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1 **How does psychiatric diagnosis affect young people's self-concept and**

2 **social identity? A systematic review and synthesis of the qualitative**

3 **literature**

4 **Abstract**

5 Receiving a psychiatric diagnosis in childhood or adolescence can have numerous social,

6 emotional and practical repercussions. Among the most important of these are the implications

7 for a young person's self-concept and social identity. To ensure diagnoses are communicated

8 and managed in a way that optimally benefits mental health trajectories, understanding young

9 people's first-hand experience of living with a diagnosis is paramount. This systematic review

10 collates, evaluates and synthesises the qualitative research that has explored how psychiatric

11 diagnosis interacts with young people's self-concept and social identity. A search of 10

12 electronic databases identified 3,892 citations, 38 of which met inclusion criteria. The 38

13 studies were generally evaluated as moderate-to-high quality research. Thematic synthesis of

14 their findings highlighted the multifaceted ways diagnosis affects young people's self-concept

15 and social identity. Diagnosis can sometimes threaten and devalue young people's self-concept,

16 but can also facilitate self-understanding, self-legitimation and self-enhancement. A diagnosis

17 can lead to social alienation, invalidation and stigmatisation, yet can also promote social

18 identification and acceptance. Further research is needed to clarify which self and identity

19 outcomes can be expected in a given set of circumstances, and to establish how self and identity

20 effects interact with diagnoses' other clinical, practical, social and emotional consequences.

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

2

24 Holland, 2008). Diagnoses with poor prognoses (such as personality disorders) can also lead

25 to fatalism among service-providers and consequent restriction of treatment options (Nehls,

26 1999; Newton-Howes et al., 2008; Ramon et al., 2001; Stalker et al., 2005).

27 These practical implications of psychiatric diagnosis must be considered alongside diagnoses'

28 social and psychological effects, which are complex and diverse (Callard et al., 2013; Jutel,

29 2015; Perkins et al., 2018). Particularly important are implications for the *self-concept*, defined

30 as an individual's set of beliefs about herself/himself (Baumeister, 1999), and *social identity*,

31 defined as the portion of the self-concept that derives from membership of social groups

32 (Tajfel, 1981). Previous research suggests diagnostic classification can affect a person's self-

33 concept and social identity in both positive and negative ways.

34 On the positive side, diagnosis can provide a sense of relief and self-understanding by implying

35 symptoms result from a 'real', independent disease entity (Hayne, 2003; Horn et al., 2007). For

36 people whose difficulties were previously dismissed as imaginary or self-inflicted, a diagnosis

37 can be welcomed as validating their authenticity and severity (Dinos et al., 2004; Hayne, 2003;

38 Punshon et al., 2009). Diagnosis can also protect self-image by apparently lessening personal

39 culpability for undesirable behaviour and externalising the disorder from a person's 'true' self

40 (Bilderbeck et al., 2014; Pitt et al., 2009). Within everyday social settings, disclosing a

41 diagnosis can prompt more lenient treatment by facilitating access to the 'sick role' (Parsons,

42 1975) that relieves a person of usual responsibilities. Furthermore, diagnosis can introduce

43 service-users to a community of similar others and serve as a rallying-point around which

44 people assemble to gain social support and advocate for services (Brownlow and O'Dell, 2006;

45 McNamara and Parsons, 2016; Tan, 2018). Emerging research provides strong support for the

46 importance of such social identity processes in promoting and maintaining mental health

47 (Jetten et al., 2014). Diagnosis can thus have numerous positive implications for a person's

48 social identity and personal self-concept.

49 However, a diagnosis also carries risks for self-concept and social relations. Psychiatric

50 diagnosis can provoke grief and despair (Horn et al., 2007; Knight et al., 2003; Pitt et al., 2009;

51 Ramon et al., 2001), particularly if it is associated with poor prognosis and treatment options.

52 Some may struggle to reconcile a diagnosis with their previous self-image, and dislike feeling

53 marked as 'abnormal' or 'different' (Hayne, 2003; Knight et al., 2003; Schulze and

54 Angermeyer, 2003; Stalker et al., 2005). Another risk, often articulated under the rubric of

55 labelling theory (Scheff, 1974), relates to the proposition that diagnoses function as self-

56 fulfilling prophecies, i.e. that the disclosure of a diagnosis establishes expectations of certain

57 behaviours, which influence how the person is treated and therefore makes those behaviours

58 more likely. While some research has produced evidence supporting this proposal, particularly

59 regarding diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in childhood (Harris

60 et al., 1992; Sayal et al., 2010), recent longitudinal research finds no evidence prosocial

61 behaviour worsened following a diagnosis of ASD (Russell et al., 2012).

62 A further concern is that disclosure of a diagnosis might exacerbate the stigma that symptoms

63 of mental illness already attract (Ben-Zeev et al., 2010; Corrigan, 2007). People with direct

64 experience of mental illness report that diagnostic disclosure leads to disadvantage in a range

65 of interpersonal, employment, educational, health and social welfare settings (Dinos et al.,

66 2004; Schulze and Angermeyer, 2003). Numerous studies have experimentally investigated the

67 social effects of diagnosis by comparing people's attitudes to hypothetical characters with and

68 without a diagnostic label. This literature contains mixed effects, with some reporting a

69 diagnostic label increases prejudice (Batzle et al., 2010; Harris et al., 1992; Ohan et al., 2013)

70 and others that it does not (Jorm and Griffiths, 2008; Law et al., 2007; Thompson and Lefler,

71 2016). Certain diagnostic labels are more stigmatising than others, e.g. young people with

72 ADHD are perceived more negatively than those with depression (O'Driscoll et al., 2012).

73 Schizophrenia, eating disorders and substance abuse are among the most stigmatised of

74 common mental illnesses (Angermeyer and Dietrich, 2006). Moreover, mental illness stigma

75 is intersectional with socio-demographic categories: an eating disorder diagnosis, for example,

76 is more stigmatising for males than females (Jones and Morgan, 2010).

77 Thus, receiving a psychiatric diagnosis can involve both positive and negative social,

78 psychological and practical effects. This ambiguity can be reflected in service-users' attitudes

79 towards receiving a diagnosis (Hayne, 2003; Pitt et al., 2009; Voorhees et al., 2005). For

80 instance, a study of adaptation to a diagnosis of bipolar disorder found that people maintained

81 ambivalent attitudes towards the diagnosis, with attitudes constantly in-flux across time,

82 contextual circumstances, and symptomatic cycles (Inder et al., 2010). In real clinical contexts,

83 individuals' responses to a given diagnosis are not determined purely by its scientific validity

84 or clinical benefit; also important are the ways the diagnosis affects the person's self-

85 understanding and social relationships.

86 The self and identity effects of diagnosis are likely particularly profound when the diagnosis is

87 ascribed in early-life. Childhood is a time when identity is elastic and acutely sensitive to social

88 experience (Bennett, 2011; Harter, 2012). Until recently, most empirical evidence regarding

89 the psychological effects of childhood diagnoses reflected the perspective of parents (Ahern,

90 2000; Osborne and Reed, 2008; Russell and Norwich, 2012; Singh, 2004) or people who

91 receive a retrospective diagnosis of developmental disorder (e.g. ADHD) in adulthood

92 (Punshon et al., 2009; Tan, 2018; Young et al., 2008). Recent years have seen increasing

93 recognition of the need for mental health policy and practice to be informed by the perspective

94 of young people themselves (LeFrancois, 2007; Sinclair, 2004). Researchers have

95 demonstrated that, with appropriate attention to research design and ethical procedures,

96 children with cognitive and behavioural difficulties are capable of productively engaging with

97 the research process (Singh, 2007). This emerging literature has produced rich insights into the

98 active ways young people negotiate psychiatric diagnoses and other aspects of the mental

99   health system (McNamara et al., 2017; Singh, 2011). Most of this evidence is qualitative in

100   nature. The predominance of qualitative research is due to numerous factors. First, the relative

101   youth of this field means much research is still exploratory, with insufficient evidence to inform

102   hypothesis-driven quantitative studies. Second, recent policy emphasis on patient-centred care

103   has prompted an upsurge of interest in lived experiences of service-users, which qualitative

104   research is specifically suited to explore (Beresford, 2007; Davidson et al., 2008; Meyer, 2000).

105   Finally, the pragmatic and ethical challenges of conducting research with children with

106   cognitive, emotional and/or behavioural difficulties mean that standard methods such as

107   questionnaires and experiments are often not appropriate or feasible: more dynamic, interactive

108   data-elicitation methods are required (Singh, 2007; Whyte, 2005).

109   Previous literature reviews have confirmed the relevance of identity issues to the experience of

110   mental illness (e.g. Boydell et al., 2010; Livingston and Boyd, 2010; Perkins et al., 2018).

111   However, none have specifically focused on the first-hand experience of young people

112   themselves. Additionally, most previous literature has focused on issues specific to a particular

113   category of psychiatric diagnosis. Different diagnoses have widely divergent implications in

114   terms of symptoms, treatment, and social attitudes, which undoubtedly mediate their effects on

115   self-concept and social identity. However, the sociology of diagnosis has shown that useful

116   insights can be gleaned by conceptualising diagnosis as a generic *process*, as well as specific

117   category (Blaxter, 1978; Jutel, 2015). Comparisons of diagnosis' role in diverse medical fields

118   reveal consistent patterns, for instance that diagnosis may induce 'biographical disruption'

119   (Bury, 1982) or clinician-patient tensions (Jutel and Nettleton, 2011). Most youth psychiatric

120   diagnoses share common problems establishing reliability and validity (Rutter, 2011; Timimi,

121   2014), which have prompted a surge of interest in transdiagnostic approaches to research and

122   treatment (McGorry and Nelson, 2016). Given that diagnosis marks a key point in most mental

123   healthcare trajectories, a transdiagnostic approach is also appropriate for considering whether

124 this clinical practice has predictable implications for young people's developing identity and

125 self-concept. Both consistencies across and divergences between specific diagnoses' effects

126 are relevant to the ongoing debate about the role diagnosis should play in youth mental health

127 contexts.

128 Research that enlightens young people's first-hand experiences is an important source of

129 insight into how young people's self-concept and social identity are affected by receiving a

130 psychiatric diagnosis. Understanding the range of possible effects, and the contexts in which

131 they are most likely to occur, is relevant for many interest groups: clinicians deciding whether

132 to offer a formal diagnosis, service-users considering whether to seek and accept a diagnosis,

133 and families and teachers attempting to help young people adapt to a diagnostic classification.

134 This review aims to collate, evaluate and synthesise the qualitative research that has explored

135 how psychiatric diagnosis affects young people's self-concept and social identity.

136 ## Method

137 ### Design
138 A systematic literature review was conducted, which followed the procedures stipulated by the

139 PRISMA guidelines (Moher et al., 2009). Articles that met inclusion criteria were subjected to

140 a quality assessment and thematic synthesis.

141 ### Search strategy
142 Keyword-searches were conducted in the following electronic databases: PsycINFO,

143 PsycARTICLES, Academic Search Complete, Social Sciences Full Text, Embase, MEDLINE,

144 PubMed Central, Science Citation Index Expanded, Social Sciences Citation Index, Arts &

145 Humanities Citation Index.

146 As not all databases indexed entries using standardised searchable subject headings, the search

147 strategy was keyword-based. Various combinations of keywords were trialled to identify a

148   sequence with an appropriate balance of sensitivity and specificity. The following keyword-

149   string was judged to provide the optimal level of coverage, i.e. yielding a set of results that was

150   comprehensive yet feasible for the research team to manually screen (<10,000). This keyword-

151   string was adapted to suit the search functionalities of the different databases (e.g. different

152   commands to indicate truncation).

153   a)   [girl* OR boy* OR child* OR youth* OR "young person*" OR "young people"

154   OR teenag* OR adolescent*] in Title

155   AND

156   b)   [qualitative OR interview* OR "focus group*" OR ethnograph* OR

157   "participant observation"] in All Fields

158   AND

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

160   AND

161   d)   [diagnos*] in All Fields

162   AND

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

164   Line (a) targeted the relevant research population. This line of keywords was restricted to the

165   article title because searching for these terms in all fields produced an unmanageably large

166   (>470,000) set of results. Line (b) targeted qualitative methodology. There are acknowledged

167   challenges identifying qualitative articles through automated search filters, due to large

168   differences in terminology usage among qualitative researchers (Grant, 2004; DeJean et al.,

169   2016). As the review was interested in the first-hand perspective of young people, the search

170   terms specified the most common data collection methods in qualitative research with human

171   participants. The remaining lines restricted the search to articles discussing mental health,

172   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

9

198 accordance with increasingly common practice and the recommendations of the Cochrane

199 Qualitative Research Methods Group (Cochrane Qualitative and Implementation Methods

200 Group, 2013; Hannes, 2011), the current study included a structured critical appraisal stage.

201 Given the heterogeneity of theoretical and methodological approaches involved, the aim was

202 not to rank individual studies, but ensure that all met a minimum standard of research quality

203 (Hannes, 2011). The instrument chosen was the commonly-used Critical Appraisal Skills

204 Programme (CASP) Qualitative Checklist (Critical Appraisal Skills Programme, 2017). This

205 evaluates articles along 10 dimensions of research quality. For this review, one dimension –

206 adequate consideration of the researcher-participant relationship – was removed because

207 different disciplinary norms make this dimension difficult to apply to a very multidisciplinary

208 body of literature. On the remaining nine dimensions (clear statement of aims; qualitative

209 method appropriate; design appropriate; recruitment strategy appropriate; data collection

210 appropriate; ethical issues considered; data analysis rigorous; clear statement of findings; value

211 of research), each article was scored to indicate whether the quality criterion was met (score =

212 2), unclear (score = 1) or unmet (score = 0). All four authors contributed to the quality

213 assessment, with each article independently assessed by two independent reviewers. Average

214 inter-rater reliability using the CASP tool was 92.99%.

215 **Data extraction**

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

217 • Region of data collection

218 • Stated aims

219 • Diagnoses and how they were determined

220 • Theoretical framework

221 • Design

222 • Sampling strategy

223 • Sample characteristics

224 • Analytic approach.

225 Appendix A displays the information extracted.

Data analysis

227 The key step in a qualitative systematic review is the synthesis of evidence from the included

228 studies (Butler et al., 2016; Thomas and Harden, 2008). This review achieved this using

229 thematic synthesis, an approach that applies principles of thematic analysis to reports of

230 qualitative findings. Full texts of all articles were imported into ATLAS.ti. In accordance with

231 Thomas and Harden (2008), the synthesis concentrated on material presented in the 'Results'

232 or 'Findings' sections of the articles. The results of each study were inspected and any text

233 relating to the research question (the influence of diagnosis on self-concept and/or social

234 identity) was highlighted. Through an iterative process, and in discussion with the research

235 team, a coding frame was developed that captured the range of findings reported. Once the

236 coding frame was finalised, all highlighted text was revisited and appropriate codes applied.

237 Following Thomas and Harden's (2008) procedure, basic-level codes were first organised into

238 descriptive categories based on similarities in their content. ATLAS.ti's analysis tools (e.g. co-

239 occurrence analysis, sequencing) were utilised to explore relationships between codes, which

240 were visually mapped using the Network function (see Appendix B) to construct higher-level

241 analytic themes.

Results

Results of literature search

244 In total, the keyword-searches of the various databases returned 6,887 potential articles. Once

245 duplicates were removed, 3,856 remained. After exclusion of articles that clearly did not meet

246 inclusion criteria, 162 records remained. Full-text eligibility assessment found 27 met inclusion

11

247   criteria. Inspecting their reference lists revealed 36 further candidate articles, which underwent

248   full-text eligibility assessment. Eleven were retained for the final sample.

249   These procedures produced a final sample of 38 articles. Figure 1's PRISMA Flow Diagram

250   (Moher et al., 2009) presents the number of articles excluded at each stage. Table 2 and

251   Appendix A list the studies included.

252   ***Figure 1: PRISMA Flow Diagram***

253   ## Quality assessment scores
254   Reviewers' total CASP scores for each article were averaged. Scores are displayed in Appendix

255   A. Using thresholds adapted from Butler et al. (2016), most articles (78.9%; n=30) were

256   evaluated as high-quality (total score=16-18), seven articles moderate-quality (total score=13-

257   15.5) and one low-quality (total score=10-13.5). None met the predetermined threshold for

258   unacceptably low quality meriting exclusion from the review (total score<10).

259   ## Thematic synthesis
260   The thematic synthesis identified 11 analytic themes. These were organised into four

261   overarching 'super-themes': *benefits for self-concept, risks for self-concept, benefits for social*

262   *identity,* and *risks for social identity*. It should be noted that these thematic categories are

263   deployed for parsimonious presentation of the results and do not imply that the data presented

264   therein represent mutually exclusive phenomena: self-concept and social identity processes are

265   intrinsically interconnected (Ellemers et al., 2002), and many diagnostic experiences had both

266   positive and negative aspects. Themes are visually presented in Figure 2 and Appendix B and

267   described below along with illustrative quotes from participants.

268   ***Figure 2: Thematic structure***

12

Benefits for self-concept

Self-understanding

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

> *"I've never really fit in, I always felt different, and now I know why" (Kranke et al., 2011, p. 897)*

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

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

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

314   Thus, diagnosis facilitated a sense of self-understanding which was valued both intrinsically

315   and as a door to self-management and clinical intervention.

316   **Self-legitimation**

317   Numerous articles alluded to the validating function of diagnosis (Karterud et al., 2015;

318   Kendall et al., 2003; Mogensen and Mason, 2015; Wisdom and Green, 2004; Woodgate,

319   2006). The diagnostic label, and the scientific authority it contained, legitimised the

320   authenticity and severity of young people's experiences. The diagnosis reconstructed their

321   struggles as a 'real disease', rather than variations on the normal spectrum of human emotion.

322   *"I think what would help is for people to realize that it is not just feeling down, it is*

323   *actually an illness" (Woodgate, 2006, p. 266)*

324   For those who construed the diagnosis as legitimising their difficulties, the diagnosis offered a

325   sense of relief or hope (Chavez et al., 2012; Cooper and Shea, 1998; Ingesson, 2007; Karterud

326   et al., 2015; Leavey, 2005; Mogensen and Mason, 2015; Travell and Visser, 2006; Wisdom

327   and Green, 2004). This partly related to perceived absolution from blame for undesirable

328   behaviour. Several articles revealed young people using diagnoses of ADHD and ASD to

329   mitigate responsibility for disobedience or peer conflict (Honkasilta et al., 2016; Singh, 2011;

330   Singh et al., 2010; Skovlund, 2014).

331   *"Well, I realised that [...] whenever I got into trouble at school for talking and stuff, it*

332   *wasn't my fault; it was because I had ADD [...] I couldn't help being distracted and that*

333   *I wasn't concentrating properly." (Cooper and Shea, 1998, p. 43)*

334   This strategy for deflecting blame required ceding agency to the diagnosis. The disorder was

335   positioned as an independent entity that compelled certain behaviours (Honkasilta et al., 2016;

336   Kendall et al., 2003).

15

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'.

16

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

385   character (Elkington et al., 2012; Wisdom and Green, 2004; Woodgate, 2006). Thus, diagnoses

386   could be recruited as resources in maintaining a positive self-concept.

387   *Risks for self-concept*

388   **Self-threat**

389   Twelve articles presented evidence that a diagnosis can be experienced as a threat to one's self-

390   concept (Elkington et al., 2012; Floersch et al., 2009; Hallberg et al., 2010; Huws and Jones,

391   2008; Jones et al., 2015; Karterud et al., 2015; Kranke et al., 2010; Leavey, 2005; Mogensen

392   and Mason, 2015; Travell and Visser, 2006; Wisdom and Green, 2004; Woodgate, 2006).

393   Receiving a diagnosis could challenge a young person's previous self-image and force them to

394   reconsider their identity. Some participants experienced this as a radical rupture of the self.

395   *"The safety of waking up and 'knowing who you are' which most people take for granted*

396   *had suddenly vanished." (Leavey, 2005, p. 115).*

397   On hearing their diagnosis, some participants failed to identify with it or recognise themselves

398   in its formulation (Floersch et al., 2009; Huws and Jones, 2008; Karterud et al., 2015). Adapting

399   to the diagnosis therefore involved assimilating new and potentially uncomfortable attributes

400   into the self-concept (Hallberg et al., 2010; Jones et al., 2015). These attributes could be both

401   previously unrecognised symptoms and disparaging judgements such as "*crazy*" (Kranke et al.,

402   2010, p. 499). The very term "*mental illness*" was problematic for some (Karterud et al., 2015;

403   Leavey, 2005). As numerous young people acknowledged, they themselves could hold

404   negative stereotypes of people with psychological disorders (Elkington et al., 2012; Floersch

405   et al., 2009; Humphrey and Lewis, 2008; Jones et al., 2015; Karterud et al., 2015; Kranke et

406   al., 2011; Kranke et al., 2010; Leavey, 2005). This heightened the threat the diagnosis

407   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... euw! 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

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

433   validity.

434   *"At first I was like, 'no. I can't be bipolar.' That's just not me. I don't want to be it and*

435   *then when I started actually seeing what was really going on, I'm just like, oh my god, I*

436   *can't believe I just said that I wasn't this, and now I am." (Floersch et al., 2009, p. 166)*

437   While a minority ultimately came to view their diagnosis in emotionally neutral (Humphrey

438   and Lewis, 2008; Kendall et al., 2003) or even positive (Daley and Weisner, 2003; Humphrey

439   and Lewis, 2008; Lingam et al., 2013; Mogensen and Mason, 2015) terms, for most the

440   diagnosis remained a distinctly negative attribute. They had felt they had no choice but to resign

441   themselves to its presence in their lives (Daley and Weisner, 2003; Huws and Jones, 2008;

442   Kendall et al., 2003; Krueger and Kendall, 2001).

443   *"I really find it annoying to have but it's something that you've got to accept" (Huws*

444   *and Jones, 2008, p. 104)*

445   In summary, the threat a diagnosis posed to self-image meant that initial resistance of it was

446   common. Young people typically adapted to their diagnosis over time, but the self-

447   reconstruction necessary meant this was often a difficult and protracted process.

448   **Self-devaluation**

449   Assimilating a diagnosis could pose risks for young people's self-esteem. Sixteen articles

450   revealed young people expressing a distinctly negative self-image (Cheung et al., 2015; Cooper

451   and Shea, 1998; Daley and Weisner, 2003; Elkington et al., 2013, 2012; Hallberg et al., 2010;

452   Humphrey and Lewis, 2008; Ingesson, 2007; Jones, 2012; Karterud et al., 2015; Kranke et al.,

453   2011; Krueger and Kendall, 2001; Leavey, 2005; Lingam et al., 2014; Singh et al., 2010;

454   Travell and Visser, 2006). Young people variously viewed themselves as inferior (Cheung et

455   al., 2015; Elkington et al., 2012; Elkington et al., 2013; Hallberg et al., 2010), inadequate

456   (Krueger and Kendall, 2001), damaged and incomplete (Cooper and Shea, 1998), flawed

457   (Elkington et al., 2012), unintelligent (Daley and Weisner, 2003; Lingam et al., 2014; Travell

458   and Visser, 2006), and undeserving of happiness (Elkington et al., 2013).

459   *"I've had pretty negative thoughts about myself and ADHD since I was little, especially*

460   *when people are nagging me about things when I mess up. I try to do things right, but I*

461   *can't. I think it's the way I'll always be." (Krueger and Kendall, 2001, p. 66)*

462   In most articles, it was unclear whether loss of self-worth was caused by the diagnosis itself,

463   or the symptoms that presumably pre-dated it. However, the diagnosis certainly contributed to

464   lowered self-worth for some young people by confirming that there was something

465   fundamentally 'wrong' with them. The devaluing potential of diagnosis was more profound,

466   the more an individual's self was conflated with the diagnosis. For a minority of young people,

467   their diagnosis represented the defining aspect of their self-concept (Kendall et al., 2003;

468   Krueger and Kendall, 2001; Leavey, 2005; McLaughlin and Rafferty, 2014; Mogensen and

469   Mason, 2015; Moses, 2009; Wisdom and Green, 2004). Such strong self-identification with a

470   diagnosis mostly coincided with negative self-views, with the exception of some participants

471   with ASD, whose diagnosis contributed to a self-image of uniqueness (Mogensen and Mason,

472   2015).

473   Alongside young people's sense their diagnosis marked them as flawed or deficient, studies

474   also highlighted diagnoses' pragmatic consequences for personal development. Young people

475   in 11 studies stated that receiving the diagnosis had restricted their opportunities in education,

476   career and relationships (Chavez et al., 2012; Hallberg et al., 2010; Huws and Jones, 2008,

477   2015; Jones, 2012; Leavey, 2005; McLaughlin and Rafferty, 2014; Moses, 2010; Singh et al.,

478   2010; Travell and Visser, 2006; Woodgate, 2006). For instance, adolescents with ADHD

479   worried disclosing their diagnosis would invite discrimination from prospective employers

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480   (Hallberg et al., 2010). Young people positioned their diagnosis as responsible for unwanted

481   education placements (Jones, 2012; Moses, 2012), inability to pursue further education or

482   desired career trajectories (Huws and Jones, 2008, 2015; Leavey, 2005), educational

483   underperformance (Leavey, 2005; McLaughlin and Rafferty, 2014; Skovlund, 2014), unfair

484   treatment from teachers (Moses, 2010; Singh et al., 2010) and peer discord (McLaughlin and

485   Rafferty, 2014; Singh et al., 2010). These attributions caused significant resentment of the

486   diagnosis – although again, it was often difficult to disentangle the degree to which young

487   people blamed the diagnostic label itself, versus the disorder's symptoms. For some young

488   people, the diagnosis' perceived curtailment of opportunities fostered trepidation about their

489   future (Chavez et al., 2012; Hallberg et al., 2010; Huws and Jones, 2015, 2008; Ingesson, 2007;

490   Kranke et al., 2011, 2010; Krueger and Kendall, 2001; Leavey, 2005; Lingam et al., 2014;

491   Travell and Visser, 2006). Others adopted a pragmatic stance, arguing that one must simply

492   "*accept it and your limitations*" (Woodgate, 2006, p. 265). A recurrent finding was that after

493   the diagnosis, young people's expectations and aspirations for the future were revised

494   downward.

495   *"Like, my goals used to be set really high, get high marks, go to university. Now it's just*

496   *graduate high school and maybe go to college." (Leavey, 2005, p. 118).*

497   Thus, accepting a psychiatric diagnosis could lead to anxiety about future prospects and

498   realignment to less ambitious career and educational plans.

499   ## *Benefits for social identity*

500   ### Social identification

501   Thirteen articles presented evidence that young people derived a sense of social identity from

502   their diagnosis (Brady, 2014; Daley and Weisner, 2003; Elkington et al., 2012; Floersch et al.,

503   2009; Jones et al., 2015; Kranke et al., 2010; Leavey, 2005; Lingam et al., 2014; McLaughlin

504   and Rafferty, 2014; Mogensen and Mason, 2015; Moses, 2010; Skovlund, 2014; Wisdom and

505   Green, 2004). Numerous young people described bonds with peers who held similar diagnoses.

506   These were sometimes pre-existing friends who happened to also experience mental health

507   problems (Floersch et al., 2009; Moses, 2010), sometimes other users of relevant services

508   (Leavey, 2005; Lingam et al., 2013), and sometimes prior acquaintances which became closer

509   following the discovery of a shared diagnosis (Brady, 2014; McLaughlin and Rafferty, 2014).

510   Family members who experienced similar difficulties also offered social understanding and

511   acceptance (Moses, 2010).

512   Relationships with similar others had a special quality that was valued above friendships with

513   'normal' peers (Leavey, 2005). These relationships held a transparency lacking from other

514   friendships, as young people disclosed more personal information to others with shared

515   experience (Elkington et al., 2012). These friendships were an outlet for sharing mental health-

516   related experience and advice – even, on occasion, medication (Brady, 2014). Young people

517   who attended organised peer support groups appreciated the opportunity they presented to

518   forge these connections, which were valued both intrinsically and as resources for mental

519   health (Leavey, 2005; Lingam et al., 2013). Numerous young people alluded to a prior

520   isolation, that was resolved through meeting others in similar situations (Jones et al., 2015;

521   Kranke et al., 2010).

522   *"I mean it's easier to understand like other people have this condition. You're going*

523   *through it. I'm not the only one. Other people are like me. I mean it just so I don't feel*

524   *isolated." (Kranke et al., 2010, p. 500)*

525   The collective identity attached to their diagnosis was reflected in pronouns such as "*we*" and

526   "*us*", indicating identification with others in one's diagnostic category. Face-to-face contact

527   was not the only means of developing this solidarity: online communication and simply reading

528   about others with a diagnosis served similar functions (Elkington et al., 2012; Jones et al., 2015;

529   Mogensen and Mason, 2015). Contact with others who shared the diagnosis afforded a much-

530   wanted sense of belonging and validation (Jones et al., 2015).

531   *"I think of a lone jelly bean all by myself. No friends, until he realizes, I'm not alone; I'm*

532   *not the only jelly bean. There are jelly beans just like me, I'm not alone" (Jones et al.,*

533   *2015, p. 1499)*

534   Thus, one function of a diagnosis was to alert young people that there were others 'like them',

535   and many actively sought to cultivate relationships with these similar others.

536   **Social acceptance**

537   Diagnoses could have positive implications for young people's social relationships generally.

538   In eight articles, young people reported their interpersonal relationships had improved

539   following their diagnosis (Elkington et al., 2012; Hallberg et al., 2010; Humphrey and Lewis,

540   2008; Kranke et al., 2010; Leavey, 2005; Mogensen and Mason, 2015; Singh, 2011; Singh et

541   al., 2010).

542   *"After I got sick, people were so nice, they never gets [sic] angry at me" (Leavey, 2005,*

543   *p. 116)*

544   Teachers could become more tolerant after learning about a child's diagnosis (Honkasilta et

545   al., 2016; Lingam et al., 2013; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015;

546   Moses, 2010; Singh, 2011). Some young people reported that their relationships with their

547   parents had improved since their diagnosis, making interactions more accepting and open

548   (Elkington et al., 2012; Leavey, 2005). Since many only selectively disclosed their diagnosis

549   outside the home, the family often represented a comfortable setting where one's diagnosis was

550   known and understood (Hallberg et al., 2010). Reluctance to disclose the diagnosis to peers

551   was driven largely by anticipation that friends would treat one differently as a result. However,

552 these expectations were not always realised: some participants reported that revealing their

553 diagnosis to peers had led to increased understanding (Elkington et al., 2012; Humphrey and

554 Lewis, 2008), while others were gratified by their friends' indifference to their diagnosed status

555 (Kranke et al., 2010; Moses, 2010).

556 A further way diagnosis could smooth social relations was its potential deployment as a weapon

557 against unkind treatment. Some young people opted to identify themselves using the official

558 diagnostic term as a preferred alternative to derogatory slang for mental illness (Cooper and

559 Shea, 1998). Young people could also harness the fear associated with mental illness to their

560 benefit: three articles identified young people who deployed the diagnosis to offset the threat

561 of bullying (Huws and Jones, 2008; Singh et al., 2010; Singh, 2011).

562 *"I have like told people I got ADHD cos it makes them leave you alone. They're nervous*

563 *that you might really hurt them if you get wound up." (Singh, 2011, p. 894)*

564 Numerous young people recounted experiences of positive discrimination or 'special

565 treatment' resulting from their diagnosis (Daley and Weisner, 2003; Elkington et al., 2012;

566 Humphrey and Lewis, 2008; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015;

567 Moses, 2010; Singh, 2011; Woodgate, 2006). Diagnoses alerted others to young people's

568 challenges in certain domains, prompting more benevolent attitudes and practical assistance.

569 However, although participants acknowledged this was kindly meant, they were often

570 uncomfortable with these experiences, which contradicted their desire to retain a sense of

571 normality (Daley and Weisner, 2003; Elkington et al., 2012; McLaughlin and Rafferty, 2014).

572 Intensive monitoring or overprotective responses from parents were not appreciated (Leavey,

573 2005; Moses, 2010). Young people also disliked when teachers were overly attentive or lenient

574 due to their diagnosis, thereby drawing attention to their difference from their peers. This

575 rejection of preferential treatment or "*extra attention*" (Humphrey and Lewis, 2008, p. 38)

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

577 assistants.

578 *"I don't want people to treat me differently because people with Aspergers [get treated]*

579 *differently to everybody else and I don't like it at all. I don't like this sort of thing you*

580 *know I don't like people coming to my lessons. [...] If they were following me then the*

581 *other students know that there's something different about me and I don't like it at all.*

582 *[...] Often it's like – I don't really like the extra attention." (Humphrey and Lewis, 2008,*

583 *p. 38)*

584 Thus, young people often reported that their diagnosis had fostered a more tolerant,

585 understanding social environment. However, this was qualified by discomfort when disclosure

586 of a diagnosis led other people to dramatically change their behaviour towards them (Moses,

587 2010). Most young people wished to preserve a continuity of identity pre- and post-diagnosis,

588 and so it was important that others acknowledge their essential identity was unaffected by the

589 diagnosis (Karterud et al., 2015; Woodgate, 2006).

590 **Social comparison**

591 Holding a diagnosis afforded young people a classification unique among their peers, which

592 left many in some confusion regarding their social positioning. The literature illuminated the

593 social cognitive processes by which young people sought to orient themselves in their social

594 milieu. Twelve articles observed young people spontaneously engaging in social comparison,

595 i.e. evaluating their own social status in relation to others (Cooper and Shea, 1998; Daley and

596 Weisner, 2003; Elkington et al., 2012; Huws and Jones, 2015; Jones, 2012; Jones et al., 2015;

597 Kendall et al., 2003; McCann et al., 2012; McLaughlin and Rafferty, 2014; Moses, 2009; Singh

598 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, greeeaaat. 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,

763   2007; Jones, 2012; Jones et al., 2015; Kendall et al., 2003; Kranke et al., 2011, 2010; Leavey,

764   2005; McCann et al., 2012; Mogensen and Mason, 2015; Moses, 2010; Singh, 2011; Singh et

765   al., 2010; Travell and Visser, 2006; Woodgate, 2006). The most commonly discussed source

766   of stigma, present in 11 articles, was the young person's peer-group (Daley and Weisner, 2003;

767   Elkington et al., 2012; Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007;

768   Jones, 2012; Kendall et al., 2003; Kranke et al., 2011, 2010; McCann et al., 2012; Singh, 2011).

769   In seven articles, most involving developmental disorders, young people related experiences

770   of bullying from classmates or friends (Daley and Weisner, 2003; Hallberg et al., 2010;

771   Humphrey and Lewis, 2008; Huws and Jones, 2008; Ingesson, 2007; Kranke et al., 2010;

772   Singh, 2011).

773   *"Persecution! Being beaten up, assaulted. You don't get much worse than that. Assault*

774   *is pretty, pretty bad" (Daley and Weisner, 2003, p. 38)*

775   In several cases the bullying was directly attributed to the disclosure of a diagnosis, which

776   made people a target for victimisation.

777   *"Because I told [peers] about my ADHD, they thought if they could wind me up I'd get*

778   *really upset and they love to do that" (Singh, 2011, p. 893)*

779   The second most frequently mentioned sources of stigma, manifesting in six articles

780   encompassing a range of diagnoses, were school authorities (Cooper and Shea, 1998; Elkington

781   et al., 2012; Humphrey and Lewis, 2008; Kranke et al., 2011; Moses, 2010; Singh et al., 2010).

782   Numerous young people saw their diagnosis as negatively impacting their educational

783   experience due to the bad reputation it afforded them (Singh et al., 2010). Specific complaints

784   ranged from placement in inappropriate classroom contexts, undemanding work, intensive

785   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; Mongensen 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).

877   *"I was kind of like ashamed 'cause I don't want to be bipolar. Who does?" (Kranke et*

878   *al., 2010, p. 499)*

879   It should be noted that the experience of prejudice was not ubiquitous. In five studies, young

880   people stated that they had not experienced discrimination arising from their diagnosis

881   (Elkington et al., 2012, 2013; Huws and Jones, 2008; Mogensen and Mason, 2015; Moses,

882   2010). They also observed individual differences in attitudes to mental illness, with some

883   people more open-minded and accepting than others (Elkington et al., 2012). One teenager

884   indicated awareness of the proposed negative effects of labelling, but stated they were

885   outweighed by the positive consequences of diagnosis (Mogensen and Mason, 2015).

886   *"a lot of people think 'Oh, it's a label' and all of a sudden it has to be some sort of*

887   *prejudice – but I think that is sort of like a secure sort of thing for me. And just finding*

888   *out that problems that I was dealing with were real problems and that they actually had*

889   *names and labels and that they have diagnosis and treatments for that sort of thing. And*

890   *that was a really secure thing for me." (Mogensen and Mason, 2015, p. 259)*

891   In summary, stigma was a very common although not universal experience following a

892   diagnosis. This could have damaging implications when internalised into young people's

893   identity. Young people actively sought to avert this fate by concealing their diagnosis or using

894   a range of strategies to resist the stigma they encountered.

895   **Discussion**

896   This review has revealed the existence of a sizable body of qualitative research illuminating

897   the multifaceted ways psychiatric diagnosis affects young people's self-concept and social

898   identity. Thirty-eight articles, mostly reporting good quality qualitative research, were

899   identified by the systematic literature search. This literature was notably multidisciplinary, and

900   published in a diverse range of journals. One key contribution of this review is therefore to

901   collate and synthesise this disparate literature. This paper's value lies in providing an accessible

902   first port-of-call for researchers, practitioners and laypeople interested in understanding how

903   diagnosis impacts pragmatically, emotionally and socially on children and adolescents.

904   The thematic synthesis identified numerous implications that diagnosis holds for young

905   people's self-concept and social identity. A diagnosis can be experienced as a threat to a young

906   person's established self-concept and can lower self-worth by implying inferiority and

907   incapacity. However, a diagnosis can also be marshalled to promote a positive self-concept by

908   facilitating greater self-understanding, legitimising and mitigating culpability for emotional

909   and behavioural difficulties, and sensitising young people to their unique attributes and

910   abilities. A diagnosis can negatively affect a young person's social identity by exposing them

911   to stigma, and some young people feel their diagnosis invalidates them in others' eyes and

912   leads to social alienation and interpersonal strife. Yet a diagnosis can also promote

913   interpersonal tolerance and prompt the development of enriching relationships with similar

914   others. Moreover, young people engage in creative cognitive strategies to bolster their social

915   status, and a diagnostic label can be an important resource in facilitating self-protective social

916   comparison processes.

917   The diversity in diagnoses' implications for self-concept and social identity is undoubtedly

918   matched by the diversity in young people's relationships with their diagnosis. Different

919   orientations to a diagnosis were apparent both between individuals and within individuals at

920   different time points. The process of assimilating a diagnosis is a gradual one, and young people

921   can fluctuate through numerous stages of acceptance, rejection and ambivalence towards their

922   diagnosis. Given this diversity in diagnostic responses and outcomes, one important emergent

923   question is whether any meaningful patterns underlie the variation. For instance, do responses

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

925   The literature reviewed revealed some suggestive patterns in this regard.

926   First, it must be emphasised that while speaking of 'diagnosis' in general terms is useful in

927   orienting attention towards a defined stage in the clinical process, the variation in the specific

928   diagnoses offered means that as a global concept, 'diagnosis' has limited conceptual value. The

929   various diagnoses available within psychiatric diagnostic systems capture radically different

930   symptoms that have equally disparate practical implications and socio-cultural connotations.

931   The literature reviewed suggests some trends in specific diagnoses' differential effects on self-

932   concept and social identity. For instance, the tendency to reconstruct symptoms as positive or

933   life-enhancing, and thereby promote a positive self-concept, was more prominent in samples

934   with ASD (Daley and Weisner, 2003; Humphrey and Lewis, 2008; Huws and Jones, 2015;

935   Jones et al., 2015; McLaughlin and Rafferty, 2014; Mogensen and Mason, 2015) than affective

936   disorders. However, the greater prevalence of affective disorders and their continuity with

937   universal facets of human emotion made them easier to normalise and de-stigmatise (Elkington

938   et al., 2012; Floersch et al., 2009; Moses, 2010; Wisdom and Green, 2004). Elkington et al.

939   (2012) suggest youth with psychotic disorders experience more blatant forms of prejudice than

940   nonpsychotic diagnoses. Such findings are consistent with research demonstrating a hierarchy

941   of diagnoses in adult populations, with psychotic disorders more stigmatised than mood

942   disorders (Angermeyer and Dietrich, 2006). Yet the patterns suggested by the current literature

943   review remain inconclusive, since very few studies directly compared individuals with

944   different diagnostic classifications. Further confusions arise from the inconsistency in studies'

945   approaches to determining diagnostic status, with some using self-reports, others clinician-

946   reports, and others providing no relevant information. Moreover, the studies reviewed focused

947   on a limited set of diagnostic populations, most prominently ADHD and ASD. Young people

948   with psychotic, affective, anxiety and eating disorders are under-represented in this literature.

41

949 Neither is there representation of young people who may qualify for a diagnosis, but who have

950 avoided or withdrawn from the mental health system. This is understandable given most

951 recruitment methods' reliance on purposive sampling through clinics or services. Nonetheless,

952 tapping into populations who have rejected any diagnostic classification is necessary to develop

953 a comprehensive understanding of diagnosis' effects. One limitation of the review is the

954 difficulty disentangling the degree the processes identified followed from the diagnostic label

955 itself, versus the symptoms that presumably preceded it. To fully isolate the effects of a

956 diagnostic label, research would need to compare groups of children who hold a diagnosis but

957 no debilitating symptoms, and who hold symptoms but no diagnosis. This scientifically ideal

958 scenario may be challenging to achieve, given the former group are likely rare (and difficult to

959 define, given the subjective nature of symptom severity), and the latter very challenging to

960 sample. Nevertheless, some effort to track the longitudinal outcomes of young people who

961 display equivalent symptoms but never receive a diagnosis would be very helpful in

962 understanding the unique effects of diagnostic labels.

963 Another variable that might differentiate outcomes is the age the diagnosis is received. Young

964 people who received a delayed diagnosis generally believed an earlier diagnosis would have

965 improved their life (Cheung et al., 2015; Huws and Jones, 2008; Mogensen and Mason, 2015).

966 Again, the literature reviewed does not facilitate any definitive conclusions regarding the

967 optimal age to receive a psychiatric diagnosis. Most research has been conducted with older

968 adolescents: only five studies included children younger than 10 years (Brady, 2014; Kendall

969 et al., 2003; Singh et al., 2010; Singh, 2011; Skovlund, 2014). Understanding how young

970 children respond to diagnostic classifications should be a priority for future research.

971 Further demographic imbalances in the literature relate to gender. Males were more represented

972 in these studies than females: a rough estimate, based only on studies that specified the

973 sample's gender breakdown, is that 340 females and 456 males participated in the research

974   reviewed. This may reflect studies' focus on ASD and ADHD, which have higher prevalence

975   among males. No studies sought to directly investigate potential gender differences in

976   responses to diagnosis. Issues specific to LBGTQI populations were similarly neglected.

977   Furthermore, few studies specifically explored cultural or ethnic factors (Chavez et al., 2012;

978   Cheung et al., 2015; Elkington et al., 2013, 2012). This is a highly significant gap, given

979   extensive evidence of cultural and ethnic differences in experience of and attitudes towards

980   mental illness (U.S. Department of Health and Human Services, 2001). The studies reviewed

981   were predominantly conducted in North American and European countries. This may partly be

982   an artefact of the review's inclusion criteria, which restricted the review to English-language

983   publications. However, it should be noted that numerous included studies were conducted with

984   non-English speaking populations, with data translated for publication (Avisar and Lavie-

985   Ajayi, 2014; Chavez et al., 2012; Cheung et al., 2015; Hallberg et al., 2010; Honkasilta et al.,

986   2016; Ingesson, 2007; Karterud et al., 2015; Skovlund, 2014; Tidefors and Strand, 2012).

987   The difficulty reliably segmenting findings across demographic or clinical variables partly

988   follows from the review's exclusive focus on qualitative research. This has formed the

989   dominant methodological approach for research on this topic thus far, for the reasons outlined

990   in the Introduction. The value of qualitative research lies in affording a rich, nuanced insight

991   into the range of perspectives and experiences that exist in a given social context. Qualitative

992   research is not generally concerned with performing direct comparisons between predefined

993   groups of participants: this is a task more suited to quantitative designs. Future quantitative

994   research should seek to clarify the clinical and demographic variables that correlate with the

995   varied responses to diagnosis revealed by the qualitative literature. Quantitative research may

996   be particularly helpful in identifying 'clusters' of variables relating to the child (e.g. gender,

997   age, IQ), their social context (e.g. familial and cultural variables) and the diagnosis in question,

998   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

44

1024   disparate conceptual perspectives. This may reflect the relative youth of the field: only one

1025   study was identified pre-2000 (Cooper and Shea, 1998) and 63% (*n*=24) were published since

1026   2010. To capitalise on empirical insights and streamline the complexity of factors involved,

1027   theoretical development should be prioritised. This may involve both generating new theories

1028   and borrowing from established theoretical frameworks. For instance, understanding how

1029   cultural representations of mental illness interact with individual self-concept would benefit

1030   from incorporating insights from social psychological theories of social categorisation, social

1031   identity, social representations, stigma, prejudice and intergroup relations. Research and

1032   clinical practice would be particularly served by theoretical frameworks that incorporate the

1033   multiplicity of responses to diagnoses, and attempt to disentangle and predict the

1034   simultaneously positive and negative implications diagnosis may have.

1035   The surge in publications post-2010 may reflect the relatively recent attention to child-centred

1036   research and policy (LeFrancois, 2007; Sinclair, 2004; Singh, 2007). The literature reviewed

1037   clearly demonstrates the value of research on the first-person lived experience of young people

1038   with psychiatric diagnoses. The research uncovered novel experiences that have been largely

1039   neglected in debates about youth psychiatric diagnosis; for instance, young people's strong

1040   dislike of preferential treatment, and the creativity with which young people marshal and

1041   interpret diagnostic classifications to serve their self-concept and social identity needs.

1042   Acknowledging the active, pragmatic ways children negotiate diagnoses and therapies is

1043   critical to ensure debates about youth psychiatric diagnosis avoid perpetuating paternalistic

1044   views of children (Singh, 2011). It is also important to recognise common themes in debates

1045   about diagnosis that did not emerge in this empirical literature: for instance, few young people

1046   mentioned the media as a source of stigma or the proposed 'self-fulfilling prophecy' effects of

1047   diagnosis. This is not evidence that such concerns are invalid or insignificant, but it is notable

1048   they do not feature strongly in young people's first-person experience.

1049 The review has several methodological limitations which should be acknowledged when

1050 considering its results. First, due to resource restrictions, the search did not include grey

1051 literature or material published in books. Since much qualitative research is published outside

1052 peer-reviewed journals (Grant, 2004), this may have excluded some relevant studies. The

1053 review was also restricted to studies published in English, and the lack of standardised terms

1054 for indexing qualitative research in electronic databases meant the search relied on a

1055 purposively-selected set of keywords. Second, a systematic review protocol was not registered

1056 in advance of completing the review. Third, an analytical priority on capturing common themes

1057 across the literature, as well as the diversity of studies' methodological approaches, meant that

1058 it was not possible to conduct detailed subgroup analyses. The precise ways results diverge

1059 across age, gender, culture and diagnostic category therefore remain unclear.

1060 These limitations notwithstanding, this review is the first to systematically collate, evaluate

1061 and synthesise studies of this important topic. The review contributes to the heated debate

1062 currently underway regarding whether dominant systems of psychiatric diagnosis are fit-for-

1063 purpose, particularly in youth contexts (Callard et al., 2013; Hyman, 2010; Insel et al., 2010;

1064 Rutter, 2011; Timimi, 2014). While most prior debate has focused on reliability and validity

1065 issues, the current review draws attention to the social and psychological outcomes that ensue

1066 from the meanings people derive of their diagnosis. Diagnoses are not purely clinical

1067 judgements that occur in a vacuum: they have pragmatic repercussions, which are central to

1068 real-world diagnostic decisions. In deciding whether to pursue or accept a diagnosis, clinicians,

1069 parents and young people themselves must trade off its potential risks and benefits, which are

1070 specific to the child's individual characteristics, familial circumstances, cultural environment,

1071 and institutional structures where access to educational and/or health resources may be

1072 contingent on diagnostic status. The current review aims to inform these decisions by collating

1073 the positive and negative implications a diagnosis can have for a young person's self-concept

1074 and social identity. Further research is needed to clarify which self and identity outcomes can

1075 be expected in a given set of circumstances, and to establish how self and identity effects

1076 interact with diagnoses' other clinical, practical, social and emotional ramifications.

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1415 **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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Table 2: Articles included in review

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