis affects the person's self-understanding and social relationships.

The self and identity effects of diagnosis are likely particularly profound when the diagnosis is ascribed in early-life. Childhood is a time when identity is elastic and acutely sensitive to social experience (Bennett, 2011; Harter, 2012). Until recently, most empirical evidence regarding the psychological effects of childhood diagnoses reflected the perspective of parents (Ahern, 2000; Osborne and Reed, 2008; Russell and Norwich, 2012; Singh, 2004) or people who receive a retrospective diagnosis of developmental disorder (e.g. ADHD) in adulthood (Punshon et al., 2009; Tan, 2018; Young et al., 2008). Recent years have seen increasing recognition of the need for mental health policy and practice to be informed by the perspective of young people themselves (LeFrancois, 2007; Sinclair, 2004). Researchers have demonstrated that, with appropriate attention to research design and ethical procedures, children with cognitive and behavioural difficulties are capable of productively engaging with the research process (Singh, 2007). This emerging literature has produced rich insights into the active ways young people negotiate psychiatric diagnoses and other aspects of the mental

health system (McNamara et al., 2017; Singh, 2011). Most of this evidence is qualitative in nature. The predominance of qualitative research is due to numerous factors. First, the relative youth of this field means much research is still exploratory, with insufficient evidence to inform hypothesis-driven quantitative studies. Second, recent policy emphasis on patient-centred care has prompted an upsurge of interest in lived experiences of service-users, which qualitative research is specifically suited to explore (Beresford, 2007; Davidson et al., 2008; Meyer, 2000). Finally, the pragmatic and ethical challenges of conducting research with children with cognitive, emotional and/or behavioural difficulties mean that standard methods such as questionnaires and experiments are often not appropriate or feasible: more dynamic, interactive data-elicitation methods are required (Singh, 2007; Whyte, 2005).

Previous literature reviews have confirmed the relevance of identity issues to the experience of mental illness (e.g. Boydell et al., 2010; Livingston and Boyd, 2010; Perkins et al., 2018). However, none have specifically focused on the first-hand experience of young people themselves. Additionally, most previous literature has focused on issues specific to a particular category of psychiatric diagnosis. Different diagnoses have widely divergent implications in terms of symptoms, treatment, and social attitudes, which undoubtedly mediate their effects on self-concept and social identity. However, the sociology of diagnosis has shown that useful insights can be gleaned by conceptualising diagnosis as a generic *process*, as well as specific category (Blaxter, 1978; Jutel, 2015). Comparisons of diagnosis' role in diverse medical fields reveal consistent patterns, for instance that diagnosis may induce 'biographical disruption' (Bury, 1982) or clinician-patient tensions (Jutel and Nettleton, 2011). Most youth psychiatric diagnoses share common problems establishing reliability and validity (Rutter, 2011; Timimi, 2014), which have prompted a surge of interest in transdiagnostic approaches to research and treatment (McGorry and Nelson, 2016). Given that diagnosis marks a key point in most mental healthcare trajectories, a transdiagnostic approach is also appropriate for considering whether

this clinical practice has predictable implications for young people's developing identity and self-concept. Both consistencies across and divergences between specific diagnoses' effects are relevant to the ongoing debate about the role diagnosis should play in youth mental health contexts.

Research that enlightens young people's first-hand experiences is an important source of insight into how young people's self-concept and social identity are affected by receiving a psychiatric diagnosis. Understanding the range of possible effects, and the contexts in which they are most likely to occur, is relevant for many interest groups: clinicians deciding whether to offer a formal diagnosis, service-users considering whether to seek and accept a diagnosis, and families and teachers attempting to help young people adapt to a diagnostic classification. This review aims to collate, evaluate and synthesise the qualitative research that has explored how psychiatric diagnosis affects young people's self-concept and social identity.

Method

Design

A systematic literature review was conducted, which followed the procedures stipulated by the PRISMA guidelines (Moher et al., 2009). Articles that met inclusion criteria were subjected to a quality assessment and thematic synthesis.

Search strategy

Keyword-searches were conducted in the following electronic databases: PsycINFO, PsycARTICLES, Academic Search Complete, Social Sciences Full Text, Embase, MEDLINE, PubMed Central, Science Citation Index Expanded, Social Sciences Citation Index, Arts & Humanities Citation Index.

As not all databases indexed entries using standardised searchable subject headings, the search strategy was keyword-based. Various combinations of keywords were trialled to identify a

sequence with an appropriate balance of sensitivity and specificity. The following keyword-string was judged to provide the optimal level of coverage, i.e. yielding a set of results that was comprehensive yet feasible for the research team to manually screen (<10,000). This keyword-string was adapted to suit the search functionalities of the different databases (e.g. different commands to indicate truncation).

a) [girl* OR boy* OR child* OR youth* OR "young person*" OR "young people" OR teenag* OR adolescent*] in Title

AND

b) [qualitative OR interview* OR "focus group*" OR ethnograph* OR "participant observation"] in All Fields

AND

c) [psychiatr* OR psycholog* OR mental] in All Fields

AND

d) [diagnos*] in All Fields

AND

e) [self* OR identit*] in All Fields

Line (a) targeted the relevant research population. This line of keywords was restricted to the article title because searching for these terms in all fields produced an unmanageably large (>470,000) set of results. Line (b) targeted qualitative methodology. There are acknowledged challenges identifying qualitative articles through automated search filters, due to large differences in terminology usage among qualitative researchers (Grant, 2004; DeJean et al., 2016). As the review was interested in the first-hand perspective of young people, the search terms specified the most common data collection methods in qualitative research with human participants. The remaining lines restricted the search to articles discussing mental health, diagnosis, and self or identity.

Inclusion and exclusion criteria

Table 1 presents the inclusion and exclusion criteria that guided the selection of articles. The review was restricted to original qualitative studies where data was contributed by young people who held a recognised, DSM-listed psychiatric diagnosis. In accordance with the review's focus, results had to specifically address the question of how participants' diagnosis had affected their self-concept and/or social identity. For practical reasons relating to research resources, the review was restricted to articles published in peer-reviewed English-language journals. There were no restrictions regarding research location or publication date. The search was conducted in March 2017.

Screening & eligibility assessment

All references were imported into a reference manager software (Endnote) for screening. Initial screening of articles' eligibility was based on inspection of their title and abstract. Articles that did not meet inclusion criteria were excluded and the full texts of remaining articles (excepting one (Green, 1971) that proved impossible to access from existing databases or author requests) were acquired for eligibility assessment. To expand the review's comprehensiveness, the reference lists of included articles, along with those of any review/meta-analysis papers identified in the search process, were inspected for additional relevant papers.

Three reviewers independently screened a randomly-selected 10% ($N=20$) of the articles that underwent full-text eligibility assessment to establish inter-reviewer reliability. Reviewers agreed on 95% of articles. Any ambiguities regarding articles' eligibility were resolved through team discussion, guided by the aim of ensuring maximal comprehensiveness of the review (i.e. erring on the side of inclusion rather than exclusion).

Quality assessment

There is little consensus regarding the most appropriate way of evaluating qualitative evidence within systematic reviews (Butler et al., 2016; Dixon-Woods et al., 2007; Hannes, 2011). In

accordance with increasingly common practice and the recommendations of the Cochrane Qualitative Research Methods Group (Cochrane Qualitative and Implementation Methods Group, 2013; Hannes, 2011), the current study included a structured critical appraisal stage. Given the heterogeneity of theoretical and methodological approaches involved, the aim was not to rank individual studies, but ensure that all met a minimum standard of research quality (Hannes, 2011). The instrument chosen was the commonly-used Critical Appraisal Skills Programme (CASP) Qualitative Checklist (Critical Appraisal Skills Programme, 2017). This evaluates articles along 10 dimensions of research quality. For this review, one dimension – adequate consideration of the researcher-participant relationship – was removed because different disciplinary norms make this dimension difficult to apply to a very multidisciplinary body of literature. On the remaining nine dimensions (clear statement of aims; qualitative method appropriate; design appropriate; recruitment strategy appropriate; data collection appropriate; ethical issues considered; data analysis rigorous; clear statement of findings; value of research), each article was scored to indicate whether the quality criterion was met (score = 2), unclear (score = 1) or unmet (score = 0). All four authors contributed to the quality assessment, with each article independently assessed by two independent reviewers. Average inter-rater reliability using the CASP tool was 92.99%.

Data extraction

A data extraction tool was designed to record information about each study's:

- Region of data collection
- Stated aims
- Diagnoses and how they were determined
- Theoretical framework
- Design
- Sampling strategy

criteria. Inspecting their reference lists revealed 36 further candidate articles, which underwent full-text eligibility assessment. Eleven were retained for the final sample.

These procedures produced a final sample of 38 articles. Figure 1's PRISMA Flow Diagram (Moher et al., 2009) presents the number of articles excluded at each stage. Table 2 and Appendix A list the studies included.

Figure 1: PRISMA Flow Diagram

Quality assessment scores

Reviewers' total CASP scores for each article were averaged. Scores are displayed in Appendix A. Using thresholds adapted from Butler et al. (2016), most articles (78.9%; $n=30$) were evaluated as high-quality (total score=16-18), seven articles moderate-quality (total score=13-15.5) and one low-quality (total score=10-13.5). None met the predetermined threshold for unacceptably low quality meriting exclusion from the review (total score<10).

Thematic synthesis

The thematic synthesis identified 11 analytic themes. These were organised into four overarching 'super-themes': *benefits for self-concept*, *risks for self-concept*, *benefits for social identity*, and *risks for social identity*. It should be noted that these thematic categories are deployed for parsimonious presentation of the results and do not imply that the data presented therein represent mutually exclusive phenomena: self-concept and social identity processes are intrinsically interconnected (Ellemers et al., 2002), and many diagnostic experiences had both positive and negative aspects. Themes are visually presented in Figure 2 and Appendix B and described below along with illustrative quotes from participants.

Figure 2: Thematic structure

269 ***Benefits for self-concept***

270 **Self-understanding**

271 The explanatory value of a diagnosis, in providing a sense of self-insight, was evident in 14
272 articles (Cheung et al., 2015; Cooper and Shea, 1998; Honkasilta et al., 2016; Huws and Jones,
273 2008; Karterud et al., 2015; Kranke et al., 2011; Leavey, 2005; Lingam et al., 2013;
274 McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009; Singh, 2011;
275 Skovlund, 2014; Wisdom and Green, 2004). Numerous young people defined their diagnosis
276 as an explanation of their unusual behavioural traits (Cooper and Shea, 1998; Kranke et al.,
277 2011).

278 *“I’ve never really fit in, I always felt different, and now I know why” (Kranke et al.,*
279 *2011, p. 897)*

280 In these cases, diagnosis was presented as a revelation that afforded new means of making
281 sense of the self. Some adolescents related being struck by a powerful sense of synchrony
282 between the diagnosis and self.

283 *“Everything matched. In a way I got the answers” (Karterud et al., 2015, p. 110)*

284 In certain studies, participants’ diagnoses were assigned some time after the problematic
285 behaviours first emerged. Participants who experienced delayed diagnosis stated their
286 preference to have been diagnosed earlier (Cheung et al., 2015; Huws and Jones, 2008;
287 Mogensen and Mason, 2015). A late diagnosis reframed biographical narratives, providing
288 retrospective clarity on prior experiences. For instance, in three studies, a delayed diagnosis of
289 ASD helped young people understand previously unexplained events, such as their struggles
290 in school (Huws and Jones, 2008; McLaughlin and Rafferty, 2014; Mogensen and Mason,
291 2015).

292 *Knowing what I have has helped me find out why I was always struggling at school and*
293 *[...] getting into trouble” (Huws and Jones, 2008, p. 103)*

294 Valuation of diagnoses’ informative function was evident in some participants’ belief one
295 should know as much about one’s diagnosis as possible. In seven articles, young people
296 expressed a wish for more information or stated they had actively sought information about
297 their disorder (Cheung et al., 2015; Floersch et al., 2009; Jones et al., 2015; Karterud et al.,
298 2015; Kranke et al., 2010; Leavey, 2005; Wisdom and Green, 2004).

299 *“Let the children know more about this disorder...if I know what is happening to myself,*
300 *the attitude, even the effect of the treatment will be different” (Cheung et al., 2015, p. 7)*

301 Some young people found the self-insight diagnosis afforded intrinsically meaningful, even in
302 cases where the diagnosis did not indicate clear treatment options, such as psychogenic non-
303 epileptic seizures (Karterud et al., 2015). For other participants, the insights diagnosis provided
304 were valued for more pragmatic reasons, as a gateway to intervention and self-management.

305 *“I wanted to be labelled because I suddenly knew what I could do and I knew there was*
306 *a way I could cope with that problem once it had been identified.” (Mogensen and*
307 *Mason, 2015, p. 259)*

308 For instance, in one study, a diagnosis of ASD heightened young people’s self-awareness of
309 problematic habits, which enabled them implement positive behaviour change (Mogensen and
310 Mason, 2015). In another study of children with ADHD, the diagnosis was conflated with the
311 introduction of pharmaceutical treatment (Cooper and Shea, 1998). Most participants construed
312 access to treatment as a positive effect of diagnosis, although a minority portrayed intervention
313 as intrusive (Avisar and Lavie-Ajayi, 2014; Kendall et al., 2003; Mogensen and Mason, 2015).

Thus, diagnosis facilitated a sense of self-understanding which was valued both intrinsically and as a door to self-management and clinical intervention.

Self-legitimation

Numerous articles alluded to the validating function of diagnosis (Karterud et al., 2015; Kendall et al., 2003; Mogensen and Mason, 2015; Wisdom and Green, 2004; Woodgate, 2006). The diagnostic label, and the scientific authority it contained, legitimised the authenticity and severity of young people's experiences. The diagnosis reconstructed their struggles as a 'real disease', rather than variations on the normal spectrum of human emotion.

"I think what would help is for people to realize that it is not just feeling down, it is actually an illness" (Woodgate, 2006, p. 266)

For those who construed the diagnosis as legitimising their difficulties, the diagnosis offered a sense of relief or hope (Chavez et al., 2012; Cooper and Shea, 1998; Ingesson, 2007; Karterud et al., 2015; Leavey, 2005; Mogensen and Mason, 2015; Travell and Visser, 2006; Wisdom and Green, 2004). This partly related to perceived absolution from blame for undesirable behaviour. Several articles revealed young people using diagnoses of ADHD and ASD to mitigate responsibility for disobedience or peer conflict (Honkasilta et al., 2016; Singh, 2011; Singh et al., 2010; Skovlund, 2014).

"Well, I realised that [...] whenever I got into trouble at school for talking and stuff, it wasn't my fault; it was because I had ADD [...] I couldn't help being distracted and that I wasn't concentrating properly." (Cooper and Shea, 1998, p. 43)

This strategy for deflecting blame required ceding agency to the diagnosis. The disorder was positioned as an independent entity that compelled certain behaviours (Honkasilta et al., 2016; Kendall et al., 2003).

337 *“it’s something I can’t control, really. It’s like a part of you, like it’s hard... like even if*
338 *you try to control it, it’s still like the better part of you is still in there, you know. So it’s*
339 *not all the kid’s fault.” (Kendall et al., 2003, p. 122)*

340 Singh’s (2011) analysis of children with ADHD proposed that such renunciations of personal
341 control were employed for strategic purposes in specific contextual circumstances, and did not
342 necessarily indicate an omnipresent loss of agency. This accorded with numerous other studies.
343 While some articles did contain quotes from young people indicating a sense of helplessness
344 or passivity (e.g. *“It’s like a disease eating on you, you know, like you try to behave but it keeps*
345 *on going on in your head to stop you behaving, and I always got in trouble for it.”* (Travell and
346 Visser, 2006, p. 207)), other participants explicitly emphasised their control over their
347 symptoms (Honkasilta et al., 2016; Kendall et al., 2003; Leavey, 2005; Skovlund, 2014;
348 Wisdom and Green, 2004; Woodgate, 2006).

349 *“I own the illness; the illness doesn’t own me.” (Leavey, 2005, p. 118)*

350 Thus, attributing one’s behaviour to a diagnosis did not erode young people’s sense of agency.
351 Rather, by legitimising the notion of a disease-entity, diagnosis allowed young people
352 externalise their difficulties from their ‘core’ self and thereby protect their self-image.

353 **Self-enhancement**

354 Receiving a diagnosis did not necessarily engulf a person’s sense of self. In sixteen articles,
355 young people articulated a self-concept that was clearly independent of their diagnosis
356 (Floersch et al., 2009; Hallberg et al., 2010; Honkasilta et al., 2016; Huws and Jones, 2015;
357 Jones, 2012; Karterud et al., 2015; Kendall et al., 2003; Kranke et al., 2011; Huws and Jones,
358 2008; Huws and Jones, 2015; Moses, 2010; Skovlund, 2014; Tidefors and Strand, 2012; Travell
359 and Visser, 2006; Wisdom and Green, 2004; Woodgate, 2006). The disorder was something
360 they ‘had’ rather than something they ‘were’.

361 *“At the end of the day, people with autism are just the same as people who haven’t [got*
362 *it], but they’ve just got something wrong with them, that’s it.” (Huws and Jones, 2015,*
363 *p. 89)*

364 Neither did receiving a diagnosis necessarily impair a young person’s self-image. Thirteen
365 articles presented young people expressing a distinctly positive self-concept (Daley and
366 Weisner, 2003; Elkington et al., 2012; Honkasilta et al., 2016; Humphrey and Lewis, 2008;
367 Huws and Jones, 2015; Jones et al., 2015; Krueger and Kendall, 2001; Lingam et al., 2015;
368 McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Skovlund, 2014; Wisdom and
369 Green, 2004; Woodgate, 2006). In some cases, they achieved this by focusing on positive
370 personal traits that existed independently of the disorder, for instance *“my personality”* (Daley
371 and Weisner, 2003; Lingam et al., 2013). More frequently, however, they reconstructed
372 components of the disorder itself as positive (Daley and Weisner, 2003; Humphrey and Lewis,
373 2008; Huws and Jones, 2015; Jones et al., 2015; Krueger and Kendall, 2001; McLaughlin and
374 Rafferty, 2014; Mogensen and Mason, 2015; Skovlund, 2014). This perspective was most
375 prominent for diagnoses of ASD. In two studies, participants explicitly oriented towards a
376 characterisation of ASD as a *“gift”* and rejected its definition as *“disability”* (Daley and
377 Weisner, 2003; Jones et al., 2015).

378 *“Most people with Asperger’s are very gifted. They learn things quick. They got good*
379 *memories... They’re beyond extremely high functioning... And they’re mostly normal.*
380 *[...] most of them are good looking.” (Daley and Weisner, 2003, p. 34)*

381 For disorders defined by negative emotional symptoms, such as depression, positive
382 reconstrual of the symptoms themselves was less likely. However, in three studies of young
383 people with depression, participants had nevertheless fashioned a self-affirming narrative
384 around their diagnoses, by determining their experiences had ultimately strengthened their

character (Elkington et al., 2012; Wisdom and Green, 2004; Woodgate, 2006). Thus, diagnoses could be recruited as resources in maintaining a positive self-concept.

Risks for self-concept

Self-threat

Twelve articles presented evidence that a diagnosis can be experienced as a threat to one's self-concept (Elkington et al., 2012; Floersch et al., 2009; Hallberg et al., 2010; Huws and Jones, 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et al., 2010; Leavey, 2005; Mogensen and Mason, 2015; Travell and Visser, 2006; Wisdom and Green, 2004; Woodgate, 2006). Receiving a diagnosis could challenge a young person's previous self-image and force them to reconsider their identity. Some participants experienced this as a radical rupture of the self.

"The safety of waking up and 'knowing who you are' which most people take for granted had suddenly vanished." (Leavey, 2005, p. 115).

On hearing their diagnosis, some participants failed to identify with it or recognise themselves in its formulation (Floersch et al., 2009; Huws and Jones, 2008; Karterud et al., 2015). Adapting to the diagnosis therefore involved assimilating new and potentially uncomfortable attributes into the self-concept (Hallberg et al., 2010; Jones et al., 2015). These attributes could be both previously unrecognised symptoms and disparaging judgements such as "crazy" (Kranke et al., 2010, p. 499). The very term "mental illness" was problematic for some (Karterud et al., 2015; Leavey, 2005). As numerous young people acknowledged, they themselves could hold negative stereotypes of people with psychological disorders (Elkington et al., 2012; Floersch et al., 2009; Humphrey and Lewis, 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et al., 2011; Kranke et al., 2010; Leavey, 2005). This heightened the threat the diagnosis represented to their self-image.

408 *“Sometimes I don’t like myself because, having to go through a mental illness is such a*
 409 *bad thing that I label myself and look down on myself. Like the way I see other people*
 410 *who have illness, like this is a very stereotypical view, but [...] when I say the word*
 411 *‘mental illness’ it reminds me of bad, just bad in that... eww! Bad, who’d want that?”*
 412 *(Leavey, 2005, p. 114)*

413 These threatening connotations meant that initial responses to the diagnosis often involved
 414 shock, dejection or distress, present in 14 articles (Chavez et al., 2012; Floersch et al., 2009;
 415 Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Karterud et al., 2015;
 416 Kendall et al., 2003; Kranke et al., 2010; Leavey, 2005; McLaughlin and Rafferty, 2014;
 417 Mogensen and Mason, 2015; Pope, 2015; Travell and Visser, 2006; Wisdom and Green, 2004).
 418 One participant vocalised his first reaction to his diagnosis of Asperger’s disorder as *“Oh my*
 419 *God I’m a freak!”* (Humphrey and Lewis, 2008, p. 31). Dissonance with self-image sometimes
 420 prompted outright rejection of the diagnostic classification. Sixteen articles illustrated young
 421 people resisting or denying their diagnosis (Boughtwood and Halse, 2010; Cooper and Shea,
 422 1998; Daley and Weisner, 2003; Floersch et al., 2009; Huws and Jones, 2008; Jones, 2012;
 423 Karterud et al., 2015; Kendall et al., 2003; Kranke et al., 2011; Kranke et al., 2010; Leavey,
 424 2005; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009; Pope, 2015;
 425 Travell and Visser, 2006). Other young people recounted having previously undergone stages
 426 of rejecting their diagnosis, although they now accepted it (Floersch et al., 2009; Kendall et al.,
 427 2003; Kranke et al., 2011; Kranke et al., 2010; Mogensen and Mason, 2015). The latter cases
 428 reflected the common finding that young people’s relationships with their diagnosis were
 429 unstable and changed over time (Elkington et al., 2012; Floersch et al., 2009; Hallberg et al.,
 430 2010; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Jones et al., 2015;
 431 Karterud et al., 2015; Kranke et al., 2010; Leavey, 2005; Pope, 2015). All cases of temporal

change in relationship with the diagnosis ran in the direction of increased acceptance of its validity.

“At first I was like, ‘no. I can’t be bipolar.’ That’s just not me. I don’t want to be it and then when I started actually seeing what was really going on, I’m just like, oh my god, I can’t believe I just said that I wasn’t this, and now I am.” (Floersch et al., 2009, p. 166)

While a minority ultimately came to view their diagnosis in emotionally neutral (Humphrey and Lewis, 2008; Kendall et al., 2003) or even positive (Daley and Weisner, 2003; Humphrey and Lewis, 2008; Lingam et al., 2013; Mogensen and Mason, 2015) terms, for most the diagnosis remained a distinctly negative attribute. They had felt they had no choice but to resign themselves to its presence in their lives (Daley and Weisner, 2003; Huws and Jones, 2008; Kendall et al., 2003; Krueger and Kendall, 2001).

“I really find it annoying to have but it’s something that you’ve got to accept” (Huws and Jones, 2008, p. 104)

In summary, the threat a diagnosis posed to self-image meant that initial resistance of it was common. Young people typically adapted to their diagnosis over time, but the self-reconstruction necessary meant this was often a difficult and protracted process.

Self-devaluation

Assimilating a diagnosis could pose risks for young people’s self-esteem. Sixteen articles revealed young people expressing a distinctly negative self-image (Cheung et al., 2015; Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2013, 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Ingesson, 2007; Jones, 2012; Karterud et al., 2015; Kranke et al., 2011; Krueger and Kendall, 2001; Leavey, 2005; Lingam et al., 2014; Singh et al., 2010; Travell and Visser, 2006). Young people variously viewed themselves as inferior (Cheung et al., 2015; Elkington et al., 2012; Elkington et al., 2013; Hallberg et al., 2010), inadequate

(Krueger and Kendall, 2001), damaged and incomplete (Cooper and Shea, 1998), flawed (Elkington et al., 2012), unintelligent (Daley and Weisner, 2003; Lingam et al., 2014; Travell and Visser, 2006), and undeserving of happiness (Elkington et al., 2013).

“I’ve had pretty negative thoughts about myself and ADHD since I was little, especially when people are nagging me about things when I mess up. I try to do things right, but I can’t. I think it’s the way I’ll always be.” (Krueger and Kendall, 2001, p. 66)

In most articles, it was unclear whether loss of self-worth was caused by the diagnosis itself, or the symptoms that presumably pre-dated it. However, the diagnosis certainly contributed to lowered self-worth for some young people by confirming that there was something fundamentally ‘wrong’ with them. The devaluing potential of diagnosis was more profound, the more an individual’s self was conflated with the diagnosis. For a minority of young people, their diagnosis represented the defining aspect of their self-concept (Kendall et al., 2003; Krueger and Kendall, 2001; Leavey, 2005; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009; Wisdom and Green, 2004). Such strong self-identification with a diagnosis mostly coincided with negative self-views, with the exception of some participants with ASD, whose diagnosis contributed to a self-image of uniqueness (Mogensen and Mason, 2015).

Alongside young people’s sense their diagnosis marked them as flawed or deficient, studies also highlighted diagnoses’ pragmatic consequences for personal development. Young people in 11 studies stated that receiving the diagnosis had restricted their opportunities in education, career and relationships (Chavez et al., 2012; Hallberg et al., 2010; Huws and Jones, 2008, 2015; Jones, 2012; Leavey, 2005; McLaughlin and Rafferty, 2014; Moses, 2010; Singh et al., 2010; Travell and Visser, 2006; Woodgate, 2006). For instance, adolescents with ADHD worried disclosing their diagnosis would invite discrimination from prospective employers

(Hallberg et al., 2010). Young people positioned their diagnosis as responsible for unwanted education placements (Jones, 2012; Moses, 2012), inability to pursue further education or desired career trajectories (Huws and Jones, 2008, 2015; Leavey, 2005), educational underperformance (Leavey, 2005; McLaughlin and Rafferty, 2014; Skovlund, 2014), unfair treatment from teachers (Moses, 2010; Singh et al., 2010) and peer discord (McLaughlin and Rafferty, 2014; Singh et al., 2010). These attributions caused significant resentment of the diagnosis – although again, it was often difficult to disentangle the degree to which young people blamed the diagnostic label itself, versus the disorder’s symptoms. For some young people, the diagnosis’ perceived curtailment of opportunities fostered trepidation about their future (Chavez et al., 2012; Hallberg et al., 2010; Huws and Jones, 2015, 2008; Ingesson, 2007; Kranke et al., 2011, 2010; Krueger and Kendall, 2001; Leavey, 2005; Lingam et al., 2014; Travell and Visser, 2006). Others adopted a pragmatic stance, arguing that one must simply “accept it and your limitations” (Woodgate, 2006, p. 265). A recurrent finding was that after the diagnosis, young people’s expectations and aspirations for the future were revised downward.

“Like, my goals used to be set really high, get high marks, go to university. Now it’s just graduate high school and maybe go to college.” (Leavey, 2005, p. 118).

Thus, accepting a psychiatric diagnosis could lead to anxiety about future prospects and realignment to less ambitious career and educational plans.

Benefits for social identity

Social identification

Thirteen articles presented evidence that young people derived a sense of social identity from their diagnosis (Brady, 2014; Daley and Weisner, 2003; Elkington et al., 2012; Floersch et al., 2009; Jones et al., 2015; Kranke et al., 2010; Leavey, 2005; Lingam et al., 2014; McLaughlin

and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2010; Skovlund, 2014; Wisdom and Green, 2004). Numerous young people described bonds with peers who held similar diagnoses. These were sometimes pre-existing friends who happened to also experience mental health problems (Floersch et al., 2009; Moses, 2010), sometimes other users of relevant services (Leavey, 2005; Lingam et al., 2013), and sometimes prior acquaintances which became closer following the discovery of a shared diagnosis (Brady, 2014; McLaughlin and Rafferty, 2014). Family members who experienced similar difficulties also offered social understanding and acceptance (Moses, 2010).

Relationships with similar others had a special quality that was valued above friendships with ‘normal’ peers (Leavey, 2005). These relationships held a transparency lacking from other friendships, as young people disclosed more personal information to others with shared experience (Elkington et al., 2012). These friendships were an outlet for sharing mental health-related experience and advice – even, on occasion, medication (Brady, 2014). Young people who attended organised peer support groups appreciated the opportunity they presented to forge these connections, which were valued both intrinsically and as resources for mental health (Leavey, 2005; Lingam et al., 2013). Numerous young people alluded to a prior isolation, that was resolved through meeting others in similar situations (Jones et al., 2015; Kranke et al., 2010).

“I mean it's easier to understand like other people have this condition. You're going through it. I'm not the only one. Other people are like me. I mean it just so I don't feel isolated.” (Kranke et al., 2010, p. 500)

The collective identity attached to their diagnosis was reflected in pronouns such as “we” and “us”, indicating identification with others in one’s diagnostic category. Face-to-face contact was not the only means of developing this solidarity: online communication and simply reading

about others with a diagnosis served similar functions (Elkington et al., 2012; Jones et al., 2015; Mogensen and Mason, 2015). Contact with others who shared the diagnosis afforded a much-wanted sense of belonging and validation (Jones et al., 2015).

“I think of a lone jelly bean all by myself. No friends, until he realizes, I’m not alone; I’m not the only jelly bean. There are jelly beans just like me, I’m not alone” (Jones et al., 2015, p. 1499)

Thus, one function of a diagnosis was to alert young people that there were others ‘like them’, and many actively sought to cultivate relationships with these similar others.

Social acceptance

Diagnoses could have positive implications for young people’s social relationships generally. In eight articles, young people reported their interpersonal relationships had improved following their diagnosis (Elkington et al., 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Kranke et al., 2010; Leavey, 2005; Mogensen and Mason, 2015; Singh, 2011; Singh et al., 2010).

“After I got sick, people were so nice, they never gets [sic] angry at me” (Leavey, 2005, p. 116)

Teachers could become more tolerant after learning about a child’s diagnosis (Honkasilta et al., 2016; Lingam et al., 2013; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2010; Singh, 2011). Some young people reported that their relationships with their parents had improved since their diagnosis, making interactions more accepting and open (Elkington et al., 2012; Leavey, 2005). Since many only selectively disclosed their diagnosis outside the home, the family often represented a comfortable setting where one’s diagnosis was known and understood (Hallberg et al., 2010). Reluctance to disclose the diagnosis to peers was driven largely by anticipation that friends would treat one differently as a result. However,

these expectations were not always realised: some participants reported that revealing their diagnosis to peers had led to increased understanding (Elkington et al., 2012; Humphrey and Lewis, 2008), while others were gratified by their friends' indifference to their diagnosed status (Kranke et al., 2010; Moses, 2010).

A further way diagnosis could smooth social relations was its potential deployment as a weapon against unkind treatment. Some young people opted to identify themselves using the official diagnostic term as a preferred alternative to derogatory slang for mental illness (Cooper and Shea, 1998). Young people could also harness the fear associated with mental illness to their benefit: three articles identified young people who deployed the diagnosis to offset the threat of bullying (Huws and Jones, 2008; Singh et al., 2010; Singh, 2011).

"I have like told people I got ADHD cos it makes them leave you alone. They're nervous that you might really hurt them if you get wound up." (Singh, 2011, p. 894)

Numerous young people recounted experiences of positive discrimination or 'special treatment' resulting from their diagnosis (Daley and Weisner, 2003; Elkington et al., 2012; Humphrey and Lewis, 2008; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2010; Singh, 2011; Woodgate, 2006). Diagnoses alerted others to young people's challenges in certain domains, prompting more benevolent attitudes and practical assistance. However, although participants acknowledged this was kindly meant, they were often uncomfortable with these experiences, which contradicted their desire to retain a sense of normality (Daley and Weisner, 2003; Elkington et al., 2012; McLaughlin and Rafferty, 2014). Intensive monitoring or overprotective responses from parents were not appreciated (Leavey, 2005; Moses, 2010). Young people also disliked when teachers were overly attentive or lenient due to their diagnosis, thereby drawing attention to their difference from their peers. This rejection of preferential treatment or "*extra attention*" (Humphrey and Lewis, 2008, p. 38)

sometimes extended to learning supports to which they were entitled, such as special needs assistants.

“I don’t want people to treat me differently because people with Aspergers [get treated] differently to everybody else and I don’t like it at all. I don’t like this sort of thing you know I don’t like people coming to my lessons. [...] If they were following me then the other students know that there’s something different about me and I don’t like it at all. [...] Often it’s like – I don’t really like the extra attention.” (Humphrey and Lewis, 2008, p. 38)

Thus, young people often reported that their diagnosis had fostered a more tolerant, understanding social environment. However, this was qualified by discomfort when disclosure of a diagnosis led other people to dramatically change their behaviour towards them (Moses, 2010). Most young people wished to preserve a continuity of identity pre- and post-diagnosis, and so it was important that others acknowledge their essential identity was unaffected by the diagnosis (Karterud et al., 2015; Woodgate, 2006).

Social comparison

Holding a diagnosis afforded young people a classification unique among their peers, which left many in some confusion regarding their social positioning. The literature illuminated the social cognitive processes by which young people sought to orient themselves in their social milieu. Twelve articles observed young people spontaneously engaging in social comparison, i.e. evaluating their own social status in relation to others (Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2012; Huws and Jones, 2015; Jones, 2012; Jones et al., 2015; Kendall et al., 2003; McCann et al., 2012; McLaughlin and Rafferty, 2014; Moses, 2009; Singh et al., 2010; Skovlund, 2014). In almost all cases, the direction of comparison was downward,

599 with young people enhancing their own self-esteem by comparing themselves positively to
600 more impaired others.

601 The spectrum formulation of ASD provided a particularly amenable platform for these social
602 comparison processes (Huws and Jones, 2015; Jones et al., 2015). The distinction between
603 ‘Asperger’s’ and ‘autism’ was important to some participants (Huws and Jones, 2015;
604 McLaughlin and Rafferty, 2014). In one ASD study, every participant alluded to variation in
605 the severity of autism symptoms, and all defined their own symptoms as mild relative to
606 individuals who were “*really, really autistic*” or who have “*got it very bad*” (Huws and Jones,
607 2015, p. 87).

608 *“I’m not as bad as the others here.” (Huws and Jones, 2015, p. 87)*

609 Such patterns were also visible for other diagnoses. Children with a diagnosis of ADD
610 distinguished themselves from a diagnosis of ADHD, which they saw as more extreme (Cooper
611 and Shea, 1998). Adolescents with intellectual disabilities differentiated between “*normal*” and
612 “*disabled*” children, aligning themselves with the former (Daley and Weisner, 2003), and
613 distinguished between “*just*” having a mental disability and having a “*proper*” (i.e. physical)
614 disability (Huws and Jones, 2015; Jones et al., 2015). Young people whose difference from
615 typically developing peers was materialised in their separation into special classrooms
616 dissociated themselves from their more impaired classmates (Jones, 2012). Young people with
617 emotional disorders minimised their own difficulties by observing that others had more severe
618 symptoms (McCann et al., 2012; Moses, 2009). One study observed that young people
619 distanced themselves from the category of “*crazy*” by locating it with more extreme cases they
620 encountered in clinical settings or the media (Elkington et al., 2013). However, this strategy
621 was restricted to individuals with nonpsychotic disorders; youth with psychotic disorders did
622 not engage in this form of social comparison (Elkington et al., 2013).

623 In only one case – an adolescent with multiple comorbidities in Moses (2009) – was upward
624 social comparison (i.e. comparison with a higher-functioning person) employed to emphasise
625 the severity of one’s own difficulties. All other cases of social comparison were directed
626 downward to more impaired others, which made oneself appear relatively robust in
627 comparison. Just as young people distanced themselves from more severely impaired
628 individuals, they also took pains to emphasise their similarity to “normal” peers (Avisar and
629 Lavie-Ajayi, 2014; Daley and Weisner, 2003; Elkington et al., 2012; Humphrey and Lewis,
630 2008; Huws and Jones, 2015; Ingesson, 2007; Mongensen and Mason, 2015; Moses, 2010;
631 Singh, 2011; Wisdom and Green, 2004).

632 *“I am normal. I do bleed red blood. I do know how to read. I know how to do everything*
633 *the kids do.” (Daley and Weisner, 2003, p. 31)*

634 Older adolescents were particularly keen to emphasise that they were no different from their
635 friends or siblings (Moses, 2010). Participants with mood disorders achieved this normalisation
636 by emphasising the ubiquity of the experience of emotional distress (Elkington et al., 2012) or
637 observing parallels between their own difficulties and those of their peers (Wisdom and Green,
638 2004).

639 Thus, a psychiatric diagnosis should not be equated with an inevitable designation of social
640 deviance or inferiority: young people actively engaged in creative social cognitive strategies
641 for preserving their sense of worth. They organised their own and others’ diagnoses into
642 hierarchies that set themselves in a relatively advantaged position. It should be noted that these
643 social comparison processes are not optimal at a systemic level, as they can undermine
644 solidarity and fuel stigmatisation of the most impaired young people. Their benefits lie purely
645 at an individual level: diagnoses afford young people tangible markers to identify targets
646 relative to whom they can feel advantaged.

Risks for social identity

Social alienation

In eighteen articles, young people expressed acute awareness of their difference from their peers (Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2015; Ingesson, 2007; Jones, 2012; Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2011, 2010; Leavey, 2005; McCann et al., 2012; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Travell and Visser, 2006; Woodgate, 2006). In some cases, young people had been aware of their atypicality prior to the diagnosis, and the diagnosis had simply helped them make sense of it (Mogensen and Mason, 2015). In other cases, awareness of difference was prompted by the diagnosis itself: for instance, one study suggested that young people's sense of deviance arose only after they received an ADHD diagnosis (Hallberg et al., 2010). In both scenarios, the diagnostic label was critical in alerting *other* people to the young person's deviance, which was generally experienced as unpleasant (Elkington et al., 2012; Humphrey and Lewis, 2008; Jones et al., 2015).

"I kind of just feel, I feel like I am just marked. Like people just have, some people just kind of treat me different, and I don't want to be treated different, I just wanted to be treated how I was" (Jones et al., 2015, p. 1498)

As outlined above, some young people fostered a positive self-concept by emphasising their unique talents (Jones et al., 2015; Mogensen and Mason, 2015). However, when young people explicitly defined themselves as "*different*" from peers, this was almost exclusively presented as a negative attribute (Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2015; Kendall et al., 2003; Kranke et al., 2011; Lingam et al., 2013; Travell and Visser, 2006). The status of

671 “different” was often conflated with “abnormal” (Humphrey and Lewis, 2008; Kranke et al.,
672 2011), with deviations from normality described using terminology such as “weird”, “odd” or
673 “strange”. Perceiving oneself as different from others was therefore bound up with a
674 devaluation of one’s relative worth (Cooper and Shea, 1998; Huws and Jones, 2015; Ingesson,
675 2007).

676 *“Sometimes, when I was little, I thought that I was an alien [...] I thought that I was*
677 *different from the others, and I didn't really care about me because - well like, I cared*
678 *about me – but I didn't care about me much, because I just thought that I was really*
679 *different. And that I wasn't the type of person I should be.” (Cooper and Shea, 1998, p.*
680 *42)*

681 Young people believed their difference was evident to others and found it difficult to “fit in”
682 (Mogensen and Mason, 2015, p. 259) with their peers (McLaughlin and Rafferty, 2014). The
683 effort involved in trying to appear “as everyone else” (Hallberg et al., 2010, p. 215) was
684 burdensome (Hallberg et al., 2010; Humphrey and Lewis, 2008). Several young people
685 expressed a wish for a magical intervention that would “make me normal” (Humphrey and
686 Lewis, 2008, p. 31) (Hallberg et al., 2010; Humphrey and Lewis, 2008; Leavey, 2005; McCann
687 et al., 2012).

688 *“I wish that this diagnose [sic] vanished, so I became normal” (Hallberg et al., 2010, p.*
689 *215)*

690 As well as the intrinsic dislike participants felt towards their “different” status, difference had
691 the pragmatic effect of contributing to social isolation (Kranke et al., 2011; McLaughlin and
692 Rafferty, 2014; Mogensen and Mason, 2015). In three studies (Daley and Weisner, 2003;
693 Elkington et al., 2012; Woodgate, 2006), young people defined themselves as “outcasts”.

694 *"I don't like being classified. Like I'm not classified as regular. I'm classified as outcast.*
695 *[...] outcasts don't have a life, outcasts are dogs in other people's eyes."* (Daley and
696 Weisner, 2003, p. 38)

697 Young people directly attributed social exclusion (Hallberg et al., 2010; Jones, 2012) or
698 victimisation (Humphrey and Lewis, 2008) to being recognised as different.

699 *"I just don't feel normal... me being different may be one of the reasons I ain't got no*
700 *friends or something"* (Kranke et al., 2011, p. 897)

701 In 12 articles, young people reported that their interpersonal relationships had suffered due to
702 their diagnosis (Chavez et al., 2012; Elkington et al., 2012, 2013; Hallberg et al., 2010;
703 Ingesson, 2007; Jones, 2012; Kranke et al., 2010; Leavey, 2005; McCann et al., 2012;
704 McLaughlin and Rafferty, 2014; Moses, 2010; Singh, 2011). For some, the diagnosis had made
705 them a target for ridicule and bullying (Chavez et al., 2012; Elkington et al., 2012; Ingesson,
706 2007; Singh, 2011). Young people described rejection and abandonment from previous friends
707 (Elkington et al., 2012; Leavey, 2005; Moses, 2010) and blamed the diagnosis for the absence
708 of friends they would otherwise have had (Kranke et al., 2011; McLaughlin and Rafferty,
709 2014). Among older participants, a sense of isolation was heightened by a belief that the
710 diagnosis impeded the formation of fulfilling romantic relationships.

711 *"I wish I could get rid of my diagnosis, it holds me back in relation to girls"*(Hallberg et
712 al., 2010, p. 215)

713 Adolescents believed the diagnosis would lead prospective partners to expect they were
714 unreliable or burdensome (Elkington et al., 2013; Hallberg et al., 2010; Leavey, 2005). In one
715 study, this sense of low desirability as a romantic partner led some young people to accept
716 abusive or unfulfilling relationships (Elkington et al., 2013)

717 Thus, many young people felt their social connections had been impoverished by their
718 diagnosis, because it drew others' attention to their difference from the norm.

719 **Social invalidation**

720 In 11 articles, young people complained of low awareness of mental illness within their social
721 circle and society generally (Elkington et al., 2012; Honkasilta et al., 2016; Humphrey and
722 Lewis, 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et al., 2011, 2010; Leavey, 2005;
723 Lingam et al., 2014; Mogensen and Mason, 2015; Singh et al., 2010). They expressed a wish
724 for greater public education about their disorders (Humphrey and Lewis, 2008; Jones et al.,
725 2015; Mogensen and Mason, 2015; Singh et al., 2010).

726 *“It is the teachers [that] are rubbish – they know about their subject but they know*
727 *nothing about us with Asperger’s syndrome but then why should they – they’ve never*
728 *been told – they’re not specially trained to deal with people with special needs”*
729 *(Humphrey and Lewis, 2008, p. 39)*

730 Young people bemoaned misunderstandings of their diagnosis they encountered in others.
731 These misunderstandings could arise even within the family home, with some young people
732 indicating their parents did not correctly understand the implications of their diagnosis (Kranke
733 et al., 2011, 2010). Young people felt that following their diagnosis, they were viewed as less
734 capable and competent than they had previously been. They were no longer trusted with the
735 level of responsibility they had previously been afforded (Elkington et al., 2012; Leavey, 2005;
736 Moses, 2010).

737 *“[They] treat me differently since I got diagnosed with an illness. I think*
738 *subconsciously, yeah. They don’t realize it either, because they’re overprotective. They*
739 *want me home by a certain time” (Leavey, 2005, p. 116)*

740 As discussed above, young people were often uncomfortable receiving ‘special help’ at school
741 or home, especially if this was seen as motivated by pity (Moses, 2010). Some also suggested
742 overly benevolent treatment denied young people agency and the opportunity to challenge
743 themselves (Daley and Weisner, 2003).

744 *“I mean [the other teens] really liked me and helped me, but they treated me as if I was*
745 *helpless. And they treated me as if I didn't know how to do anything. Like, greeaaaat. So,*
746 *at times it was kind of fun but at other times it was kind of boring, because, you know, I*
747 *can do things, I'm not dumb. I can figure it out. And the only way I'm going to get*
748 *independent is by trying.” (Daley and Weisner, 2003, p. 33)*

749 Some participants suggested the diagnosis had involved a loss of identity: in other people’s
750 eyes, they became a unidimensional being defined solely by their diagnosis (Elkington et al.,
751 2012). Equally problematic as others investing too much importance in the diagnosis, were
752 instances of people refusing to accept the diagnosis as a legitimate medical condition. A
753 minority of young people related experiences of such resistance to their diagnosis from school
754 authorities (Brady, 2014; Singh, 2011), family (Elkington et al., 2012; Moses, 2010), healthcare
755 providers (Karterud et al., 2015) and friends (Moses, 2010).

756 *“they think I’m just doing it for attention” (Moses, 2010, p. 988)*

757 Others’ refusal to accept one’s diagnosis as valid was experienced as distressing, particularly
758 for young people who invested deeply in the diagnosis in articulating their identity.

759 **Social stigmatisation**

760 Direct experience of stigma arose in 23 of the papers reviewed (Avisar and Lavie-Ajayi, 2014;
761 Chavez et al., 2012; Cooper and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2013,
762 2012; Hallberg et al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson,

2007; Jones, 2012; Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2011, 2010; Leavey, 2005; McCann et al., 2012; Mogensen and Mason, 2015; Moses, 2010; Singh, 2011; Singh et al., 2010; Travell and Visser, 2006; Woodgate, 2006). The most commonly discussed source of stigma, present in 11 articles, was the young person's peer-group (Daley and Weisner, 2003; Elkington et al., 2012; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Jones, 2012; Kendall et al., 2003; Kranke et al., 2011, 2010; McCann et al., 2012; Singh, 2011). In seven articles, most involving developmental disorders, young people related experiences of bullying from classmates or friends (Daley and Weisner, 2003; Hallberg et al., 2010; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Kranke et al., 2010; Singh, 2011).

"Persecution! Being beaten up, assaulted. You don't get much worse than that. Assault is pretty, pretty bad" (Daley and Weisner, 2003, p. 38)

In several cases the bullying was directly attributed to the disclosure of a diagnosis, which made people a target for victimisation.

"Because I told [peers] about my ADHD, they thought if they could wind me up I'd get really upset and they love to do that" (Singh, 2011, p. 893)

The second most frequently mentioned sources of stigma, manifesting in six articles encompassing a range of diagnoses, were school authorities (Cooper and Shea, 1998; Elkington et al., 2012; Humphrey and Lewis, 2008; Kranke et al., 2011; Moses, 2010; Singh et al., 2010). Numerous young people saw their diagnosis as negatively impacting their educational experience due to the bad reputation it afforded them (Singh et al., 2010). Specific complaints ranged from placement in inappropriate classroom contexts, undemanding work, intensive monitoring, false accusations of trouble-making and verbal abuse from teachers.

786 *“He (teacher) was like... we're going' push you down and shove that medication down*
787 *your throat, (if) you keep on acting crazy” (Kranke et al., 2010, p. 501)*

788 In three studies, young people positioned their family as a source of stigma (Elkington et al.,
789 2012; Kranke et al., 2010; Moses, 2010). In these families, the diagnosis was seen as shameful
790 and relatives worried they would be contaminated by their association with the young person.
791 Extended family might distance themselves from the diagnosed individual (Moses, 2010),
792 while immediate family might encourage secrecy about the diagnosis (Elkington et al., 2012).

793 *“My dad asks ‘Why do I have to talk to a stranger about my problems?’” (Elkington et*
794 *al., 2012, p. 300)*

795 The media was faulted for propagating stigmatising representations of mental illness in three
796 studies (Elkington et al., 2012; Kranke et al., 2011; Leavey, 2005).

797 *“usually when you see images of a mental institution on TV, it’s perceived as a place*
798 *where dangerous and violent people are kept” (Elkington et al., 2012, p. 299)*

799 Less commonly mentioned outlets for stigma were interactions with health professionals
800 (Avisar and Lavie-Ajayi, 2014; Mogensen and Mason, 2015), intimate relationships (Elkington
801 et al., 2013) and the workplace (Hallberg et al., 2010).

802 Participants attributed their personal experience of social rejection to negative cultural
803 representations of their diagnosis (Elkington et al., 2012). The diagnostic label was blamed for
804 encouraging preconceptions about a person that may not align with their actual attributes: as
805 one participant put it, *“the problem with having a label is that people always prejudge you”*
806 (Huws and Jones, 2008, p. 103). These prejudgements were shaped by common stereotypes of
807 mental illness, of which young people were aware and resentful. Young people specifically
808 criticised the association of various psychiatric diagnoses with attributes of aggression and

809 violence (Elkington et al., 2012; Singh, 2011), unreliability (Elkington et al., 2013), volatility
810 (Elkington et al., 2013; Moses, 2010), low intelligence (Kendall et al., 2003; Singh et al., 2010),
811 poor social skills (Mogensen and Mason, 2015), incompetence (Elkington et al., 2012; Leavey,
812 2005; Mogensen and Mason, 2015; Moses, 2010), and disobedience (Moses, 2010; Singh,
813 2011). These stereotypes were experienced as oppressive and gave rise to feelings of being
814 radically misunderstood. Young people particularly objected to stereotypes that inflated the
815 severity of their presumed disturbance.

816 *“They think you’re a murderer” (Elkington et al., 2012, p. 298)*

817 Young people strongly and repeatedly objected to derogatory terms for mental illness. Specific
818 words mentioned were “retard”, “weirdo”, “crazy”, “psycho”, “nuts”, “cuckoo”, “zombie”,
819 “freak” and “loser”. Young people exposed to such language felt mischaracterised and
820 demeaned, and positioned this language as a risk factor for poor self-worth.

821 *“Crazy. Psycho. Nuts. 'Cause that's what I heard from everyone else. My mom would be*
822 *like, 'You're psycho. You're crazy.' My brother would be like, 'You're freakin' psychotic.*
823 *You're a nut case,' so I'd just, you know, those were my words for what I had.” (Kranke*
824 *et al., 2010, p. 500)*

825 Young people’s responses to stigma could be classified into three main forms: *stigma*
826 *internalisation*, *stigma resistance*, and *stigma avoidance*. The latter strategy was visible in 18
827 articles, where young people sought to conceal or selectively disclose their diagnosis (Cooper
828 and Shea, 1998; Elkington et al., 2012, 2013; Hallberg et al., 2010; Honkasilta et al., 2016;
829 Humphrey and Lewis, 2008; Ingesson, 2007; Kendall et al., 2003; Kranke et al., 2010, 2011;
830 Leavey, 2005; Lingam et al., 2014; McCann et al., 2012; Mogensen and Mason, 2015; Moses,
831 2010; Singh et al., 2010; Singh, 2011; Wisdom and Green, 2004). Some were emphatic they

832 did not want other people to know of their diagnosis, due to the differential treatment they
833 anticipated (Humphrey and Lewis, 2008).

834 *“I’d prefer they didn’t know because everyone treats me differently and I don’t like being*
835 *treated differently.” (Humphrey and Lewis, 2008, p. 31)*

836 At times, concealing one’s diagnosis simply involved refraining from volunteering the
837 information in social interactions. At other times, more active deception strategies were
838 necessary, for instance lying about reasons for hospitalisations (Elkington et al., 2012), hiding
839 medication (Kranke et al., 2010, 2011), or curtailing the development of relationships ((Kranke
840 et al., 2010; McCann et al., 2012).

841 Eighteen articles contained evidence of direct resistance of stigma (Avisar and Lavie-Ajayi,
842 2014; Daley and Weisner, 2003; Elkington et al., 2012; Floersch et al., 2009; Honkasilta et al.,
843 2016; Huws and Jones, 2015; Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2010, 2011;
844 Krueger and Kendall, 2001; Leavey, 2005; McLaughlin and Rafferty, 2014; Mogensen and
845 Mason, 2015; Moses, 2009; Moses, 2010; Pope, 2015; Wisdom and Green, 2004). Stigma
846 resistance was achieved in various ways. On some occasions, young people directly
847 contradicted stereotypes attached to their diagnosis (Honkasilta et al., 2016; Jones et al., 2015;
848 Leavey, 2005; Mogensen and Mason, 2015).

849 *“we are not stupid... we can think for ourselves” (Mogensen and Mason, 2015, p. 261)*

850 Other participants articulated moral arguments that invalidated discrimination and the
851 individuals who practiced it (Jones et al., 2015; Mogensen and Mason, 2015).

852 *“Who you call retard is my friend and if you call me retard I’m not going to talk to you*
853 *because it’s obvious that you do not respect what’s inside. You respect what’s on the*

854 *outside. You judge people before you even know them and that's wrong* (Jones et al.,
855 2015, p. 1498)

856 Other young people resisted stigma by normalising their diagnosis (Daley and Weisner, 2003;
857 Elkington et al., 2012; Honkasilta et al., 2016; Kendall et al., 2003). They trivialised the
858 symptoms themselves (e.g. presenting ADHD as merely “*small problems with self-control*”
859 (Honkasilta et al., 2016, p. 253)) or their effect on their life (Daley and Weisner, 2003; Lingam
860 et al., 2014; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2009).

861 *“It just means I have to do things a little differently, but I can still do them. I can still*
862 *have a normal life”* (Daley and Weisner, 2003, pp. 37–38)

863 For those who minimised the severity of their difficulties, their diagnosis was simply one “*part*
864 *of who they were*” (Kendall et al., 2003, p. 123) rather than the defining event of their life.
865 Several studies noted a tendency for young people to describe their difficulties in purely
866 behavioural terms, rather than medicalised terminology of symptoms and disorders (Cooper
867 and Shea, 1998; Moses, 2009; Pope, 2015). Young people, usually with emotional disorders,
868 also normalised their difficulties by emphasising the common nature of mental health problems
869 (Elkington et al., 2012; Floersch et al., 2009; Moses, 2010; Wisdom and Green, 2004).

870 *“everybody has something wrong with them”* (Elkington et al., 2012, p. 303)

871 The final and most negative response to stigma was to internalise it. The processes of self-
872 devaluation described above enlighten how a diagnosis’ undesirable connotations could be
873 absorbed into a person’s identity. In eight articles, the stigma associated with a diagnosis
874 fostered shame, embarrassment or humiliation (Elkington et al., 2012; Hallberg et al., 2010;
875 Ingesson, 2007; Jones, 2012; Karterud et al., 2015; Kendall et al., 2003; Kranke et al., 2011,
876 2010).

“I was kind of like ashamed 'cause I don't want to be bipolar. Who does?” (Kranke et al., 2010, p. 499)

It should be noted that the experience of prejudice was not ubiquitous. In five studies, young people stated that they had not experienced discrimination arising from their diagnosis (Elkington et al., 2012, 2013; Huws and Jones, 2008; Mogensen and Mason, 2015; Moses, 2010). They also observed individual differences in attitudes to mental illness, with some people more open-minded and accepting than others (Elkington et al., 2012). One teenager indicated awareness of the proposed negative effects of labelling, but stated they were outweighed by the positive consequences of diagnosis (Mogensen and Mason, 2015).

“a lot of people think ‘Oh, it’s a label’ and all of a sudden it has to be some sort of prejudice – but I think that is sort of like a secure sort of thing for me. And just finding out that problems that I was dealing with were real problems and that they actually had names and labels and that they have diagnosis and treatments for that sort of thing. And that was a really secure thing for me.” (Mogensen and Mason, 2015, p. 259)

In summary, stigma was a very common although not universal experience following a diagnosis. This could have damaging implications when internalised into young people's identity. Young people actively sought to avert this fate by concealing their diagnosis or using a range of strategies to resist the stigma they encountered.

Discussion

This review has revealed the existence of a sizable body of qualitative research illuminating the multifaceted ways psychiatric diagnosis affects young people's self-concept and social identity. Thirty-eight articles, mostly reporting good quality qualitative research, were identified by the systematic literature search. This literature was notably multidisciplinary, and

published in a diverse range of journals. One key contribution of this review is therefore to collate and synthesise this disparate literature. This paper's value lies in providing an accessible first port-of-call for researchers, practitioners and laypeople interested in understanding how diagnosis impacts pragmatically, emotionally and socially on children and adolescents.

The thematic synthesis identified numerous implications that diagnosis holds for young people's self-concept and social identity. A diagnosis can be experienced as a threat to a young person's established self-concept and can lower self-worth by implying inferiority and incapacity. However, a diagnosis can also be marshalled to promote a positive self-concept by facilitating greater self-understanding, legitimising and mitigating culpability for emotional and behavioural difficulties, and sensitising young people to their unique attributes and abilities. A diagnosis can negatively affect a young person's social identity by exposing them to stigma, and some young people feel their diagnosis invalidates them in others' eyes and leads to social alienation and interpersonal strife. Yet a diagnosis can also promote interpersonal tolerance and prompt the development of enriching relationships with similar others. Moreover, young people engage in creative cognitive strategies to bolster their social status, and a diagnostic label can be an important resource in facilitating self-protective social comparison processes.

The diversity in diagnoses' implications for self-concept and social identity is undoubtedly matched by the diversity in young people's relationships with their diagnosis. Different orientations to a diagnosis were apparent both between individuals and within individuals at different time points. The process of assimilating a diagnosis is a gradual one, and young people can fluctuate through numerous stages of acceptance, rejection and ambivalence towards their diagnosis. Given this diversity in diagnostic responses and outcomes, one important emergent question is whether any meaningful patterns underlie the variation. For instance, do responses

to diagnosis systematically differ according to demographic, contextual or clinical variables?

The literature reviewed revealed some suggestive patterns in this regard.

First, it must be emphasised that while speaking of ‘diagnosis’ in general terms is useful in orienting attention towards a defined stage in the clinical process, the variation in the specific diagnoses offered means that as a global concept, ‘diagnosis’ has limited conceptual value. The various diagnoses available within psychiatric diagnostic systems capture radically different symptoms that have equally disparate practical implications and socio-cultural connotations. The literature reviewed suggests some trends in specific diagnoses’ differential effects on self-concept and social identity. For instance, the tendency to reconstruct symptoms as positive or life-enhancing, and thereby promote a positive self-concept, was more prominent in samples with ASD (Daley and Weisner, 2003; Humphrey and Lewis, 2008; Huws and Jones, 2015; Jones et al., 2015; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015) than affective disorders. However, the greater prevalence of affective disorders and their continuity with universal facets of human emotion made them easier to normalise and de-stigmatise (Elkington et al., 2012; Floersch et al., 2009; Moses, 2010; Wisdom and Green, 2004). Elkington et al. (2012) suggest youth with psychotic disorders experience more blatant forms of prejudice than nonpsychotic diagnoses. Such findings are consistent with research demonstrating a hierarchy of diagnoses in adult populations, with psychotic disorders more stigmatised than mood disorders (Angermeyer and Dietrich, 2006). Yet the patterns suggested by the current literature review remain inconclusive, since very few studies directly compared individuals with different diagnostic classifications. Further confusions arise from the inconsistency in studies’ approaches to determining diagnostic status, with some using self-reports, others clinician-reports, and others providing no relevant information. Moreover, the studies reviewed focused on a limited set of diagnostic populations, most prominently ADHD and ASD. Young people with psychotic, affective, anxiety and eating disorders are under-represented in this literature.

Neither is there representation of young people who may qualify for a diagnosis, but who have avoided or withdrawn from the mental health system. This is understandable given most recruitment methods' reliance on purposive sampling through clinics or services. Nonetheless, tapping into populations who have rejected any diagnostic classification is necessary to develop a comprehensive understanding of diagnosis' effects. One limitation of the review is the difficulty disentangling the degree the processes identified followed from the diagnostic label itself, versus the symptoms that presumably preceded it. To fully isolate the effects of a diagnostic label, research would need to compare groups of children who hold a diagnosis but no debilitating symptoms, and who hold symptoms but no diagnosis. This scientifically ideal scenario may be challenging to achieve, given the former group are likely rare (and difficult to define, given the subjective nature of symptom severity), and the latter very challenging to sample. Nevertheless, some effort to track the longitudinal outcomes of young people who display equivalent symptoms but never receive a diagnosis would be very helpful in understanding the unique effects of diagnostic labels.

Another variable that might differentiate outcomes is the age the diagnosis is received. Young people who received a delayed diagnosis generally believed an earlier diagnosis would have improved their life (Cheung et al., 2015; Huws and Jones, 2008; Mogensen and Mason, 2015). Again, the literature reviewed does not facilitate any definitive conclusions regarding the optimal age to receive a psychiatric diagnosis. Most research has been conducted with older adolescents: only five studies included children younger than 10 years (Brady, 2014; Kendall et al., 2003; Singh et al., 2010; Singh, 2011; Skovlund, 2014). Understanding how young children respond to diagnostic classifications should be a priority for future research.

Further demographic imbalances in the literature relate to gender. Males were more represented in these studies than females: a rough estimate, based only on studies that specified the sample's gender breakdown, is that 340 females and 456 males participated in the research

reviewed. This may reflect studies' focus on ASD and ADHD, which have higher prevalence among males. No studies sought to directly investigate potential gender differences in responses to diagnosis. Issues specific to LGBTQI populations were similarly neglected. Furthermore, few studies specifically explored cultural or ethnic factors (Chavez et al., 2012; Cheung et al., 2015; Elkington et al., 2013, 2012). This is a highly significant gap, given extensive evidence of cultural and ethnic differences in experience of and attitudes towards mental illness (U.S. Department of Health and Human Services, 2001). The studies reviewed were predominantly conducted in North American and European countries. This may partly be an artefact of the review's inclusion criteria, which restricted the review to English-language publications. However, it should be noted that numerous included studies were conducted with non-English speaking populations, with data translated for publication (Avisar and Lavie-Ajayi, 2014; Chavez et al., 2012; Cheung et al., 2015; Hallberg et al., 2010; Honkasilta et al., 2016; Ingesson, 2007; Karterud et al., 2015; Skovlund, 2014; Tidefors and Strand, 2012).

The difficulty reliably segmenting findings across demographic or clinical variables partly follows from the review's exclusive focus on qualitative research. This has formed the dominant methodological approach for research on this topic thus far, for the reasons outlined in the Introduction. The value of qualitative research lies in affording a rich, nuanced insight into the range of perspectives and experiences that exist in a given social context. Qualitative research is not generally concerned with performing direct comparisons between predefined groups of participants: this is a task more suited to quantitative designs. Future quantitative research should seek to clarify the clinical and demographic variables that correlate with the varied responses to diagnosis revealed by the qualitative literature. Quantitative research may be particularly helpful in identifying 'clusters' of variables relating to the child (e.g. gender, age, IQ), their social context (e.g. familial and cultural variables) and the diagnosis in question, which reliably predict adaptive and detrimental outcomes. This would help clinicians, families

999 and young people themselves anticipate the likely outcomes in a particular case, and adapt their
1000 diagnostic decisions accordingly.

1001 This said, one lesson of the qualitative literature reviewed is the sheer complexity of
1002 individuals' psychological and social responses to diagnosis. It may not be possible to predict
1003 cases where receiving a diagnosis leads to unambiguously positive or negative outcomes, since
1004 divergent responses exist within as well as between individuals. A diagnosis may prompt
1005 negative self-evaluations that would not otherwise have arisen, yet may simultaneously afford
1006 a valuable sense of self-understanding and means of repairing damage to the self-concept.
1007 Similarly, a diagnosis may expose a young person to stigma they would not otherwise
1008 experience, yet may also be a gateway to new social identities and rewarding relationships.
1009 These multifaceted implications for self-concept and social identity function alongside
1010 diagnosis' equally complex implications on other emotional, practical, social and clinical levels
1011 (Callard et al., 2013; Jutel, 2009; Perkins et al., 2018). Deciding whether to give, seek or accept
1012 a diagnosis requires complex calculations that weigh up the costs and benefits it is likely to
1013 afford for a certain individual in a certain context. It is particularly important to raise awareness
1014 of this complexity among clinicians: while clinical rationale may remain paramount in
1015 diagnostic decisions, clinical outcomes will undoubtedly be compromised if a diagnosis
1016 impairs a young person's self-worth or social relationships. Clinical benefits must therefore be
1017 balanced against psychological and social risks. If these risks are high, clinicians and service-
1018 users may opt to decline or defer a diagnosis, or to implement strategies for communicating
1019 and conceptualising diagnoses that offset risks and encourage the positive social and self-
1020 processes revealed by this review.

1021 Greater attention to theoretical development is critical for developing such targeted strategies
1022 to mitigate the negative repercussions diagnoses can have. Many of the studies included in this
1023 review were atheoretical, and studies that did specify a theoretical framework drew on very

disparate conceptual perspectives. This may reflect the relative youth of the field: only one study was identified pre-2000 (Cooper and Shea, 1998) and 63% ($n=24$) were published since 2010. To capitalise on empirical insights and streamline the complexity of factors involved, theoretical development should be prioritised. This may involve both generating new theories and borrowing from established theoretical frameworks. For instance, understanding how cultural representations of mental illness interact with individual self-concept would benefit from incorporating insights from social psychological theories of social categorisation, social identity, social representations, stigma, prejudice and intergroup relations. Research and clinical practice would be particularly served by theoretical frameworks that incorporate the multiplicity of responses to diagnoses, and attempt to disentangle and predict the simultaneously positive and negative implications diagnosis may have.

The surge in publications post-2010 may reflect the relatively recent attention to child-centred research and policy (LeFrancois, 2007; Sinclair, 2004; Singh, 2007). The literature reviewed clearly demonstrates the value of research on the first-person lived experience of young people with psychiatric diagnoses. The research uncovered novel experiences that have been largely neglected in debates about youth psychiatric diagnosis; for instance, young people's strong dislike of preferential treatment, and the creativity with which young people marshal and interpret diagnostic classifications to serve their self-concept and social identity needs. Acknowledging the active, pragmatic ways children negotiate diagnoses and therapies is critical to ensure debates about youth psychiatric diagnosis avoid perpetuating paternalistic views of children (Singh, 2011). It is also important to recognise common themes in debates about diagnosis that did not emerge in this empirical literature: for instance, few young people mentioned the media as a source of stigma or the proposed 'self-fulfilling prophecy' effects of diagnosis. This is not evidence that such concerns are invalid or insignificant, but it is notable they do not feature strongly in young people's first-person experience.

The review has several methodological limitations which should be acknowledged when considering its results. First, due to resource restrictions, the search did not include grey literature or material published in books. Since much qualitative research is published outside peer-reviewed journals (Grant, 2004), this may have excluded some relevant studies. The review was also restricted to studies published in English, and the lack of standardised terms for indexing qualitative research in electronic databases meant the search relied on a purposively-selected set of keywords. Second, a systematic review protocol was not registered in advance of completing the review. Third, an analytical priority on capturing common themes across the literature, as well as the diversity of studies' methodological approaches, meant that it was not possible to conduct detailed subgroup analyses. The precise ways results diverge across age, gender, culture and diagnostic category therefore remain unclear.

These limitations notwithstanding, this review is the first to systematically collate, evaluate and synthesise studies of this important topic. The review contributes to the heated debate currently underway regarding whether dominant systems of psychiatric diagnosis are fit-for-purpose, particularly in youth contexts (Callard et al., 2013; Hyman, 2010; Insel et al., 2010; Rutter, 2011; Timimi, 2014). While most prior debate has focused on reliability and validity issues, the current review draws attention to the social and psychological outcomes that ensue from the meanings people derive of their diagnosis. Diagnoses are not purely clinical judgements that occur in a vacuum: they have pragmatic repercussions, which are central to real-world diagnostic decisions. In deciding whether to pursue or accept a diagnosis, clinicians, parents and young people themselves must trade off its potential risks and benefits, which are specific to the child's individual characteristics, familial circumstances, cultural environment, and institutional structures where access to educational and/or health resources may be contingent on diagnostic status. The current review aims to inform these decisions by collating the positive and negative implications a diagnosis can have for a young person's self-concept

and social identity. Further research is needed to clarify which self and identity outcomes can be expected in a given set of circumstances, and to establish how self and identity effects interact with diagnoses' other clinical, practical, social and emotional ramifications.

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Tables

1416 *Table 1: Inclusion & exclusion criteria*

Inclusion Criteria
a. Primary, original research
b. Published in peer-reviewed journal
c. Study sample primarily children or adolescents (i.e. majority of participants must be <18 years; if sample includes any additional older participants, they must be <25 years)
d. Sample purposively selected for having a recognised, DSM-listed psychiatric diagnosis
e. Results illuminate how diagnosis affects self and/or identity
f. Presents original qualitative data and analysis (including qualitative elements of mixed-methods studies)
Exclusion criteria
a. Study not published in English
b. Review, commentary, theoretical or case-study ($N < 3$) papers
c. Studies exploring adults' perspective on children's diagnosis
d. Studies exploring how children react to other people's diagnosis (e.g. peers, parents)
e. Studies exploring non-psychiatric medical diagnoses
f. Studies exploring aspects of mental health beyond diagnosis (e.g. treatment)
g. Studies whose results do not address self and/or identity

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ID	Article	Region	Diagnosis	Sample size	Sample gender	Sample age
1	Avisar and Lavie-Ajayi (2014)	Israel	ADHD	N=14	6F, 8M	Range = 12.5-16.5
2	Boughtwood and Halse (2010)	Australia	Anorexia nervosa	N=25	All F	Mean = 14.8
3	Brady (2014)	UK	ADHD	N=7	1F, 6M	Range = 6-15
4	Chavez, Mir and Canino (2012)	Puerto Rico	Range of diagnoses*	N=60*	21F, 39M	Range = 12-18
5	Cheung, Wong, Ip, Chan, Lin, Wong, and Chan (2015)	Hong Kong	ADHD	N=40	13F, 27M	Range = 16-23; mean = 18
6	Cooper and Shea (1998)	UK	ADHD	N=16	6F, 10M	Range = 11-16
7	Daley and Weisner (2003)	USA	Developmental delay	N=23	10F, 13M	Range = 17-19; mean = 18.2
8	Elkington, Hackler, McKinnon, Borges, Wright, and Wainberg (2012)	USA	Range of diagnoses*	N=24	10F, 14M	Range = 13-24; mean = 18.1
9	Elkington, Hackler, Walsh, Latack, McKinnon, Borges, Wright, and Wainberg (2013)	USA	Range of diagnoses*	N=20	9F, 11M	Range = 16-24
10	Floersch, Townsend, Longhofer, Munson, Winbush, Kranke, Faber, Thomas, Jenkins, and Findling (2009)	USA	Range of diagnoses*	N=20	11F, 9M	Range = 12-17; mean = 14.75
11	Hallberg, Klingber, Setsaa, and Moller (2010)	Sweden	ADHD	N=10	5F, 5M	Range = 13-18
12	Honkasilta, Vehmas, and Vehkakoski (2016)	Finland	ADHD	N=13	2F, 11M	Range = 11-16; mean = 13.7
13	Humphrey and Lewis (2008)	UK	Asperger's syndrome	N=20	Unspecified	Range = 11-17
14	Huws and Jones (2008)	UK	Autism	N=9	3F, 6M	Range = 16-21
15	Huws and Jones (2015)	UK	Autism	N=9	3F, 6M	Range = 16-21
16	Ingesson (2007)	Sweden	Dyslexia	N=75	27F, 48M	Mean = 19
17	Jones (2012)	USA	Intellectual and developmental disabilities	N=51	13F, 38M	Range = 11-20; mean = 15.97
18	Jones, Gallus, Viering, and Oseland (2015)	USA	ASD	N=10	2F, 8M	Range = 13-20; mean = 16.24
19	Karterud, Risør, and Haavet (2015)	Norway	Non-epileptic (psychogenic) seizures	N=11	All F	Range = 14-24
20	Kendall, Hatton, Beckett, and Leo (2003)	USA	ADHD	N=39	13F, 26M	Range = 6-17; mean = 11.2
21	Kranke, Floersch, Kranke, and Munson (2011)	USA	Range of diagnoses*	N=27	18F, 9M	Range = 12-17; mean = 14.4

22	Kranke, Floersch, Townsend, and Munson (2010)	USA	Range of diagnoses*	N=40	24F, 16M	Range = 12-17; mean = 14.2
23	Krueger and Kendall (2001)	USA	ADHD	N=11	3F, 8M	Range = 13-19
24	Leavey (2005)	Canada	Range of diagnoses*	N=13	6F, 7M	Range = 17-23
25	Lingam, Novak, Emond, and Coad (2013)	UK	Developmental Coordination Disorder	N=11	4F, 7M	Range = 11-16
26	McCann, Lubman, and Clark (2012)	Australia	Depression	N=26	16F, 10M	Range = 16-25; mean = 18
27	McLaughlin and Rafferty (2014)	UK	Asperger's syndrome	N=6	1F, 5M	Range = approx. 14-18
28	Mogensen and Mason (2015)	Australia	Autism	N=5	2F, 3M	Range = 13-19
29	Moses (2009)	USA	Range of diagnoses*	N=54	20F, 34M	Range = 12-18; mean = 14.9
30	Moses (2010)	USA	Range of diagnoses*	N=56	21F, 35M	Range = 12-18; mean = 14.9
31	Pope (2015)	USA	Range of diagnoses*	N=100*	All F	Range = 11-20; mean = 15.8
32	Singh (2011)	UK	ADHD	N=150*	Unspecified	Range = 9-14
33	Singh, Kendall, Taylor, Mears, Hollis, Batty, and Keenan (2010)	UK	ADHD	N=16	2F, 14M	Range = 9-14
34	Skovlund (2014)	Denmark	Range of diagnoses*	N=8	Unspecified	Range = 7-11
35	Tidefors and Strand (2012)	Sweden	ADHD	N=11	All M	Range = 14-19; mean = 16.2
36	Travell and Visser (2006)	UK	ADHD	N=17	Unspecified	Range = 11-16
37	Wisdom and Green (2004)	USA	Depression	N=22*	13F, 9M	Range = 14-19; mean = 16.3
38	Woodgate (2006)	Canada	Depression	N=14;	11F, 3M	Range = 13.5-18; mean = 14

1420 *See further details in Appendix A