Review article

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

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ABSTRACT

Receiving a psychiatric diagnosis in childhood or adolescence can have numerous social, emotional and practical repercussions. Among the most important of these are the implications for a young person's self-concept and social identity. To ensure diagnoses are communicated and managed in a way that optimally benefits mental health trajectories, understanding young people's first-hand experience of living with a diagnosis is paramount. This systematic review collates, evaluates and synthesises the qualitative research that has explored how psychiatric diagnosis interacts with young people's self-concept and social identity. A search of 10 electronic databases identified 3892 citations, 38 of which met inclusion criteria. The 38 studies were generally evaluated as moderate-to-high quality research. Thematic synthesis of their findings highlighted the multifaceted ways diagnosis affects young people's self-concept and social identity. Diagnosis can sometimes threaten and devalue young people's self-concept, but can also facilitate self-understanding, self-legitimation and self-enhancement. A diagnosis can lead to social alienation, invalidation and stigmatisation, yet can also promote social identification and acceptance. Further research is needed to clarify which self and identity outcomes can be expected in a given set of circumstances, and to establish how self and identity effects interact with diagnoses' other clinical, practical, social and emotional consequences.

1. Introduction

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

A diagnosis serves many functions for mental health service-users. At a practical level, a diagnosis can explain symptoms and facilitate access to resources, treatment and prognosis (Jutel, 2009). Research suggests ascribing appropriate diagnostic labels to psychological symptoms positively affects help-seeking and symptom management decisions (Wright et al., 2007). Service-users may further benefit from the 'common language' that diagnoses provide, which streamline communication between the different services and clinicians involved in their care. However, diagnoses can also have negative consequences for mental healthcare provision. Diagnoses may exclude people from certain services: for example, some child and adolescent mental health clinics do not accept clients with a primary diagnosis of Autistic Spectrum Disorder (ASD), and persons with a dual diagnosis of substance misuse and mental illness can fall between the cracks of different services' admission policies (Schulte and Holland, 2008). Diagnoses with poor prognoses (such as personality disorders) can also lead to fatalism among service-providers and consequent restriction of treatment options (Nehls, 1999; Newton-Howes et al., 2008; Ramon et al., 2001; Stalker et al., 2005).

These practical implications of psychiatric diagnosis must be considered alongside diagnoses' social and psychological effects, which are

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

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

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

A further concern is that disclosure of a diagnosis might exacerbate the stigma that symptoms of mental illness already attract (Ben-Zeev et al., 2010; Corrigan, 2007). People with direct experience of mental illness report that diagnostic disclosure leads to disadvantage in a range of interpersonal, employment, educational, health and social welfare settings (Dinos et al., 2004; Schulze and Angermeyer, 2003). Numerous studies have experimentally investigated the social effects of diagnosis by comparing people's attitudes to hypothetical characters with and without a diagnostic label. This literature contains mixed effects, with some reporting a diagnostic label increases prejudice (Batzle et al., 2010; Harris et al., 1992; Ohan et al., 2013) and others that it does not (Jorm and Griffiths, 2008; Law et al., 2007; Thompson and Lefler, 2016). Certain diagnostic labels are more stigmatising than others, e.g. young people with ADHD are perceived more negatively than those with depression (O'Driscoll et al., 2012). Schizophrenia, eating disorders and substance abuse are among the most stigmatised of common mental illnesses (Angermeyer and Dietrich, 2006). Moreover, mental illness stigma is intersectional with socio-demographic categories: an eating disorder diagnosis, for example, is more stigmatising for males than females (Jones and Morgan, 2010).

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

The self and identity effects of diagnosis are likely particularly profound when the diagnosis is ascribed in early life. Childhood is a time when identity is elastic and acutely sensitive to social experience (Bennett, 2011; Harter, 2012). Until recently, most empirical evidence regarding the psychological effects of childhood diagnoses reflected the perspective of parents (Ahern, 2000; Osborne and Reed, 2008; Russell and Norwich, 2012; Singh, 2004) or people who receive a retrospective diagnosis of developmental disorder (e.g. ADHD) in adulthood (Punshon et al., 2009; Tan, 2018; Young et al., 2008). Recent years have seen increasing recognition of the need for mental health policy and practice to be informed by the perspective of young people themselves (LeFrancois, 2007; Sinclair, 2004). Researchers have demonstrated that, with appropriate attention to research design and ethical procedures, children with cognitive and behavioural difficulties are capable of productively engaging with the research process (Singh, 2007). This emerging literature has produced rich insights into the active ways young people negotiate psychiatric diagnoses and other aspects of the mental health system (McNamara et al., 2017; Singh, 2011). Most of this evidence is qualitative in nature. The predominance of qualitative research is due to numerous factors. First, the relative youth of this field means much research is still exploratory, with insufficient evidence to inform hypothesis-driven quantitative studies. Second, recent policy emphasis on patient-centred care has prompted an upsurge of interest in lived experiences of service-users, which qualitative research is specifically suited to explore (Beresford, 2007; Davidson et al., 2008; Meyer, 2000). Finally, the pragmatic and ethical challenges of conducting research with children with cognitive, emotional and/or behavioural difficulties mean that standard methods such as questionnaires and experiments are often not appropriate or feasible: more dynamic, interactive data-elicitation methods are required (Singh, 2007; Whyte, 2005).

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