The Experience of Parenting a Child With Dyslexia: An Australian perspective

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Abstract
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Keywords
dyslexia, parenting, Australian perspective, personal empowerment, disability, interpretational phenomenological analysis, IPA

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The Experience of Parenting a Child With Dyslexia: An Australian perspective

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Dyslexia is a complex multi-faceted concept that hinders literacy development across the lifespan. Literature reports that parenting a child with dyslexia can be traumatic. This qualitative study begins to bridge a gap in the literature to explore the experience of parenting a child with dyslexia in Australia. A small homogenous sample of five mothers participated in an individual one-off, semi-structured, audio-recorded interview. Using interpretative phenomenological analysis, the overarching core of the participant’s experience was ‘A long difficult journey toward personal empowerment’. Five themes conceptualised this journey: grieving the loss of normal; fierce but reluctant warriors; navigating system failures; the changing sense of self; and hope for the future. This is the first known study to apply disability literature and a model of psychological empowerment (PE) to explain the evolving nature of parenting a child with dyslexia. Future research, therefore, could expand these findings across wider demographic samples to further validate these findings and inform the development of relevant support services to assist parents in the long difficult journey of parenting a child with dyslexia in Australia.

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**Defining dyslexia**
Dyslexia is a highly contentious concept (Nugent, 2008). Over several decades experts have strongly debated the constitution of ‘dyslexia’ (Elliott & Grigorenko, 2014) without reaching consensus regarding specific criteria for research, diagnosis and the underlying processes (Bell, McCallum & Cox, 2003). Literally, the word dyslexia is of Greek origin, meaning the condition of having an impairment (dys) using words (lexicon) (Berninger, Richards & Abbott, 2015). A core feature lies in phonological processing (Vellutino et al., 2004) or encoding and decoding words (Snowling, 2013). This, in turn, impacts more specifically on the acquisition of skills, particularly in reading and spelling (Thompson et al., 2015).

While dyslexia can occur across all levels of intelligence (Rose, 2009), difficulties in skill acquisition have been historically explained by a discrepancy model of dyslexia (Shaywitz et al., 1990). In this model intelligence is of average ability but, despite conventional classroom experiences (Bishop & Snowling, 2004), there is an unexpected difficulty in acquiring reading skills (International Dyslexia
Association, 2013). Children who do possess average intelligence but symptomatic dyslexic reading are frequently misunderstood as unintelligent and lazy (Thompson, Bacon & Auburn, 2015). This is due to difficulties in phonological processing also being implicated in the development of wider language skills (International Dyslexia Association, 2013). For example, poor automaticity impedes fluency and reading comprehension (Peterson & Pennington, 2015), which decreases reading experiences, thus affecting the growth of vocabulary and acquisition of knowledge (International Dyslexia Association, 2013). Similarly, poor spelling affects the development of writing skills (Youman & Mather, 2013).

While a deficit in phonological processing is a characteristic feature of dyslexia, it does not encompass the whole concept (Snowling, 2013). Further characteristics may include deficits in verbal memory and verbal processing speed (Rose, 2009). This is evidence that dyslexia is rooted at a neural-level dysfunction (Moreau & Waldie, 2016). This is supported by the use of functional magnetic resonance imaging (fMRI) (Raschle, Chang & Gaab, 2011) with a differentiated pattern of blood flow and brain activation being established between participants with and without dyslexia during reading tasks (Bell, McCallum & Cox, 2003). Twin studies support this neurological basis as a genetic factor as well as supporting a second, equally important, environmental basis (Berninger & Richards, 2010). Dyslexia, therefore, may be thought of as a complex behavioural outcome of multiple risk factors, both genetic and environmental (Hulme & Snowling, 2009).

This is reflected in the the Diagnostic and Statistical Manual (DSM-V) (American Psychiatric Association, 2013), which places dyslexia within the broad category of ‘neurodevelopmental disorders’ as a descriptive subset of reading within ‘specific learning disorders’. This acknowledges the fact that dyslexia is difficult to identify as a discrete diagnostic category (Snowling, 2013). There is potential to have multiple interpretations of the term (Serry & Hammond, 2015) due to inconsistent operational definitions in the literature (Macdonald, 2009). This lack of consistency stems from the complex interactions between genetic and environmental factors and the highly individual presentation of symptoms (Hulme & Snowling, 2009).

Overall, dyslexia is a complex, multifaceted concept (van der Leij, 2013) that hinders literacy development in both children and adults (Youman & Mather, 2013) and remains persistent across the lifespan (Snowling, 2013). Without consensus regarding the specific definition, empirical and practical definitions will continue to have different foci and employ different assessment procedures (Tonnessen, 1997). It is, therefore, important to be aware of the individual strengths and weaknesses of each student (Wennäs Brante, 2013) and to tailor intervention for individual learning needs (Moreau & Waldie, 2016). There is no ‘one size fits all’ for dyslexia, instead, evidence-based differential diagnosis is required for relevant treatment to be implemented (Berninger, Richards & Abbott, 2015).

Labelling dyslexia

In reality, the effects of dyslexia go beyond biological or genetic mechanisms to include psychosocial and cultural processes, which are influenced by society’s reactions to the term (Elliott & Grigorenko, 2014). There is debate, therefore, as to whether or not it is relevant to distinguish and label students as dyslexic, as the term itself does not provide any clear basis for intervention (Gibbs & Elliott, 2015). It can
be argued that the term and associated diagnosis of dyslexia creates confusion for parents, teachers and professionals, as the emphasis is moved from teaching methods to assessment and diagnosis of a specific controversial subgroup (Elliott & Grigorenko, 2014). However, a dyslexia label may be a positive and anticipated relief after a long battle to come to terms with a child’s difficulties (Earey, 2013), as it provides a more-specific explanation than ‘learning disabled’ (Thompson, Bacon & Auburn, 2015). It may also relieve parents of blame regarding the child’s difficulties with reading (Ho, 2004).

Further benefits of obtaining a label of dyslexia may include access to specific specialist services (Cameron & Billington, 2015), technology and support, which otherwise would be refused if the child were seen as a low achiever (Ho, 2004). Accommodations may be available, such as longer time to complete exams (Skinner, 2011), access to predictive spelling programs or a note taker (Mullins & Preyde, 2013), while a formal psycho-educational assessment may enable eligibility for support through government-funded schemes for students with disabilities (Harkin, Doyle & McGuckin, 2015). A further significant factor is that a diagnosis of dyslexia may enable ownership of the label, separating reading difficulties from intelligence (Glazzard, 2010) and assisting students to the realisation that, as learners, they are not stupid, thick or necessarily lazy (Glazzard & Dale, 2015).

On the other hand, the negative effects of labelling dyslexia may include academic underachievement and the risk of psychosocial problems (Green et al., 2009). Evidence suggests that many students with dyslexia in mainstream schools do not receive optimum academic support and as a result struggle to keep up with their non-dyslexic peers (Nalavany, Carawan & Brown, 2011). Students with dyslexia need to work harder for their grades (Bishop & Snowling, 2004), investing considerable time in homework and studies (Wennås Brante, 2013), but the results seldom reflect the input of work (Bishop & Snowling, 2004). This may lead to dealing with issues such as low self-esteem, prejudice and time pressures (Wennås Brante, 2013) with school stress being a related consequence (Undheim & Sund, 2008).

**Psychological impacts**

Students with dyslexia show increased levels of emotional difficulties and lower opinions of their scholastic competence than their non-dyslexic peers (Snowling, Muter & Carroll, 2007). Years of repeated struggles with reading manifest in signs of stress, worry, fear and anxiety (Carroll & Iles, 2006) when placed in situations requiring literacy, especially relating to interactions with teachers and examinations (Alexander-Passe, 2008). With the negative impact of teacher accusations of unintelligence well documented (Thompson, Bacon & Auburn, 2015), criticisms take an emotional toll, often causing self-deprecation and students giving up after multiple failures (Kannangara, 2015). This may result in the alienation of a young student with dyslexia as they fail academically and fail to be recognised as needing help (Alexander-Passe, 2008).

Learning to read is a key developmental task of early childhood with success or failure occurring within the public setting of the classroom (Maughan et al., 2003). At school, social factors and academic achievements intertwine with academic peers often forming an integral part of social networks (Carroll & Iles, 2006). Students labelled as dyslexic often feel isolated and rejected in their schools (Glazzard, 2010),
as well as bullied (Skinner, 2011), ridiculed and ostracised from their classmates (Carroll & Iles, 2006). This can lead to lower self-esteem (Burden, 2008) and poor mental health outcomes for students, with links between severe, persistent dyslexia and risk of depression (Maughan et al., 2003).

Students with dyslexia may choose to cope with their constant high-anxiety levels by either avoiding stressful situations requiring literacy skills or engaging in other distracting behaviours (Kannangara, 2015). This behaviour often degenerates from academic failures to social liabilities in adulthood, creating great individual, family and social difficulties (Riddick, 2000). Many adults with dyslexia describe their early school experiences as traumatic, with recollections of feeling different, inferior and ashamed (Nalavany, Carawan & Brown, 2011). With societal barriers continuing to influence aspirations and opportunities beyond school (Thompson, Bacon & Auburn, 2015), people with dyslexia are often being required to re-adapt to the difficulties they had struggled with and overcame in schooling across the lifespan (de Beer et al., 2014). Therefore, it is not as simple as analysing whether formal labelling is constructive or destructive, as there are often positive and negative issues in each case and at the different stages of life (Riddick, 2000).

**Parental impact**

Dyslexia represents significant challenges not just for the student but can also be traumatic for their parents (Elliott & Nicolson, 2016). Given that learning to read is a fundamental core skill of schooling and becoming literate opens doors to education, employment and adult wellbeing (Snowling & Hulme, 2012), parents of students with dyslexia show higher levels of anxiety than parents of non-dyslexic students (Snowling & Melby-Lervag, 2016). Parents experience stress in coping with their child’s apparent poor academic progress (Karande & Kuril, 2011), particularly if they lack understanding of the dyslexic implications (Karande et al., 2009). Mothers, in particular, show higher levels of stress and depression and report significant impacts on family (Snowling, Muter & Carroll, 2007) and increased difficulties in everyday life (Bonifacci et al., 2014).

The most-common maternal worries involve both emotional and practical difficulties (Earey, 2013), as their child’s chronic poor performance at school relates to the child losing self-esteem, getting frustrated and developing withdrawn or aggressive behaviour (Karande et al., 2009). In addition, maternal anxiety is increased when attempting to seek appropriate help for their child (Earey, 2013) especially when bureaucratic processes appear to move slowly in providing effective interventions to help students overcome dyslexic difficulties (Rose, 2009). Mothers, by necessity, become advocates for their child (Poon-McBrayer & McBrayer, 2014) and are frequently required to face school teachers who appear uncooperative and unconcerned about their child’s dyslexia (Karande et al., 2009) requiring parents to return repeatedly to the schools to remind them of their child’s needs (Earey, 2013).

Mothers become emotionally and physically drained as they become heavily involved in their child’s remedial education (Bonifacci et al., 2014) and worry for the child’s future (Karande et al., 2009). Many mothers choose to quit their jobs to focus their energy and time attending to their child (Poon-McBrayer & McBrayer, 2014). Overall, the literature reports ongoing difficulties for parents as they struggle to support their child before, during and after the assessment of dyslexia (Earey, 2013).
Ongoing chronic stress can lead to negative parenting practices and adversely affect the parent–child relationships and outcomes (Karande & Kuril, 2011). Poor attachment to parents by students with dyslexia may be due to a higher load of schoolwork straining the relationships within the family (Undheim & Sund, 2008). This is then compounded by higher parental distress related to the perception of having a relationship with a ‘difficult child’ (Bonifacci et al., 2014). Parental awareness of dyslexia as a lifelong disorder would empower parents to guide their child through to adulthood (Karande, Mehta, & Kulkarni, 2007) and provide ongoing support to reconcile the complex array of emotions that are inherent in living with dyslexia (Nalavany & Carawan, 2012).

Family support, therefore, can be a protective factor that may positively impact self-esteem (Nalavany, Carawan, & Rennick, 2011). Parents who support the strengths of their child help to provide the opportunity for more-positive outcomes (Kannangara, 2015), which is important, because the perception of support in childhood is related to satisfaction with adult life (Nalavany & Carawan, 2012). The ability to become a team and offer mutual support to each other (Poon-McBrayer & McBrayer, 2014) enhances feelings of being understood and accepted that can bring confidence and improvements in study attitude and even enhance performance in children with dyslexia (Tsang & Leung, 2006). Realistic parental expectations are reflected in the child’s own educational expectations and, in turn, their academic achievement (Rimkute et al., 2014). The existing literature overwhelmingly shows the significance of a supportive home environment (Karande, Mehta & Kulkarni, 2007) and parent involvement regarding the educational achievement of children with dyslexia (Poon-McBrayer & McBrayer, 2014).

This means that parents are often at the front, driving to get assistance for their child (Alexander-Passe, 2008). Many parents spend considerable time and resources in gaining access to assistance (Macdonald, 2009), seeking help outside the school system (Rose, 2009). Assessments and remedial education for dyslexia are expensive (Karande, Mehta & Kulkarni, 2007) and often beyond the financial means of students and their families (Harkin, Doyle & McGuckin, 2015). This then disadvantages children with dyslexia from working-class families and families with low socioeconomic backgrounds who are unable to pay for this support (Gillies, 2005). The literature suggests that this appears to be an international issue, with similar discrepancies reported in England, USA, Ireland and Australia, as well as having been reported by the United Nations (Earey, 2013). The Rose report (Rose, 2009) from the United Kingdom highlights the importance of parents knowing that they are getting the best possible support for their child at school. In reality, however, children are largely supported due to their parents’ intervention and persistence (Oga & Haron, 2012) and, even then, not as well as the parents would like (Earey, 2013).

An Australian perspective
Dyslexia is the most common neurobiological disorder that affects the development of reading and spelling skills (Youman & Mather, 2013). It is estimated that as high as 10% of the student population experience dyslexia worldwide (Bodea Hategan, Talas & Monsneag, 2015) with impairment associated with dyslexia being universal across languages (Thomson, Leong, & Goswami, 2012). Despite multiple international
studies, however, there are no current prevalence estimates for dyslexia in Australia (MacCullagh, 2014).

One Australian study shows that educators in Australia have a generally high level of accurate, research-based knowledge about dyslexia and how to support individuals with significant reading issues (Serry, & Hammond, 2015). Theoretically, this should provide greater assistance for students with dyslexia in Australian classrooms, however, there is a major gap in the literature with regard to Australian students with dyslexia (MacCullagh, 2014). Internationally, there is a lack of empirical data and, significantly, a dearth of information about the views and experiences of children and parents (Nugent, 2008). Nalavany and Carawan (2012) recommend that future research should include the voices of parents to further understand their experiences and perspectives.

In order to start bridging the gap in the literature, this study aims to explore the question: ‘How do parents experience parenting a child with dyslexia in Australia?’ Qualitative methodology using interviews with interpretative phenomenological analysis (IPA) will provide rich, in-depth data to give voice to parents’ experiences from an Australian perspective.

Method

This research uses qualitative methods to allow an in-depth exploration of subjective personal experience (Willig, 2013). While quantitative methods seek to measure specific characteristics from an impartial or objective perspective (Smith & Rhodes, 2015), phenomenological qualitative methods seek meaning and understanding gleaned from complex human dynamics (Pritchard & van Nieuwerburgh, 2016). Interpretative phenomenological analysis (IPA) is a rigorous (Smith, Flower & Larkin, 2009) qualitative methodological framework (Pietkiewicz & Smith, 2012) that provides guidelines ideal for dynamic, contextual and subjective topics (Smith, Flower & Larkin, 2009) such as the experience of parenting a child with dyslexia. The issues of importance then relate to identity, the self and sense making of that lived experience (Smith, 2004).

IPA is informed by three fundamental principles: phenomenology, hermeneutics and ideography (Pietkiewicz & Smith, 2014). Phenomenological epistemology aims to bring out the full richness of description (Brocki & Wearden, 2006) and capture the true essence of lived human experience (Finlay, 2011). A phenomenological attitude is a disciplined way of seeing with fresh, curious eyes (Finlay, 2014), and it is the core element distinguishing phenomenology from other research approaches (Rhodes & Smith, 2010). With a disciplined attitude, the researcher becomes fully engaged in exploration (Smith, 2011) and interpretation of the experience (Smith & Rhodes, 2015).

Hermeneutics is the theory of interpretation used in IPA (Smith et al., 2009). Experience is represented by language (Brocki & Wearden, 2006) and is interpreted and understood within a relational context (Wertz, 2011). The interpretation begins with how the participant makes sense of their own world (Smith, Flower & Larkin, 2009) and then revolves and intertwines with interpreting how the researcher makes sense of the participants making sense of their own world (Smith & Osborn, 2008). The analysis becomes a process of dual interpretation or double hermeneutics (Pietkiewicz & Smith, 2012). Cyclic interpretations of questions and answers
(Eatough & Smith, 2007) provides an evolving understanding that further draws out how the participant themselves finds meaning in their experience (Smith & Osborn, 2008). Relationships between implicit pre-understandings and more-explicit understandings emerge (Smith, Flower & Larkin, 2009), as the researcher is actively involved in this dynamic process (Smith, 2011), influencing the extent to which each participant’s experience can be accessed (Brocki & Wearden, 2006).

Through an ideographic lens (Smith & Rhodes, 2015) the researcher focuses in great detail on each case individually before moving cautiously toward more general conclusions (Eatough & Smith, 2007). This necessitates small numbers of purposive (Smith & Osborn, 2007), homogenous samples of participants (Smith & Osborn, 2008) with common characteristics and experiences (Callary, Rathwell & Young, 2015). Through purposive sampling, therefore, IPA finds a more-closely defined group for whom the research question will be significant (Smith & Osborn, 2008). This then supports greater depth in understanding (Smith, Flower & Larkin, 2009) of the experience of the participants’ individual perspectives (Smith & Rhodes, 2015) within their unique contexts (Pietkiewicz & Smith, 2012). For a small-scale study, between three and six participants are ideal for ideographic detail (Smith, Flower & Larkin, 2009).

With small numbers of participants (Smith & Osborn, 2007) and language as a core of understanding in IPA (Brocki & Wearden, 2006) semi-structured interviews provide a method of data collection that provides maximum opportunity for richer, authentic data to be obtained through dialogue (Smith & Osborn, 2008). With an ideographic focus on individual experience, a flexible interview schedule with broadly constructed questions allows for unanticipated themes to emerge (Callary, Rathwell, & Young, 2015). A semi-structured approach allows a skilled researcher to investigate in more detail with further pertinent questions (Pietkiewicz & Smith, 2012).

**Participants**

This study used qualitative IPA as an ideal methodology to explore in detail a small number of experiences of parenting a child with dyslexia. Participants were parents who had at least one child diagnosed with dyslexia and resided in Australia. Due to the wide variation in the definition of dyslexia (Elliott & Grigorenko, 2014), the inclusion criteria required that a professional had assessed and diagnosed the child as dyslexic. Professionals in this study included paediatricians, psychologists and dyslexic specialists with a postgraduate diploma in dyslexia. In addition to this, without exception, parents had also sought further confirmation of the diagnosis and intervention for dyslexia. These included other services offering dyslexic-specific intervention, such as behavioural optometrists and tutors, or specific dyslexia treatment and management techniques, such as Alison Lawson Centres and Irlen Clinics. The participant’s length of experience since the initial diagnosis of their first child with dyslexia ranged 4–12 years, with four of the five participants having more than one child diagnosed as dyslexic.

Demographically, by coincidence, all participants were Caucasian, middle-class mothers, aged 40–49 years. Four participants resided in New South Wales and one participant was from Queensland. Informed written consent was obtained prior to commencement of data collection with confidentiality assured by the use of
pseudonyms. Participation was voluntary, with no incentive offered, and participants were able to withdraw at any time without penalty.

**Procedure**

Ethics approval was obtained from the relevant authorities and complies with the stated requirements. Flyers outlining the research were distributed by specialised dyslexic tutoring services to their clients as well as posted to parents known to have a child with dyslexia. Parents registered their willingness to participate by responding via email, at which time they were sent by return email a participant information sheet. This provided further details explaining the aims and requirements as well as potential risks and benefits. Five responses were received, with all agreeing to be interviewed. This represents a suitable sample size for IPA analysis (Smith & Osborn, 2007).

Data was collected using semi-structured interviews (Smith, Flower & Larkin, 2009). A flexible open interview schedule was designed with four main questions and several prompt options. The main questions were: ‘What were some early indications you noticed that your child may have had difficulties with reading?’; ‘How did you go about seeking help for your child?’; ‘What has been the outcome to date for your child?’; and ‘What advice would you give to other parents who suspect their child may have dyslexia?’ The central focus of the interview was to prompt the participant to tell their experience of parenting a child with dyslexia from the earliest suspicion or detection of dyslexia to the present time. Participants were involved in a one-off, audio-recorded, semi-structured interview with the researcher. Interviews were in the range of 45–90 minutes duration. Four interviews were conducted face to face in a location convenient to the participant, while one was conducted by telephone. All five interviews were transcribed verbatim by the researcher using pseudonyms to protect confidentiality.

**Data analysis**

An IPA four-stage guideline of analysis – as described by Smith, Flower and Larkin (2009) – was used to explore the transcripts. Firstly, detailed ideographic analysis began with each transcript treated independently with several close readings. Exploratory notations including descriptive, linguistic and conceptual comments were then recorded in the margin of the transcript. The second stage involved identifying emergent themes that captured the essential quality of the individual transcript with these notated in the opposite margin. The third stage linked and labelled crucial themes. This process was repeated several times for each of the five transcripts individually before finally collating and analysing patterns across all transcripts to create super-ordinate or master themes that conceptualised the data to capture the core themes of the phenomenon as a whole. This was again checked against the original data to ensure authenticity.

**Results and discussion**

The overarching core of the phenomenon of parenting a child with dyslexia in Australia was: ‘A long difficult journey toward personal empowerment’. Five themes emerged from the data that evidenced and conceptualised key components of this journey. These were: grieving the loss of normal; fierce but reluctant warriors;
navigating system failures; the changing sense of self; and hope for the future. Each of these five themes will be presented and discussed in relation to existing literature and models. Transcript extracts are provided verbatim as evidence for each theme. Original grammatical and speech errors are maintained in the extracts to ensure the transparency of interpretation and to accurately present the true essence of the participant’s voices. Discussion of the five themes will be followed by the wider implications of this study and conclude with suggestions for future research.

**Theme 1: Grieving the loss of ‘normal’**

From the data there was a strong sense of parents grieving:

> dyslexia is a disability that impacts in – in a big way – in a completely different way to if it was some kind of physical disability – and I think in some ways that almost makes it harder because you try and live a normal life and pretend it’s all normal when actually it isn’t normal. (Heidi)

While dyslexia is categorised as a ‘disorder’ in the DSM-V (American Psychiatric Association, 2013), Heidi labels dyslexia as a ‘disability’, a disability that is harder to accept than a physical disability because it is not as concrete in identification (Bell, McCallum & Cox, 2003) or as obviously visible (Earey, 2013). Viewing dyslexia through a lens of ‘hidden’ disability suggests that participants identified significant impairment (Wennås Brante, 2013) or a ‘wrongness’ that interrupted the expected continuation of normal development (Cologon, 2016). The participants grieved the loss of this normality in their children (Allred & Hancock, 2012). Pippa laments the day when she first took her son for an assessment:

> Matthew cried in the back of the car the whole way – I cried in the front of the car – mum cried – we got over there – the tutor we’d never met looked at it – she started doing something – she just said – I have nothing to work with – she couldn’t assess him – because there was nothing there. (Pippa)

Needing an assessment from a professional and finding ‘there was nothing there’ was not only heart breaking for the participant but posits dyslexia as a disability within a medical model or deficit model where something is broken or missing and needs fixing (Cologon, 2016). A medical model purports that an external source is the only means of intervention to change a child so that they ‘fit in’ with society (Runswick-Cole, 2008). In reality, however, ‘experts’ are not able to ‘fix’ the manifestations of dyslexia to match society’s expectations (Snowling, 2013). As a result of this discrepancy, frustration at this point in time was a common theme.

> we could tell – just that he was a bit slow – to catch on to reading – just seemed to be a bit of a fog really – we thought he just didn’t seem to – click with it … he’d go over things again and again and again and he just wouldn’t get things. (Ruth)

Without exception, it was during their child’s first year of formal schooling, at age five or six, when participants identified a deficit. This is consistent with the existing literature (Bishop & Snowling, 2004). Australian children with other common developmental disabilities, however, such as autism spectrum disorder
(ASD), are usually diagnosed before commencing school and typically access ‘early intervention’ services (Gavidia-Payne, Meddis & Mahar, 2015). These are well-coordinated, specialised support services aimed at facilitating smooth transitions between home and school (Aytekin & Bayhan, 2016). Heidi expresses her frustration at the lack of similar services for dyslexia:

> at the moment in Australia there’s just not any clear avenues – at all – and it feels like there’s – there’s a whole industry of people – all working away with kids that fit into this broad bucket and no-one’s interacting properly – which just leaves parents at sea. (Heidi)

Despite a similar prevalence to ASD (Mulligan et al., 2012), there are no clear paths for diagnosis or intervention for parents of children with dyslexia in Australia. This may be due in part to the lack of consensus regarding the specific criteria for dyslexia (Bell, McCallum & Cox, 2003). Sarah explains how deeply she was affected by an overwhelming sense of hopelessness in the early years of her experience without support:

> plenty of times I have sat on my couch out there and not been able to leave the house because I’ve been so desperate … so alone – nobody I could even ask for help or knew how to help or anything. (Sarah)

Problems accessing needed services leave parents feeling defeated and stressed (Krauss et al., 2001) and at significant risk of psychosocial distress and decreased quality of life (Feldman et al., 2007). Therefore, creating supportive environments for parents is vital for positive adjustment (Resch, Benz & Elliott, 2012), however, this appears to be lacking for parents of children with dyslexia in Australia. Sarah continues her story, blaming herself for not knowing what to do to help her son:

> so I have had plenty of times where I have felt very very bad and very bad for him just cause I just keep sending him – I just keep sending him – you know – into a place that’s just – not … right and quite damaging to him as well but what do you do – there wasn’t a better place. (Sarah)

Parents frequently experience self-blame or guilt, regardless of the nature of their child’s disability (Findler, Jacoby & Gabis, 2016). Without appropriate resources and support, Sarah identifies the very real threat of psychological ‘damage’ (Resch, Benz & Elliott, 2012), but she felt she had no alternative. She is emotionally and physically drained, attempting to cope with her own feelings of guilt and grief as she attempts to help her son (Bonifacci et al., 2014).

From this first theme, grieving the loss of normal, it can be seen that the participants view dyslexia as a disability, which is predominantly a deficit discourse in a medical model (Cologon, 2016). They experienced feelings of grief and guilt that began unexpectedly in their child’s first year of formal schooling. Overwhelming frustration and hopelessness are dominant as clear avenues towards diagnosis and intervention in Australia are lacking which, as Heidi lamented, ‘leaves parents at sea’. As their journey continued through great hardship, the participants began to gain some understanding of dyslexia. As a result, they were able to shift their perspectives
from a medical model to a broader social model of disability, which forms the basis of the next theme.

**Theme 2: Fierce but reluctant warriors**

ey had to poke the bear one too many times and then I just went in 100 percent hard – just smashed it – like and with the backing of the Board of Studies – obviously that gave me the confidence to go we’re OK here – I – I actually do know what I’m talking about and as much as you’re trying to bully me with four people and baffle me with what you’re saying – I’m very clear on what we are allowed to have. (Sarah)

This theme captures the increased confidence participants gained along their journey, by which parents of children with disabilities are more-accurately viewed as adaptive and evolving (Ferguson, 2002). This illustrates a more-sophisticated theory of parental functioning (Hassall, Rose, & McDonald, 2005). As parents armed themselves with information and understanding regarding dyslexia, their position changed from one of grief to one of assertiveness, like a warrior heading into battle for the betterment of their children. Armed with knowledge, all five participants experienced situations where they had to ‘fight’, a position that was outside their personal comfort zones.

I’m going to butt heads there – and if I butt heads enough and bring it up and make it an issue – not rudely – but maybe it will make a path in the future for the other two who are coming up – and my poor Olivia can be the crash test – someone has to pioneer it … if you just sit back every little person suffers. (Gabbie)

Gabbie justifies her actions by pioneering a path for the greater good (DePape & Lindsay, 2015), that of her other two children, also dyslexic, and for all other children with dyslexia at that particular school. The participants have evolved from accepting a simplistic medical model of disability, where dyslexia itself is seen as the disability (Cologon, 2016), to a more-refined perspective, that of a social model (Allred, 2015). Dyslexia is now viewed as separate from the impairment (Ferguson, 2002), only becoming a disability when social barriers are imposed (Llewellyn & Hogan, 2000). In reality, however, the medical model remains dominant and pervasive within society (Cologon, 2016). For example, schools may designate impairment by labelling children with dyslexia as ‘unintelligent’ or ‘lazy’ (Thompson, Bacon & Auburn, 2015), thereby denying assistance to access the curriculum (Cologon & Thomas, 2014). This conflicting view of dyslexia between participants and the education system leaves parents feeling the need to ‘fight’ for the needs of their child in the school setting. Pippa demonstrates her acquired understanding of dyslexia as a socially dictated disability:

you’re not going to treat me like s*** – and you’re not going to and you’re not going to treat my boy … badly … yeah … yeah – and – yeah - but the journey that so many – some of the stories are heart breaking – you know – Matthew will never – and I will work very – he’ll never get all the emotional s*** that the other kids go through. (Pippa)
The participants are beginning to develop psychological tools for combat, or psychological empowerment (PE) (Zimmerman, 1995), which leads to improved personal health and wellbeing (Griffin et al., 2002). Positive psychological adjustments assist in striving toward personally valued goals (Locke & Latham, 2002) as parents become more effective in creating opportunities for their children with dyslexia. Gabbie’s personally valued goal was to ensure her three children with dyslexia received appropriate academic assistance in the classroom:

and for every child I have said – this is our family history – this is what I’m expecting – please tell me what you are seeing – Mia faked it until she was half way through Year One – Olivia was coping until she got to maybe Year Two and then the wheels started falling off – and Jack is still considerably behind – and I picked them all up in Kindergarten [laugh]… So I went straight to the teachers and said you need to do something – these guys are faking it! (Gabbie)

Gabbie demonstrates developing PE as she gains a sense of personal control when striving for positive change for her children (Simonet, Narayan & Nelson, 2015). She actively seeks resources (Zimmerman, 1995) by highlighting the inequity within the education system (Cattaneo & Chapman, 2010), that is, her children are denied curriculum support because they ‘fake’ understanding. Gabbie shows increased self-efficacy, an important intrapersonal aspect of PE (Perkins & Zimmerman, 1995), by positively appraising her own ability and confidence to effect change in the school environment (Vuorenmaa et al., 2014). She capably challenges her children’s teachers regarding their actual academic progress. Sarah also demonstrates her developing PE:

and then I used all those words – discrimination, disability blah blah blah – human rights issue as well … all of a sudden they all wanted to be my friend … from that I said to them – a learning plan should have been put in place for him before this – he’s not had one – you should have given him one – I’m now demanding one. (Sarah)

Sarah demonstrates an interactional component of PE (Cattaneo & Chapman, 2010). She highlights her understanding of the legal implications of ‘discrimination’ and ‘human rights’ to reduce the marginalisation of her son in the school setting (Peterson, 2014). She perceives her interaction in that setting needs to be ‘demanding’ in order to achieve success (Cleary & Zimmerman, 2004). Therefore, Sarah, as with all the participants, developed a critical awareness of the school environment by identifying causes contributing to perceived problems (Zimmerman, 1995), and so, by addressing these problems, increases her effectiveness in that particular setting (Cleary & Zimmerman, 2004). Heidi relates her experience:

but we knew she needed some sort of label before she started school in order that it could be recognised within the school community – and we didn’t want the experience of starting school – especially knowing that home schooling isn’t always looked upon favourably – we didn’t want home schooling to be blamed for her … lack of skills in reading and spelling … so we had another assessment done. (Heidi)
Heidi demonstrates competence in a behavioural component of PE (Cleary & Zimmerman, 2004). She responds to her critical awareness, that the school as a social system imposes a medical model of disability, by obtaining a medical assessment prior to her daughter re-entering the education system for high school. Heidi, therefore, takes specific proactive action (Zimmerman & Warschausky, 1998) with the aim to positively influence the school environment (Peterson, 2014).

This second theme, fierce but reluctant warriors, demonstrates that the participants have evolved from a position of grief and guilt (Findler, Jacoby & Gabis, 2016) to a position of confidence (Cleary & Zimmerman, 2004). PE (Zimmerman, 1995) explains this evolution through intrapersonal, interactional and behavioural components (Peterson, 2014). Participants have begun to understand the socially imposed impairment (Allred, 2015) and are prepared to fight to overcome this perceived inequity for their children (Cattaneo & Chapman, 2010). At this point in time, critical awareness and interaction with the school environment (Damen et al., 2016) has taught participants to ‘demand’ rather than negotiate. With further evolution, however, the participants attempt to build positive interactions with the school system and this is the focus of the next theme.

**Theme 3: Navigating system failures**

I trusted them – I trusted them and what they were telling me as they were the experts … we’ve got this – you know – we’ll get him there – blah blah blah – he essentially finished primary school as a non-reader – a non-reader – going into high school – absolutely devastating and it wasn’t because I wasn’t on to it – I was on to it from the very beginning … I believed them – I trusted them – I shouldn’t have done that. (Sarah)

This illustrates an undermining of the home–school relationship, as Sarah regrets trusting the ‘experts’ to help her son (Allred & Hancock, 2012). While supportive home–school relationships are considered essential for the welfare of parents and children (Collier, Keefe & Hirrel, 2015), there is a growing consensus that these relationships are often dysfunctional (Hassall, Rose & MacDonald, 2005). Pippa considered herself fortunate that her son’s teacher was willing to learn about dyslexia:

then we came back – and we told (his teacher) and she just said – I don’t understand much about dyslexia – but let’s make this work. (Pippa)

This was an exception within the experiences of the participants in this study, and appears to be dependent on the individual teachers’ attitude. Pippa goes on to contrast this positive response with the response she received from a senior executive within the same school:

she saw me crying – anyway – she said – don’t worry – there’s all this vocational sort of training and everything – he’ll be alright – and that really sent me crazy – I’m like – I’ve got a university degree – I’ve got dyslexia – he is going to have every single choice that we can make. (Pippa)
While the individual teacher was willing to learn about dyslexia by developing a productive relationship based on mutual engagement (Allred & Hancock, 2012), the senior executive imposed stereotypical barriers (Peterson, 2014), assuming that children with dyslexia require a remedial or ‘vocational’ path through school (Thompson, Bacon & Auburn, 2015). Pippa’s experience with the senior executive was indicative of all the participants’ experiences and highlights a home–school relationship enmeshed in the context of school culture (Allred & Hancock, 2012). This stance from within the education system potentially limits intelligent children with dyslexia accessing the curriculum (Peterson, 2014).

Dyslexic kids need different avenues rather than being forced through the same sieve as everyone else – because it’s just unkind and it’s just wasting their time and – yeah – over time they can – learn to function more but they need to – have different expectations placed on them in the first place. (Heidi)

Heidi yearns for greater diversity in learning opportunities to meet the needs of her intelligent, but dyslexic, children (Bishop & Snowling, 2004). While an Australian study shows that educators in Australia have a generally high level of accurate, research-based knowledge about dyslexia (Serry & Hammond, 2015) this does not appear to have translated into best practice in classrooms. Armed with an understanding of ‘system failures’, the participants at this point in their journey learn to navigate around dysfunctional systems for the benefit of their children.

Yeah – I’ve spent an awful lot of money on schools to home school my son [laugh] … that’s the crux of it really – that I’ve spent a lot of money and I’ve pretty much home schooled him and you know they will probably at the end of this go – well look at what we did for him and I will just be silent and go – yeah yeah you did that [laugh]. (Sarah)

The participant’s frustration with dysfunctional systems serves as an important driving force for action (Olin et al., 2010). Sarah demonstrates her successful navigation around dysfunction by educating her son at home, outside of school hours, to ensure he reached his academic potential. Pippa also explains how she plans to navigate around the system:

I think the thing that we’ve got to accept is that – every year is going to have to be – every new teacher and everything – you’re going to have to – you really do have to … make sure – that the information is handed over and – I think you’re always going to have to be an advocate for him – as a parent – I think – and I don’t want to – I thought that we’d be able to get him to a point where he’ll be able to stand on his own – but I – the more I look at it – the more I think that’s always going to have to be – something that we are going to have to do – and that disappoints me. (Pippa)

Consistent with current literature, system failures have necessitated the participants becoming advocates for their children (Poon-McBrayer & McBrayer, 2014). Pippa acknowledges the ongoing nature of her role as advocate, believing that she can challenge the inequities and positively influence resource allocations to gain potential assistance for her son’s individual needs (Holcomb-McCoy & Bryan, 2010).
Evolving self-efficacy has resulted in the participants making positive choices and successfully problem solving to benefit their children (Vuorenmaa et al., 2014).

so – on one level I would love to still have them at home and be able to – avoid school completely for them – but on another level I feel like they’ve been able to … have a richer experience for high school … enjoying the other aspects of school – that school provides – like school plays and school bands – excursions … and leadership opportunities. (Heidi)

While the participants in this study retained academia as an essential goal, they also adapted their expectations (Ho, 2004) to focus on the wider aspects and advantages of the mainstream education system (Runswick-Cole, 2008). A social model perspective of dyslexia means parents are more likely to prefer the inclusive opportunities mainstream education has to offer (Rimkute et al., 2014), such as ‘school bands’ and ‘leadership opportunities’.

I don’t want school to be a place that they don’t like to go to – I want them to like going – I want them to love the social side – I want them to love the learning – like you just listen and talk – you’re learning … I want them to learn how to problem solve – you know – I want them to learn all that other stuff that school brings. (Gabbie)

This theme, navigating system failures, demonstrates the importance of an effective home–school relationship to reduce parental stress and to meet the unique and diverse learning needs of children with dyslexia in mainstream schools (Hedges & Gibbs, 2005). The participants in this study successfully navigated around the perceived system faults by educating their children at home, advocating each year for positive outcomes and focusing on the wider benefits. There is no one size fits all for dyslexia, instead, evidence-based differentiated opportunities and expectations are required to meet the needs of children with dyslexia and their parents in mainstream schools. As the journey continued, the participants themselves adapted and changed, gaining personal growth toward wellbeing (Damen et al., 2016). This will be explored in the next theme.

**Theme 4: The changing sense of self**

fundamentally because Eleanor had – the reading difficulties – that was why we decided to home school even though I’d always been really opposed to home schooling – so that just set a whole direction for our family for nine years – which necessarily implicated me not doing paid work – and even led to us doing foster care cause I was home and – was something we could do – so it’s had – a – massive impact on our lifestyle … not that that’s necessarily been a bad thing. (Heidi)

Consistent with dyslexia literature, Heidi chose to withdraw from the paid workforce to focus on the needs of her children with dyslexia (Poon-McBrayer & McBrayer, 2014). However, contrary to the literature, Heidi did not perceive this as a negative consequence. Instead, by reframing her roles within the family to include that of ‘teacher’ and ‘foster mother’, roles she may not have developed without dyslexia in the family (Peterson et al., 2006), she reflects her increased sense of
personal confidence, competence and knowledge (Minnes, Perry & Weiss, 2015). As all five participants positively reframed their roles within the family, they were able to strengthen their parenting competencies to make decisions that enhanced the wellbeing of themselves and their children (Damen et al., 2016).

and I was like – you know what – we are this close to you getting your HSC – that is something I never thought you’d be able – actually able to do… that is such an accomplishment for us – considering where we’ve come from … we’ve done it – done my HSC for the second time – probably do better this time than last time. (Sarah)

Sarah sensed a change in herself, as she merged life roles with her son as a means to cope with dyslexia (Bonifacci et al., 2014). She sees herself as doing her HSC again as she assists her son through his studies. However, this is framed in a positive manner, with humour, as she uses her strengths to shape and give meaning to her experience (Damen et al., 2016). PE plays a protective role in Sarah’s life as she reflects on the change of focus from ‘fighting’ to ‘achieving’, thus promoting healthy behaviours and outcomes (Peterson et al., 2006).

I think John was adamant he didn’t want to go to uni – (his dad) was keen for him to go to uni – cause he went to uni and I’ve been to uni … and I said well look – it won’t be that he never goes to uni – well it might be that he never goes to uni but - just cause he’s not going now – yeah - so he was – John was completely closed off to the idea of uni – and that did cause some tension. (Ruth)

Ruth’s son with dyslexia challenged the family value of tertiary education. Through tension and stress, Ruth emphasised her personal strengths to experience a personal transformation (Scorgie, Wilgosh & Sobsey, 2004). She was able to adjust her values to accept that her son may never attend tertiary education.

This theme explored the participants’ changing sense of self. In reality, the participants experienced a positive transformation of themselves with changes in personal roles within the family, personal life activities and personal values. The participants positively embraced the unexpected changes in themselves brought about as a direct result of their experiences parenting a child with dyslexia. These changes also brought a sense of hope for the future, as discussed in the final theme.

Theme 5: Hope for the future

and he sees himself as a learner and he loves learning – and those have always been our key objectives – to keep him engaged in the learning process – and a belief that he – he can do it – and he openly tells everybody he’s dyslexic and all that sort of stuff – he has no problem – with it. (Pippa)

Pippa expresses a positive outlook, as she perceives her personally valued goal has been achieved: her son ‘loves learning’. She has realised her internal strengths and gained self-efficacy (Bandura & Locke, 2003), transforming from initial grief at the journey’s beginning to an expectation of the journey continuing into a positive future.
Pippa has decreased levels of parenting stress and minimised psychological distress (Hassall et al., 2005). Sarah expresses her feelings at this point in her journey:

but yeah I’m now looking at him going – well you can do anything now – so that’s a good feeling – yes – you’re always going to be dyslexic and your always going to have an issue around that – and we know that – but you could do anything now – yeah … now I see this really great young man … ready to go and do it – yeah – so it’s good – it’s good. (Sarah)

Although parents of children with disabilities have been consistently shown to report more stress than parents of typically developing children, parents also report positive outcomes (Minnes, Perry & Weiss, 2015). As participants reflect on their journey to date, they not only recognise potential positive outcomes for the future, but they are also able to find personal meaning in their experiences.

when I get to the end of my life I’ll be able to look back and go I did something – I actually did something – no one will remember and no one will know – but I know – I know I did it – I’ll know – they’ll never … but I think I’ve given him – that same – don’t give up – thing either – don’t ever give up – don’t let them tell you what you can’t do … yeah – it’s exhausting… [laugh]… it’s exhausting – it is exhausting. (Sarah)

All five participants expressed positive impacts they had made at some point in their journey (Burden, 2008), impacts where the participants have viewed their behaviour as able to ‘make a difference’ in the larger system (Simonet, Narayan & Nelson, 2015). In retrospect, these impacts have provided personal meaning, value and purpose to the hardships faced along their journeys (Schermuly & Meyer, 2016). The participants can now see the future potential benefits as a result of the changes, decisions and actions they made along the way (DePape & Lindsay, 2015).

This last theme, hope for the future, emphasises the power of positive personal interpretation of the effects of dyslexia (Allred & Hancock, 2012). Throughout their journeys, the participants have cycled through addressing and solving problems with respect to their particular goals, which has promoted evaluation and reflection (DePape & Lindsay, 2015). This has helped the participants give meaning and purpose to their experience (Cattaneo & Chapman, 2010), resulting in further personal growth and greater success in achieving goals (Allred & Hancock, 2012). All five participants have faced significant hardships and challenges but have developed the capacity to cope and succeed (Simonet, Narayan & Nelson, 2015). All have gained a positive outlook and sense of hope for the future. Heidi sums up the experience of parenting a child with dyslexia in Australia:

yeah … it – it’s – it is definitely a difficult journey. (Heidi)

**Limitations and future research**

This study begins to address the dearth of information about the experiences of parenting a child in Australia (Nugent, 2008). It is the first known qualitative study to apply disability literature to explain findings in dyslexic research. In doing so, an assumption has been made that dyslexia can be viewed empirically as a disability, as subjectively described by the participants. While disability literature was found to be
congruent with the participants’ experiences in this study, it would be pertinent that future research aims to expand these findings.

Similarly, a model of PE (Zimmerman, 1995) was applied to explain the positive growth and change within the participants themselves throughout their journey. This model of PE has been applied to different disabilities, such as Turner syndrome (Smith, 2015) and ASD (Mulligan et al., 2012), however, again, this is the first known study to apply this model to parents of a child with dyslexia. Further research is required to add to the validity of these initial findings.

Additionally, the sample from this study was a small homogenous group, with similar demographics, as such, caution must be exercised when generalising these findings to the experiences of the wider parent population. In reality, parents of children with dyslexia come from a variety of racial, socioeconomic and educational backgrounds, which may influence their experiences. Also, fathers’ experiences are lacking in dyslexic research. With respect to education systems, it was beyond the scope of this study to distinguish parental experiences between the two represented states of Australia, that is, Queensland and New South Wales. However, as different states have different health and education systems, experiences may also differ across Australia. Future research is required to address the experience of parenting a child with dyslexia from a wider range of demographic samples in order to build a stronger research base in this field of study.

Despite the limitations of this study, findings have highlighted the detrimental effects of a lack of support for parents, particularly in the early stages of identification and diagnosis of children with dyslexia. It also highlights that parents of children with dyslexia are able to evolve and develop strategies to cope with the challenges they face along their journeys. The expert voice provided by the participants in this study begins to generate understanding of parenting a child with dyslexia and how this impacts family life on an ongoing basis. Further research is important to inform future directions for services, such as early intervention, and a greater understanding of the specific needs of children with dyslexia in mainstream school systems. Appropriate support services are essential to minimise the hardship and improve the ongoing health and wellbeing of parents parenting a child with dyslexia in Australia.

**Conclusion**

This qualitative study bridged a gap in the literature by exploring the phenomenon: ‘How do parents experience parenting a child with dyslexia in Australia?’. Dyslexia, as a disability, is a complex, multifaceted concept that creates significant challenges not just for the child but also for their parents. High levels of stress significantly impact on the family and all aspects of everyday life.

The results showed the overarching core of this phenomenon was: ‘A long difficult journey toward personal empowerment’. Five themes emerged from the data, which reflected aspects of how parents experienced this journey: grieving the loss of normal; fierce but reluctant warriors; navigating system failures; the changing sense of self; and hope for the future. Conceptualised through the theory of personal empowerment, these findings have highlighted that parents of children with dyslexia are able to evolve and develop strategies to cope with the many challenges they face along the difficult journey. Viewing dyslexia as a disability highlights the detrimental effects of a lack of support for parents, particularly in the early stages of
identification, as they advocate for access to resources and battle to have their child’s needs addressed within social and educational systems. Personal empowerment gives purpose and meaning to these hardships faced along the way, as well as hope for a brighter future.

Further research is required to expand these findings and explore the experience of different parental demographic samples to build a solid base of research in this field. Research can then inform the development of relevant services and effective educational strategies to support parents in the long difficult journey of parenting a child with dyslexia in Australia.

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