Life experiences of individuals living with dyslexia in Malaysia: a phenomenological study
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Abstract
Dyslexia, a specific learning disability, is estimated to affect 314,000 students in Malaysia. This research aims to uncover the experiences of individuals living with dyslexia in Malaysia. A phenomenological approach was undertaken where semi-structured interview was conducted on five Malaysian dyslexics. Their experiences included being subjected to the watchful eyes of others and their negative reactions; receiving support; encountering difficulties in academic areas; reacting towards the condition of being dyslexic; having a poor sense of orientation; and possessing areas of strength and/or passion. Findings of the study call for increased intervention rigor to reduce the marginalization of dyslexics in Malaysia.

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Keywords: Life experiences, dyslexia, Malaysia, awareness

1. Introduction

Dyslexics in Malaysia are an unrecognized population (Rohaty Majzub, 2000; Thaneswari Sankaran, 2006; Zaid, 1999) and research suggests that this could be due to the absence of a standardized screening test in the school environment (Zaid, 1999; Gomez, 2004; Lee, 2008). Originally, over 100 years ago, dyslexia was termed to describe an individual’s inability to read due to brain damage (Dore, 2008; Guardiola, 2001). Currently, it is used to describe a specific learning disability that is neurobiological in origin and is characterized by difficulties in accurate word recognition, spelling and decoding abilities despite individuals having higher cognitive abilities and effective classroom experience (Reid, Shaywitz & Shaywitz, 2003). In addition, comorbidity with other academic or cognitive areas such as mathematics, attention, and self-expression is common (Reid, Shaywitz & Shaywitz, 2003). Dyslexia is often regarded as a disability (Chan, 2010). However, there is much research to suggest that dyslexics should be viewed as different rather than disabled (Gilger & Hynd, 2008; Logan, 2009; Rohaty Majzub, 2000; Reid, 2007; Tafti, Hameedy & Baghal, 2009). The difficulties that dyslexics experience could be reduced by providing the correct support (Anida Abu Bakar, 2008; Reid, 2007; Scott, Scherman & Phillips, 1992), evidence of which can be seen in examples of gifted and successful individuals with dyslexia such as Albert Einstein, Thomas Edison, Leonardo Da Vinci, Richard Branson and Whoopi Goldberg (Reid, 2007).

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There have been anecdotal accounts of Malaysian dyslexic children’s struggle with reading, writing and examinations, and of remedial classes being helpful in enhancing their performance (Low, 2010; The Star Online, 2010; Wong, 2006). However, there has been no formal documentation of life experiences of people living with dyslexia in Malaysia (Rohaty Majzub, 2000). Thus for the current study, past studies from abroad were reviewed to obtain information about the life experiences of individuals living with dyslexia. Five common themes of experiences of dyslexic individuals were identified from studies by Anderson (2008), Armstrong and Humphrey (2008), McNulty (2003), Morris and Turnbull (2006) and Riddick (2000) and these themes are listed in Table 1 below. These past studies imply the need for early intervention and supportive attention to help individuals with dyslexia adapt successfully in life.

<table>
<thead>
<tr>
<th>Common theme from past studies (CTPS)</th>
<th>Details</th>
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<tbody>
<tr>
<td>CTPS 1: A sense of being different</td>
<td>1) Differences in how they speak, coordinating self and concentrating; 2) remedial classes at school increased their marginalization; 3) they often need more time and effort to prepare and perform than others; 4) some refuse to believe they are different so to not identify with negative connotations.</td>
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<tr>
<td>CTPS 2: Reactions to diagnosis</td>
<td>1) Personal level: a) positive: relieved to finally have explanation of condition b) negative: confirms something is wrong with them; 2) Public level: a) fear of stigmatization if disclosed b) minority of them believe disclosure would bring beneficial support.</td>
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<tr>
<td>CTPS 3: Emotional aspects</td>
<td>Lack self-esteem, need to feel accepted, experience task-oriented anxiety and traumatic public embarrassment. These experiences leave them with emotional insecurities throughout life.</td>
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<tr>
<td>CTPS 4: Contending</td>
<td>Perseverance, invest in alternative areas and avoid areas of incompetence. Contending strategies depend on social support and educational opportunities.</td>
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<tr>
<td>CTPS 5: Finding a niche</td>
<td>Important to increase self-esteem by finding niche in a) friendship, b) academic setting, as well as c) career.</td>
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The current research aimed to uncover the life experiences of individuals living with dyslexia in Malaysia via a phenomenological study of exploring issues relevant to the Malaysian context; thus providing basic information that might be useful for local intervention efforts. The research question of the study was: What are the life experiences of individuals living with dyslexia in Malaysia? The researchers expected individuals living with dyslexia in Malaysia to have experiences common to the themes gathered from past studies as well as to have experiences unique to the local context.

2. Approach and Design

A phenomenological approach was adopted for this current study in order to: 1) explore the dyslexic individuals’ conscious experience of their everyday life and social interactions (Groenewald, 2004), 2) describe the basic structure of these experiences and its meaning, and 3) bracket the primary researcher (Chan Oga)’s own experience of being a dyslexic before embarking on the study so as to put aside personal prejudices, viewpoints and assumptions (Merriam, 2009).

Individual semi-structured interviews were selected as the most appropriate method of data collection as they allowed the participants to express their experiences and life accounts freely from the open question approach (Neuman, 2006). This approach also enabled participants to elaborate on their experiences. See appendix for the range of questions asked.

Five participants were recruited to the study. They were required to be at least 18 years old, to have been formally diagnosed with dyslexia, to be proficient in English and to be Malaysian citizens as well as experiencing dyslexia in the local context. As dyslexics are a highly unrecognized population in Malaysia (Rohaty Majzub, 2000; Thaneswari Sankaran, 2006; Zaid, 1999;), the participants were purposively sampled.

The procedure of the study was as follows: firstly, the primary researcher bracketed her own preconceptions about dyslexia, acknowledging the uniqueness of each participant and consciously avoided uncovering similarities
between participants or between the participants and herself; and, secondly, the individual interview was conducted either face-to-face or via e-mail and in which the opening question “What are your life experiences as an individual living with dyslexia?” was asked, followed by probe questions to get more in-depth information.

3. Data Analysis

The phenomenological analysis was adopted using the following procedure: 1) bracketing of primary researcher’s preconceptions; 2) listening and verbatim transcribing of the audio-recording of each interview; 3) extracting units of meaning from each interview and clustering common themes together; 4) e-mailing or calling each participant for validity check of extracted themes; 5) clustering common themes between transcripts to form major themes and subthemes; and finally, 6) getting participant verification of the major themes and subthemes.

4. Findings

Themes and subthemes of life experiences of individuals living with dyslexia in Malaysia that emerged are summarized in Table 2.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
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<tr>
<td>Theme 1: Subjected to the watchful eyes of others and their negative reactions</td>
<td>Incidences of public embarrassment; subjected to punishment, skepticism and name calling; being misunderstood (e.g. as lazy); subjected to misconceptions of dyslexia (e.g. equated to retardation); people’s ignorance of the condition.</td>
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<tr>
<td>Theme 2: Receiving support</td>
<td>Support from friends, colleagues, family &amp; professionals.</td>
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<tr>
<td>Theme 3: Encountering difficulties in academic related areas</td>
<td>Problematic spelling, writing, reading and speaking (i.e. replacement, inversion, misplacement, skipping letters/words/lines and difficulty to express self, slow); poor concentration; language discrepancy (i.e. face difficulties in one language but not another); difficulties in arithmetic, academic inconsistency and being slower than others.</td>
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<tr>
<td>Theme 4: Reactions towards the condition of being dyslexic</td>
<td>Attitude towards diagnosis (those who were diagnosed during childhood were apathetic, those who were diagnosed at later years were relieved with their diagnosis); selective willingness to disclose condition (disclose if important or asked; do not disclose to competitors, non-empathetic individuals); good feelings when accomplished; a mass of negative emotions (i.e. embarrassment, frustration, regret, fear, stress and task-anxiety, giving up, upset, inferior); needing to cope (i.e. with acceptance and optimism, avoidance, improvising strategies, assistance and compensating areas of incompetence with areas of competence).</td>
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<tr>
<td>Theme 5: Poor sense of orientation.</td>
<td>Poor sense of direction, poor body coordination, and poor memory.</td>
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<td>Theme 6: Areas of strength and/or passion</td>
<td>Good in art and creative work; some are high academic achievers; outstanding personality (i.e. confident, persevering, initiative, exceptionally optimistic and have great people skills); problem solving using own methods; possess great passion for career (e.g. interior design, teaching, hospitality and forestry).</td>
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5. Discussion

As expected, individuals living with dyslexia in Malaysia shared experiences that were similar to those from previous studies. However, there was one experience that appeared unique to the Malaysian context which was evident from Theme 1 (being subjected to the watchful eyes of others and their negative actions). The underlying issue behind this experience could be the lack of awareness regarding dyslexia in Malaysia. An increased awareness of the condition could help alleviate the difficulties these individuals experience.

In developed countries such as the UK, (Hammond & Hercules, 2003), there is a much greater awareness of dyslexia that is accompanied by a greater level of educational support than is the current case in Malaysia. In Malaysia, a level of ignorance exists regarding dyslexia and educational opportunities for this population are scarce; hence interventions to support dyslexic individuals are currently insufficient. However, there have been some advances in this area. For example the Dyslexia Association of Malaysia now provides assistance in the welfare of children and adults with dyslexia, and efforts have been made to raise awareness via seminars and workshops. In
addition to this, the Ministry of Education allocates special classes for dyslexic students in order to enable them to master reading, writing and arithmetic (Utusan Malaysia Online, 2011). Additionally, dyslexic students are allowed extensions for examinations.

There are three main limitations in the study: 1) the primary researcher’s own experience of being dyslexic: although bracketing was done to ensure her preconceptions did not influence the interpretation of the current study, she acknowledges that bracketing was not fully achieved in the process of interpreting and reporting participants’ experiences. Multiple interpreters could be used to increase objectivity of interpretation in future research; 2) Reliance on self-report: experiences shared by participants are subjective. There may be a tendency for bias or selective sharing in which certain unpleasant experiences may not have been shared (Morris & Turnbull, 2006). A possible way to overcome the complete reliance on subjective self-report in phenomenological studies could be to use a different qualitative approach such as a case study which could allow a greater perspective of an individual experience; 3) Sample limitations: the sample was not representative of all dyslexics in Malaysia because participants only consisted of those who were a) English speaking - those who do not speak English were not included and may have different experiences; b) from homogenous socioeconomic background - those from other socioeconomic backgrounds may have different experiences (McNulty, 2003); and c) time constrains to carry out the study limited the number of participants recruited to this research. Another limitation was that of time allowed for interpretation of the data. One suggestion to overcome sampling difficulties could be to employ research assistants who could recruit participants from different language and socioeconomic backgrounds, as well as providing assistance with the transcribing of interview data.

6. Conclusion and Implications of Study

The study uncovered six themes of experiences of dyslexics in Malaysia in which five of these themes reflect the common experiences of dyslexics studied abroad and one theme that describes the unique experience of the five Malaysian dyslexics studied. The lack of awareness of Malaysians about dyslexia may be the underlying issue behind many of the experiences reported. The findings imply that there is a need to 1) increase efforts to instill awareness of dyslexia in Malaysia in the education sector and in the general public; 2) educate the public about the nature, limitation as well as the potential of individuals with dyslexia; 3) rectify the education system that marginalizes the educational opportunities of dyslexics. The current study has only revealed the tip of the iceberg of the life experiences of individuals living with dyslexia in Malaysia. Further research is required for more in-depth understanding of dyslexics in this country.

Acknowledgement

The authors would like to gratefully acknowledge Sharon How, senior lecturer, Department of Psychology, HELP University, for proof-reading this paper.

References


**Appendix: List of interview questions**

**Opening Question:** Life experience is defined as the events, emotions and thoughts lived through by an individual. What are your significant life experiences as a person living with dyslexia?

**Probe Questions**

1) Have you ever felt different from others around you? If yes, could you describe it?
2) What was your reaction when you received the diagnosis of dyslexia?
3) How do feel about people knowing that you have dyslexia?
4) As a person living with dyslexia, could you describe your feelings?
5) How do you cope with living with dyslexia?
6) Niche is defined as a comfortable position in life. How is it like, finding a niche among
   a. your social network (i.e. friends, playmates, acquaintances)
   b. education (i.e. in classroom setting, finding the right subjects/ course)
   c. career (i.e. finding a career path, achieving the career)?
7) Is there anything else that you would like to share?