Research Proposal

An exploratory study into the experience of teenagers undergoing an individual assessment for dyslexia

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Introduction

Turner (1997 p.5) refers to assessment for dyslexia as 'in effect a single case study'. He describes the 'crisis-like nature of the assessment' as potentially the culmination of years of distress and emphasises that 'the counselling aspects of the assessment interview are quite as important as any other.' (ibid p.118). An assessment results in face-to-face feedback and the production of a report, which must meet the needs of the learner, their families, teachers and other professionals. What are the experiences of individuals going through such an assessment and what factors may influence the quality and outcomes of that experience?

Controversy surrounds the definition of dyslexia. Descriptions have varied as our knowledge and understanding of the causes and consequences of literacy difficulties have developed. A descriptor has been seen as necessary for that group of people whose literacy skills do not develop along expected lines in a literate culture. Socio-cultural aspects of dyslexia as a condition arising because of the values placed on language and orthography are important. The unexpected nature of an individual's problems is emphasised in most definitions, e.g. Snowling (1987). The Rose Review (2009) defined dyslexia as '*a learning difficulty that primarily affects the skills involved in accurate and fluent word reading and spelling. Characteristic features of dyslexia are difficulties in phonological awareness, verbal memory and verbal processing speed'.* Estimates of the prevalence of dyslexia vary depending on the definitions that are used. Miles (2004) described the difficulties inherent in estimating the prevalence, and concluded best estimates were 3% of UK 10 year olds suffering from severe dyslexia and 6% from mild dyslexia. How do individuals who receive a diagnosis of dyslexia perceive the label of dyslexia and how does this impact on their sense of self, in particular self-esteem?

The literature suggests that self-esteem changes over a life span, with a decrease during adolescence (Robins and Trzesniewski 2005). Suggested reasons for this decline include academic challenges (ibid). What is the particular experience of assessment for teenagers who may be encountering feelings of low self-esteem.

Purpose of Research

The purpose of the intended research is to explore the meaning that 13-18 year olds ascribe to the experience of an individual assessment for dyslexia. This will include the experience of the assessment itself, any diagnosis and the assessment report including recommendations. As a specialist teacher assessor and trainer, I hope to use the findings to inform my practice and the practice of my colleagues. Each assessment, each learner and each assessor are unique and combine to create a distinctive context. The intention is therefore not to attempt to generate protocols for assessments in general, but to gather rich, detailed data to further my understanding about the background against which I make decisions regarding assessment practice.

The recent Green Paper ‘Support and aspiration: A new approach to special educational needs and disability. A consultation’ (Department for Education 2011) states the government’s intention to prioritise early identification and support for learning difficulties. Traditionally many assessments have taken place privately, as a result of the stringent conditions under which statutory assessment by a Local Education Authority are granted. This intended emphasis on identification makes research, which may inform understanding of the nature of the assessment process, particularly apposite.

Literature Review

A review of literature related to assessment of dyslexia amongst all age groups, revealed no research specifically examining how the subjects of assessment experienced the assessment process. However, several relevant themes emerged from related studies.

Firstly, a number of papers have investigated the impact that a diagnosis of dyslexia may have on a learner's sense of self. Distinctions are made between self-concept and specifically academic self-concept and self-esteem. Self-concept being how a learner perceives their attributes and self-esteem how they feel about those attributes. A meta-analysis by Zeleke (2004) found that the majority of studies concluded that a diagnosis of dyslexia was not necessarily related to negative feeling of academic self-concept. However, a number studies focusing on self-esteem have suggested that it is lower in dyslexic individuals than those without literacy difficulties. These include Riddick's (1997) interviews with dyslexic and non-dyslexic university students . Humphrey (2002) concluded that dyslexic children aged 8-15 had lower self-esteem than a group of controls. Possible gender differences are highlighted by Alexander-Passe (2006). He used standardised measures of self-esteem and suggested that self-esteem is lower in female than male dyslexics. Some research has argued that dyslexic's self-esteem is mutable. Ingesson's (2007) interviews with Swedish teenagers suggested their esteem improved in secondary school. It should be noted that there was no indication of severity of dyslexia or use of controls in this study. The importance of socio-cultural influences is considered in Burden's (2005) study of dyslexic boys in a special school. He concluded that pedagogy and comparison with peers allowed the boys to have at least as positive self-esteem as those in mainstream schools. Controls were not included and the context of the study was very specific, so findings cannot be generalised. Burden emphasised that comparisons between self-esteem and dyslexia do not point to a causal relationship. He called for increased research into theory-based approaches, looking at possible links between constructs such as ‘self-efficacy’ (Bandura 1997) and ‘learned helplessness’ (Abraham, Seligman and Teasdale 1978) and reactions to dyslexia. The existing research indicates that self-esteem is likely to be adversely affected by the effects of dyslexia. There may be gender differences and it may change over time and situation.

Secondly, the impact of age of diagnosis is highlighted in a number of papers. Armstrong and Humphrey (2008) proposed a ‘resistance-accommodation’ model to help explain reactions to a dyslexia diagnosis using a grounded theory approach. This small-scale study indicated that accommodation of a diagnosis becomes harder as a learner’s sense of self consolidates. Early diagnosis is therefore preferable. Glazzard (2010) studied 9 recently diagnosed teenagers who volunteered to be interviewed. He concluded that early diagnosis helps to prevent the development of ‘learned helplessness’. Sampling methods may have affected Glazzard’s results. Ingesson (2007) also emphasised the benefits of early diagnosis. Young-Kong (2012) interviewed 6 mature students about their memories of a late diagnosis of dyslexia. She reported broadly negative feelings as adults questioned their academic abilities and became less confident and de-motivated. They worried about the social stigma and avoided disclosure. The research suggests a continuum as diagnosis has a positive impact for younger learners, it can be harder to accommodate for teenagers and can have a negative impact for adults.

Research indicates that reaction to diagnosis is not a fixed single event. Rather it is a complex process that can be influenced by multiple factors. Higgins et al (2002) proposed a 5-stage process in the acceptance of a learning disability, as a result of their longitudinal study, which adopted an ethnographic approach. Riddick's 1997 study of dyslexic university students suggested a distinction between private and public reactions. Private reactions tended to be positive and included development of self-awareness and feelings of relief. Public reactions were more mixed and included worries about stigma and potential careers. Riddick's (1996) phenomenological study of children and their mothers revealed a positive reaction amongst children and suggested that most mothers felt positively that the diagnosis would bring support. Additional influences are likely to be personality factors. Armstrong and Humphrey (2008) suggested the importance of attributional style. They also described how students distinguished between 'having dyslexia', which they were able to compartmentalise as separate from their intellect and 'being dyslexic', which they were more likely to assimilate into their whole sense of self. Other authors who theorise that the ability to compartmentalise dyslexia is likely to allow a more positive reaction to diagnosis include Glazzard (2010). Studies indicate that the consequences of a diagnosis are likely to be affected by a range of factors including stage of acceptance, personality and the terminology used for diagnosis.

Limited literature was found investigating the reaction of different recipients of an assessment report to the content and recommendations. This minimal literature painted a generally negative picture. A qualitative and quantitative study by Woods et al (2010) of 11-16 years olds with disabilities, indicated that 88% of children across 3 local authorities had not been consulted about recommended access arrangements and in fact did not want a number of the arrangements suggested. However, geographical factors may have been influential, as location of local authorities was not stated. Additionally, of the 86 participants only 39 had dyslexia. A European perspective is provided by Lebeer at al (2011). Their multi-modal research suggested that parents and professionals bemoaned the negative tone of reports and associated lists of impairments with a corresponding lack of evaluation of opportunities for learning. Parents and teachers commented on the paucity of useful recommendations. The research that is available suggests that individuals should be involved in decisions about recommendations and both strengths and weaknesses should be highlighted in learner's profiles.

Existing literature suggests that important issues in teenager's experience of dyslexia assessments are likely to include self-esteem, age of diagnosis/stage of education (KS3, KS4, FE), personality factors, terminology of diagnosis and the distinction between public and private reactions. Additionally, recommendations and the tone of the report require consideration.

Methodology

The research will utilise an interpretive qualitative methodology set within the context of phenomenology, with a focus on the common lived experiences of individuals undergoing assessment for dyslexia. A phenomenological approach has been adopted, as the intention is to describe common themes that may appear for individuals experiencing this phenomenon, the assessment process. The essential purpose of phenomenology has been described as the reduction of individual experiences with a phenomenon to a 'description of the universal essence', Creswell (2007 p.58). Phenomenology stems from the thinking of Husserl (1859-1938), who adopted the premise that reality consists only of what is understood or perceived in consciousness and not of anything outside of human consciousness. Its emphasis is on the world as lived by a person, not the world or reality as something separate from the person (Valle et al 1989 cited in Laverty 2003). Phenomenological researchers therefore attempt to separate out their own experiences so that the subjects' experiences can be the focus. Researchers may adopt an 'interpretivist' approach as adopted by Van Manen (1990 cited in Creswell 2007 p.59), hermeneutic phenomenology. This approach is 'concentrated on historical meanings of experience and their developmental and cumulative effects on individual and social levels' (Laverty 2003 p.27). This research, however, proposes to adopt a descriptive approach as described by Moustakas (1994), psychological or transcendental phenomenology. This approach is most relevant to the purpose of the research as it focuses more on description of the experience. Essential to psychological phenomenology is the attempt to bracket the researcher's own experiences, theories and suppositions so that those of the participants can be more easily appraised in isolation (Laverty 2003). It is generally accepted that this is hard to achieve. However, I intend to write down my own reflections on the assessment process in the initial stages of the research. I hope that this will enable me to be more aware of my own assumptions and help me to set them aside as I attempt to approach the research without preconceived ideas about what I will find.

Empirical Setting

The participants will be individually assessed at a specialist dyslexia centre. Assessments may be privately or bursary funded. Educational psychologists or specialist teachers will carry out the assessments. It is acknowledged that this setting represents a specific context for dyslexia assessments. Many assessments are carried out within a school setting. They can be partly group based and may involve the use of computerised screening tools. The setting is the researcher's place of work. The head of the centre has been asked for permission to carry out the research and initial permission has been granted. An outline research proposal will be submitted for approval and formal consent. All staff at the centre are known to the researcher and it is recognised that this brings implications for dealing with negative comments about professional practice. The centre's code of practice as well as the BERA Ethical Guidelines (BERA 2011) will be used to help guide decision making in case of ethical dilemmas.

Sampling

A strategy of purposeful sampling will be adopted. The participants will be chosen because they meet certain criteria, criterion sampling. As Laverty (2003 p.29) describes, the principles behind participant selection in phenomenological research are usually to select individuals who have lived the experience that is the focus of the study, are willing to talk about it and are diverse enough to enhance the possibilities of rich and unique accounts. Van der Mescht (2004) stresses that verbal fluency is critical in selecting participants as language is the only data that researchers work with. It is hoped that the researcher will be able to put participants sufficiently at their ease to allow the collection of rich data. If this is not possible alternative participants may be sought. Participants will be male and female 13-18 year olds with no previous assessment and no diagnosis of specific learning difficulties or other disability. An attempt will made to select across the age range and provide equal male and female participants. The sample will not be chosen to be representative of all assessed individuals, but to help understand the phenomena of experiencing assessment as a teenager in this particular setting.

Ethical Considerations

The participants will be recruited from individuals who have an appointment for an assessment at the dyslexia centre. Letters will be sent to parents/carers asking for permission for their child to take part. A separate letter will ask for the child's permission. The letters will include the following: an outline of the procedure, reasons for the research, a request for permission to participate, a request for permission to record interviews, the right to withdraw, confidentiality and anonymity of data, the secure storage of data, opportunity to validate data and adherence to the BERA and dyslexia centre code of ethics. The BERA (2011) Ethical Guidelines will be adhered to throughout the research process.

Data Collection

The principle method of data collection will be unstructured interviews which will be carried out by the researcher. This method of data collection allows the interviewer to 'explore the world from the perspective of the interviewee and to construct an understanding of how the interviewee makes sense of their experiences (Dowling and Brown 2010 p.78). Questions will be kept open with flexibility in format that allows the follow up questions to be led more by the participant than the researcher. Phenomenological research aims to get at what the participant has really experienced. Laverty (2003 p.29) advocates that interviews are as open as possible, to encourage the interview process to stay as close to the lived experience as possible. The unstructured interview will be preceded with a couple of particular questions that can be easily answered. This move from particular to more general personal questions suggested by Dowling and Brown (2010 p.81) is intended to help participants relax and develop their thinking about more abstract issues. Probes may be used as necessary to help clarify and develop the participant's responses. The researcher will aim to minimise possible demand characteristics in the participant's responses by emphasising affiliation with the Institute of Education and avoiding reference to affiliation with the dyslexia centre. A small number of participants will be included, 5-7. The detailed data that is likely to be collected from unstructured interviews will make transcription and analysis prohibitively time-consuming and possibly over-whelming if more participants are included.

It is intended that data collection take place in 2 phases. Pre-assessment and post assessment. The pre-assessment interviews will take place immediately before the assessment at the dyslexia centre. Parents will not be present. The addition of a pre-assessment interview is likely to create additional stress for participants and in fact alter their experience of the assessment process. This will be kept in mind during data analysis. The pre-assessment interviews will explore participant's experience of events leading up to referral, the referral process and expectations about the actual assessment and the outcomes of the assessment. They will consider participant's perceptions of the views of family, teachers and peers regarding the assessment and pre-ceding events. Post assessment interviews are intended to take place one month after assessment in the participant's home, in an effort to create a relaxed environment conducive to open exchanges. The post assessment interval is intended to allow the participants time to reflect on the assessment and for recommendations to begin to be put into place. A longer time interval, which would allow more consideration of the impact of assessment, will be impractical due to time constraints of the research process and may also involve deterioration of memories of the assessment process. Post assessment interviews will consider participant's experiences of the actuality of the assessment, face to face feedback, the report, the impact of diagnosis, private/public reactions to diagnosis and recommendations as well as their perception of the views of family, school and peers. It is intended to tape record the interviews. The use of tape recording will aid in transcription but will also allow attention to be paid to silences and delivery of responses. Kvale (1996 cited in Laverty 2003 p.29) stressed the importance of looking out not only for what is ‘said’ but what is said ‘between the lines’. Van der Mescht (2004) points out that the ‘reality’ that is sought in phenomenological research is not directly accessible to the researcher, rather it is the dialogue of individuals that is the focus. Consideration will be given throughout the interview process to the sensitive and potentially emotive nature of the topic of discussion. The feelings of participants will be respected and efforts will be made to minimise potential distress. Participants will be offered the opportunity to validate transcripts. If they would like to do this, additional meetings will be organised during which participants can have the transcript read to them. Any feedback will be considered in the process of data analysis.

The assessment process at the dyslexia centre includes the collection of background information, used by assessors to help to build a holistic picture of individuals being assessed. This includes a family questionnaire, completed by parents/carers for those under 18, and a school questionnaire. It is hoped that these will be made available. They may be used to help understand the broader context within which the participant has experienced the assessment process. They will not be read by the researcher until after the transcripts have been analysed in order to help bracket any researcher preconceptions.

Data Analysis

There are a number of approaches to analysis adopted in phenomenological research. It is envisaged that the process advocated by Moustakas (1994) will act as the basic framework. Elements of the approach to analysis adopted by grounded theorists (for example Strauss, 1987, Glaser, 1992, cited in Dowling and Brown 2010 p.85) will also be incorporated. These will include the constant comparison of emerging themes with the original data and the use of memos to aid in the conceptualisation and tracking of themes. The following framework, summarised in Creswell (2007 p.159) and described in Brown et al (2005), is envisaged: After several readings of the transcripts, significant statements will be identified. Overlapping statements will be reduced/eliminated to provide a list of ‘invariant structures’. These will be grouped into themes or ‘meaning units’. A ‘textural description’ of *what* the participants experienced will be written. Next a ‘structural description’ of *how* the experience occurred focusing on setting and context will be written. Finally, a composite description merging the textural and structural will be developed. It is hoped that this will provide the ‘essence’ of the phenomenon of assessment. The significant statements and emerging themes will be constantly compared back to the data to ensure the original data fits the descriptions and vice versa. Examples of how statements and/or invariant structures relate to meaning units and how meaning units relate to themes will be presented to provide transparency of analysis.

Validation and Evaluation

There are diverse perspectives regarding issues of validation and evaluation in qualitative research (Creswell 2007 p.202). This research will strive to ensure validity and quality through the following activities: Comparison of findings with authors in related fields, review of methods and interpretations by my tutor, attempts to bracket my own bias and expectations, participant validation of transcripts, referral to a recognised framework for data analysis (Moustakas 1994) and an attempt to examine alternative conclusions that could be reached based on the data. Limitations of the research design will be considered.

Possible Outcomes

It is hoped the research will contribute to the development of my personal practice in dyslexia assessment as well as professionals attending my training courses. Results of the research will be used to inform the format of the assessment process, face-to-face feedback, the format of the report and the production of recommendations. The proposed research could also serve as a springboard for future studies. Triangulation of data could be achieved through the use of focus groups, contributing the additional perspectives provided by participant's interactions. Future research may involve interviews with parents and teachers to explore their experiences of the assessment process. Depending on the outcomes of this research it may be that accepted protocols of the assessment could be analysed in greater detail. Aspects of this research may be further developed by exploring the influence of factors such as attributional style on the impact and accommodation of a diagnosis of dyslexia, following the call for work in this area by Burden (2008).

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