

**A pilot exploration of the relationship between temperament and psychopathology in
12-18 year-old children born at extremely low birth weight**

by

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Declaration

I declare that “A *Pilot exploration of the relationship between temperament and psychopathology in 12-18 year-old children born at extremely low birth weight.*” is my own work and that the sources that I have used or quoted have been indicated and acknowledged by complete referencing.

Dannita Borrageiro

DATE

Acknowledgments

“*Through him all things are possible*”. I thank my heavenly father for the opportunity to follow my passion and to grow as a person and for giving me strength and guidance to complete this journey. Without you none of this would have been possible.

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Acronyms

Cerebral Palsy	CP
Charlotte Maxeke Academic Hospital	CMAH
Chris Hani Baragwanath Academic Hospital	CHBAH
Extremely low Birth Weight	ELBW
Five Factor Model	FFM
Harm Avoidance	HA
Intellectual Disability Disorder	IDD
Intensive Care Unit	ICU
Intra-uterine Growth Restriction	IUGR
Low Birth Weight	LBW
Mental Component Summary	MCS
Neonatal Intensive Care Unit	NICU
Normal Birth Weight	NBW
Novelty Seeking	NS
Physical Component Summary	PCS
Quality of life	QOL
Reward dependence	RD
Very Low Birth Weight	VLBW
Revised Cheek and Buss Scale	RCBS
Mini International Neuropsychiatric Inventory	M.I.N.I.

Abstract

The aim of this study was to explore temperament, psychopathology and quality of life (QOL) in adolescents born at extremely low birth weight (ELBW), i.e., < 1000g. ELBW adolescents ($N = 15$) completed the Revised Cheek and Buss Scale and Mini International Neuropsychiatric Interview 5.0.0 (M.I.N.I.), while their legal guardians completed a biographical questionnaire and the Short Form 12 version 2. The median age of the sample was 13 $SD = 2.526$ years (60% male) and all participants spoke English. ELBW adolescents with social phobia ($n = 6$) were more shy ($p = .041$) and had poorer mental health-related QOL ($p = .041$) than those without such symptoms. The results suggest that ELBW could be a predisposing factor for increased shyness and psychological disorders including social phobia. Planning of interventions for ELBW individuals should therefore include strategies to prevent or mitigate the effects of these factors in adolescence.

Key terms

Extreme low birth weight, Temperament, Quality of life, Biopsychosocial theory, Shyness, Psychopathology, Neurodevelopmental disorders, Social phobia

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Chapter 1- Introduction

The purpose of this study was to explore the relationship between temperament and psychopathology in extremely low birth weight (ELBW) adolescents – with additional reference to the impact these variables have on quality of life (QOL). ELBW is a concept used to describe infants born weighing less than 1000 g (Kaul, 2007). In the last four decades there have been significant advances in perinatal and neonatal intensive care – resulting in increased survival rates of ELBW infants (Doyle, 2006). The increase in survival rates of such individuals has left developmental researchers with questions about the long-term effects of being born at ELBW. The reduction in mortality of ELBW new-borns was reported in countries such as the United States of America, Canada and Finland. In these countries the ELBW survival rates increased from 25% in 1970 to 75% in 2013 (Doyle, 2006; Flink et al., 2013; Tommiska et al., 2001). Mechanical support through ventilation, antenatal corticosteroids and surfactant treatment had been the frontline determinants for these increased survival rates (Strang-Karlsson, 2011).

There is a significant amount of research reporting on the immediate biological effects of ELBW – such as cerebral palsy (CP), intellectual disability disorder (IDD), developmental delays, and other neurocognitive impairments (Bassler et al., 2009; Doyle, 2006; Kaul, 2007; Saigal et al., 2007; Betty & Vohr et al., 2000). In contrast, research focusing on the long-term effects of ELBW is relatively scarce. Boyle et al. (2011), Cooke (1996) and Doyle (2006) reported that ELBW survivors were at high risk for developing poor physical and mental health in the long-term. ELBW survivors were also seen to be at risk of developing psychological disorders related to attention regulation, learning, anxiety and mood (Cooke, 1996; Olivieri et al., 2012; Pistorius, 2011). Furthermore, Burrows, Feeny and Furlong (2000) and Hoult, Saigal, and Streiner (2000) suggest that ELBW adolescents may also experience more motor and sensory motor integration impairments than their peers (Farel, Hooper, Teplin, Henry, & Kraybill, 1992). All these factors contribute to negative outcomes in terms of QOL (De Pauw & Mervielde, 2010; Flink et al., 2013; Strang-Karlsson, 2011). Even ELBW infants born without major physical impairments may exhibit higher levels of cautiousness, shyness, risk aversion and less extraversion in adolescence than their normal birth weight (NBW) peers (Boyle, Schmidt, Miskovic, & Saigal, 2008). This may predispose the ELBW child to decreased social engagement and an increased chance of experiencing loneliness and lowered

emotional well-being, thereby placing this child at risk for psychological problems (Schmidt et al., 2008).

The focus of this study was on the long-term effects of ELBW, with an emphasis on the relationship between temperament and psychopathology in ELBW adolescents. These were examined alongside the QOL outcomes for these individuals.

Aims

The aims of this study were to:

1. Explore the relationship between temperament and psychological disorders in ELBW adolescents.
2. Determine (if any) the relationship between temperament, occurrence of psychological disorders and QOL of ELBW individuals.

The objective was to assess adolescents born at ELBW with regard to temperament and psychopathology, and to interview their legal guardians about biographical details and also about their children's QOL. The legal guardians of adolescents weighing less than 1000 g at birth, born between 1996 and 2002, were approached to participate in the study. Informed consent was obtained from the guardians (all of whom were the biological parents of the adolescents) and assent was requested from the adolescents. Questionnaires related to temperament characteristics (Revised Cheek and Buss Scale or RCBS) and the biographical data sheet were completed by the legal guardians. Questionnaires related to neuropsychiatric disorders (Mini International Neuropsychiatric Interview 5.0.0, abbreviated as M.I.N.I), and QOL (Short Form 12, abbreviated to SF12v2) – were administered to the adolescents.

Research questions

This was an exploratory study around one central research question: What is the relationship between temperament and psychopathology in adolescents born at ELBW?

Two research sub-questions were posed:

1. What is the incidence of psychopathology amongst ELBW adolescents?
2. In what ways are shyness (as measured by the RCBS), psychopathology (on the M.I.N.I) and QOL (as measured by the SF12v2) related to each other in adolescents born at an ELBW?

Rationale and importance of research

Prior to 1990, public hospitals in South Africa did not record birth weights of infants weighing less than 1000 g (Kalimba & Ballot, 2013; Velaphi et al., 2005). Instead, ELBW infants were classified as miscarriages or untreatable (Kalimba & Ballot, 2013). However, over the past 20 years, ELBW infant mortality rates have been recorded and are currently at 34% in South Africa (Cooper & Sandler, 1997; Kalimba & Ballot, 2013; Krisela Steyn & Levitt, 2005; United Nations Children's Fund and World Health Organization, 2004).

According to the World Health Organization (2004), South Africa is classified as a developing country. Developing countries are characterised by a lag in medical care, QOL, infrastructure and technology – in comparison to developed countries (United Nations Children's Fund and World Health Organization, 2004). According to the United Nations Children's Fund and World Health Organization (2004), and the World Health Organisation (2012), most public hospitals in developing countries such as South Africa had restricted resources for treating ELBW and did not offer infants weighing less than 1000 g treatments such as mechanical ventilation. For example, at Chris Hani Baragwanath Academic Hospital (CHBAH) and Charlotte Maxeke Academic Hospital (CMAH), ELBW infants were treated with steroids, exogenous stimulants and alternative medical treatments – but subject to availability and the budget of the hospital (Kalimba & Ballot, 2013).

There is a limited amount of research on the long-term effects of ELBW in South Africa (Kalimba & Ballot, 2013). Research by Bassler et al. 2009, Lorenz, (2001) and Velaphi et al. (2005) indicated that, due to recent improvements in medical technology and intensive-care facilities, there has been a decrease in the mortality rates of ELBW infants (Velaphi, 2011). The decreased mortality rates leave developmental researchers with questions around the long-term effects of being born at ELBW and the corresponding impact on QOL.

Understanding the immediate and longer-term effects of ELBW for an individual will provide insight to a wide array of professionals with regard to how early life events may impact on brain development and developmental outcomes across a variety of domains (Lorenz, 2001). Such research could help develop risk profiles for this population – thereby presenting medical professionals and families with a more accurate picture of the long-term needs of ELBW

individuals in the various stages of life. This may also help with hypothesising about which interventions could act as buffers for some of the disorders associated with ELBW. Comprehensive reports will inform and assist health-care providers to formulate plans for medical services beyond those normally considered for average birth weight individuals, from infancy to old age.

Dissertation structure

In chapter one a brief summary of the research approach was presented. Chapter two contains the literature review, which includes an outline of previous research into ELBW, temperament, psychopathology and QOL. The framework for this study (the biopsychosocial approach) is used to explain the possible relationship between temperament, psychopathology and QOL in ELBW survivors. The methodology is discussed in chapter three, which includes the research design, sampling, instruments used and the procedure for gathering data. The results presented in chapter four include biographical information on the sample, correlation analysis and a comparison of various groupings (e.g., according to gender) across the RCBS, M.I.N.I., SF12v2 and biographical information. This is followed by a discussion of the findings in chapter five in which the theory, results and literature reviewed are integrated and discussed. The dissertation concludes with a review of the study, its strengths and limitations and recommendations for future studies.

Summary

There has been a significant amount of research on the immediate effects of ELBW, but few studies have been conducted to determine the longer-term effects of ELBW. There are indications that the outcomes of being born at ELBW include poor mental health and QOL. The aim of this research was primarily to explore the relationship between psychopathology and temperament in adolescents born at ELBW. The relationship of temperament and psychopathology to QOL in ELBW is explored as a secondary aim. Due to recent advances in medical technology and intensive-care services, survival rates of ELBW infants have increased significantly. Examining temperament, psychopathology and QOL in ELBW adolescents using a biopsychosocial approach may allow developmental researchers to help with the assessment and further holistic treatment of ELBW individuals at various stages of development. Information associated with this may lead to the improvement of preventative strategies at critical points in life, with consequent improved outcomes in later life.

Chapter 2: Literature review

Chapter two describes previous literature – which is needed for contextualising this empirical research. The chapter begins with the theoretical framework and then reviews literature on the current survival rates and possible causes of ELBW. The chapter closes with a discussion of the possible outcomes of ELBW from a biopsychosocial perspective.

Theoretical Framework

The biopsychosocial theory was developed by Engel and John Romano in 1970 at the University of Rochester, and is derived from general systems theory (Yagerm, 2002). The biopsychosocial theory is based on three mutually dependent systems: biological, psychological and social (Sadock & Sadock, 2007). The biological system is used to describe the anatomical, structural, and molecular substrates of disease and their effects on the individual's biological functioning. The psychological system describes how the individual's personal experiences are related to emotional and behavioural functioning. The social system describes the external influences in the environment – such as culture, family and extramural activities – on the experience of illness (Sadock & Sadock, 2007). The basic understanding of biopsychosocial theory, according to Turk and Flor (1999), is that:

Predispositional factors and current biological factors may initiate, maintain, and modulate physical perturbations; predispositional and current psychological factors influence the appraisal and perception of internal physiological signs; and social factors shape the behavioural responses of patients to the perceptions of their physical perturbations. (p. 20)

The biopsychosocial theory aims to encompass a hierarchical level of systems starting from the smallest system or unit to the largest system in the cosmos e.g., Quarks – Atoms – Molecules – Cells– Tissues– Organs – Body Systems – Human Being – Family – Community – Society – Cosmos. Engel hypothesised that all established systems are structurally and functionally interconnected and mutually influential from one level to the next through feedback loops. A thorough understanding of the individual would therefore require the

collection of data from three interconnected levels: The psychological, biological and social levels. This information needs to be integrated to form a holistic understanding of the patient (Smith et al., 2013).

In this study, the biopsychosocial approach was used as a framework for trying to understand temperament and psychopathology in ELBW adolescents, with reference to the impact of these two factors on QOL (Spenser, 2003). When examining outcomes for adolescents born at ELBW, the main biological factors include the prenatal development, genetics, cognition, and neurodevelopment. This study examines factors such as birth weight, gestational age and congenital disorders as part of the biological domain. The psychological factors important in ELBW studies include temperament, personality, affect and behaviour. The current study focuses on temperament – as well as affect and behaviour as they relate to psychopathology. Lastly, the social factors include the social and cultural environment that influence the individual's perception of, and response to, physical signs and symptoms. This study examines factors such as socio-economic circumstances (e.g. employment status of parents) and race. Ultimately, it examines how both nature and nurture might jointly influence the outcome of an ELBW adolescent.

In comparison to traditional biomedical and psychological approaches, the biopsychosocial theory is a broader, multidimensional and more complex perspective, that holistically considers the effects of being born at ELBW (Spenser, 2003). The biopsychosocial theory explains that biological, social and psychological factors play a significant role in the outcome of being born at ELBW, in a circular manner, and not a linear approach – as has been previously used (Goodman, 1991; Smith, 1961).

There are, however, several arguments against this holistic approach. For example, McLaren (1998) argues that, because this theory looks at a broader multidimensional approach of the relationship between mind and body, it fails to examine any one component thoroughly. McLaren (1998) contends that, if research focuses on the biological, social and psychological factors, emphasis is placed on an overview of the contribution of each domain, and rich information from each domain may be neglected. Contrary to McLaren (1998), Yagerm (2002) states that if biological, psychological and social factors of ELBW are independently researched, the evidence will not be integrated, and the data will be meaningless (Yagerm, 2002).

A biopsychosocial approach was chosen because – although ELBW is a medical condition that affects neurobiological makeup – one cannot exclude the impact that neurobiology will have on the ELBW adolescent’s psychological and social functioning (Snowden & Gray, 2010). This approach was considered highly useful in terms of allowing the researcher to explore the relationship between variables across different domains that may influence the individual’s outcome across the life span. The model allows for exploration of the life-course links between temperament and psychopathology or between neurodevelopment and QOL.

Acknowledging that a biopsychosocial perspective can yield information about a number of concepts, definitions of the core concepts in the dissertation are now presented. Their connections to ELBW are assessed through relevant literature.

The impact of birth weight on ELBW infants

Birth weight is defined as the first weight of the infant measured directly after birth. If an infant is born weighing below 2500 g, he or she is considered to be born at a low birth weight or LBW (Kaul, 2007). From 1000 to 2000 g is considered very low birth weight (VLBW) and any weight below 1000 g is considered ELBW (Kaul, 2007; Matsuo, 2003).

An infant’s LBW can be the result of preterm birth or restricted foetal (intra-uterine) growth (Care, House, & Manual, 2004; Farel, Hooper, Teplin, Henry, & Kraybill, 1992; Reichman, 2005). Preterm birth means that a foetus is delivered before 37 weeks. At this time the foetus is not yet fully developed and carries the increased risk of mortality, developing infections, and developmental delays (Tommiska et al., 2001). Preterm birth is the leading cause of new-born (the first four weeks of life after birth) morbidities. There are three sub-categories of preterm birth, which are based on gestational age: moderate to late preterm (32-37 weeks), very preterm (28-32 weeks) and extremely preterm (<28 weeks). Intra-uterine growth restriction (IUGR) refers to the poor growth of a baby while in the mother's womb during pregnancy. Specifically, it means the developing baby weighs less than 90% of what other babies weigh at the same gestational age. This is associated with cognitive, emotional and behavioural problems (Bassler et al., 2009; Cooper & Sandler, 1997; Manual, 2004; Richter, Norris, Pettifor, Yach, & Cameron, 2007; United Nations Children’s Fund and World Health Organization, 2004). IUGR can be caused by foetal infections, placental abnormalities, or maternal disease (Tommiska et

al., 2001). This study focuses on the impact of birth weight < 1000 g, which is characteristic of most children born extremely small for their gestational age (Boyle et al., 2011; Olivieri et al., 2012; Picuch, Leonard, Cooper, & Sehring, 1997; Resnick et al., 1999; Vohr et al., 2000).

Globally, an estimated 15.5 % of babies are born at LBW; more than 90% of those babies are born in developing countries (Wielligh, 2012). According to the World Health Organisation (2011), in more than 100 developing countries, including South Africa, LBW rates are estimated to be around 10% (World Health Organisation, 2013). South Africa has a LBW rate of 10% per annum (World Health Organisation, 2012). An estimated 18 million babies worldwide are born each year at LBW: 9.3 million of them in South Asia and 3.1 million in Southern Africa (World Health Organisation, 2013; Velaphi et al., 2005). There is incomplete statistical data on the current ELBW rates globally and specifically related to South Africa. However, one of the first recorded ELBW rates was released by Official Statistics of Finland, Statistical Summary 14/2010 reporting that the ELBW rate in Finland was 0.4% (Strang-Karlsson, 2011). There is no reliable data to correspond these statistics to, and ultimately it is not known if these statistics are comparable globally.

Figure 1.1 (below) illustrates the incidence of LBW globally as well as the number of infants not weighed per year – with the exclusion of China (United Nations Childrens Fund and World Health Organisation, 2004). There was no available data on the current statistic of LBW in South Africa, but it is likely that the statistics for Sub-Saharan Africa are the most accurate reflection of statistics in South Africa. Sub-Saharan Africa had the third highest percentage (54%) of infants not weighed at birth, and also 13% of infants born at LBW in 2004.

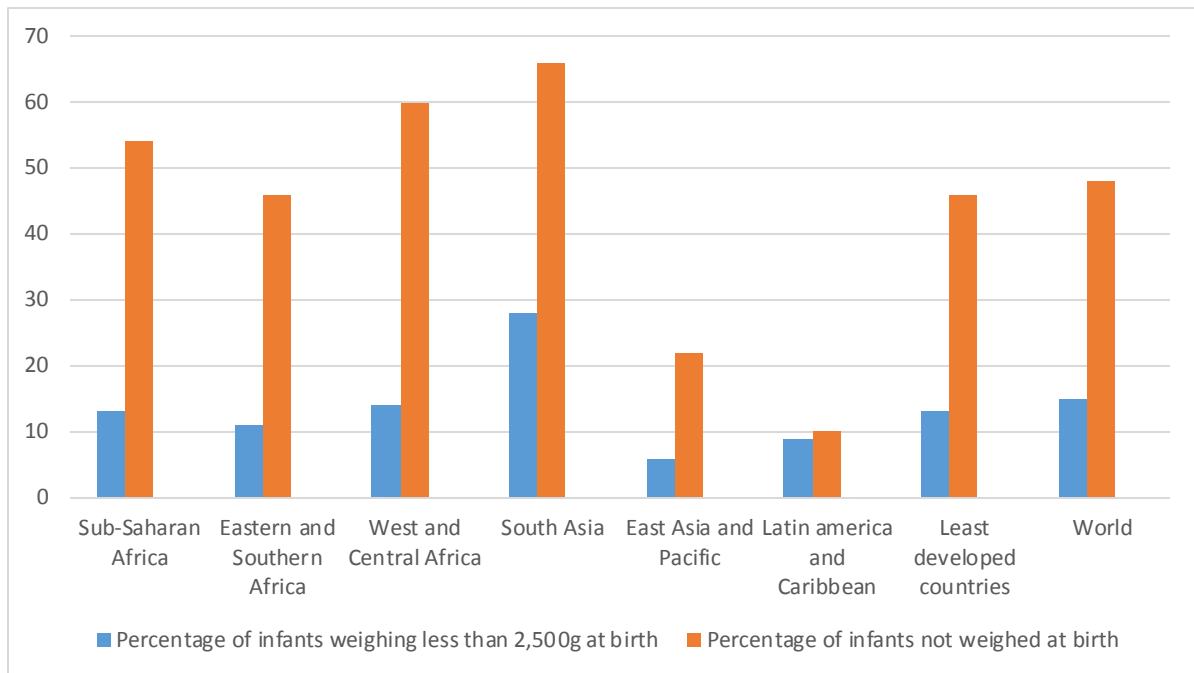


Figure 1.1. Global estimates of LBW and percentage of infants not weighed at birth (United Nations Childrens Fund and World Health Organisation, 2004)

Current survival rates of ELBW infants

Globally, over the last 30 years, an increasing number of infants have survived being born at ELBW due to advancements in general perinatology and neonatology (Olivieri et al., 2012; Strang-Karlsson, 2011; Velaphi et al., 2005). This improvement is considered to be a result of an increase in the number of infants offered intensive care; mothers being given antenatal maternal steroids; infants being given surfactant therapy (which has been shown to reduce the severity of respiratory distress syndrome); and improvements in delivery-room care, parenteral nutrition and thermoregulation for infants (Cooke, 1996; Lorenz, 2001; Simeoni, Vendemmia, Rizzotti, & Gamberre, 2004; Strang-Karlsson, 2011). Yet there is still a significant disparity in mortality between developed and developing countries.

Comparison of survival rates of LBW infants in South Africa and developed countries

According to the World Health Organisation (2012), there are distinct inequalities in survival rates of LBW infants around the world. In developing countries, half of the VLBW infants born below 32 weeks in low socio-economic groups die due to lack of resources, cost-effective care, breastfeeding support and breathing difficulties. In developed countries, 80% of these infants survive.

Since the late 1970s, developed countries such as Australia, Canada and Japan invested capital into their neonatal programmes (Doyle, 2006). Over the past 33 years there has been more research related to these neonatal intensive care programmes and units globally – which helps illustrate how improved resources and access to such resources has influenced ELBW mortality (Nishida & Oishi, 1996; Boyle, Sinclair, Torrance & Horwood, 1984). A study in Victoria, Australia, reported that the ELBW survival rates have risen from 25% in the 1970s to 75% in the 1990s. A possible reason for increased survival is that the percentage of ELBW babies offered intensive care has risen from 25% in 1979 to 73% in 1997 (Doyle, 2006). The results are comparable to other studies around the world – e.g., Fanaroff et al. (2005) compared data across the USA for the years 1987 to 1992. The data showed that ELBW infants’ survival rates increased from 33% to 45% across 12 different institutes (Fanaroff & Wright, 1995). In Japan, the mortality rates decreased from 55.3% in 1980 to 41.2% in 1985, with a further decrease to 26.8% in 1990 (Nishida & Oishi, 1996).

It is estimated that 14.6% of babies born in South Africa are born below 2500 g, but the survival rate is judged to be one in four, which is only comparable to survival rates in developed countries such as Australia and USA in the 1970s (Cooper & Sandler, 1997; Doyle, 2006). This indicates that South Africa’s survival rate lags more than three decades behind that of developed countries.

Factors influencing survival rates of ELBW infants in South Africa

According to Statistics South Africa, 10% of infants are born at LBW in both public and private sectors (Lehohla, 2011). However, the poor survival rates of ELBW infants can be attributed to the limited availability of resources, and the quality of antenatal treatment received in hospital (Sabet et al., 2009; Velaphi & Rhoda, 2012), in particular in public hospitals. For example, CHBAH and CMAH, prenatal steroids, exogenous surfactant and the use of mechanical ventilation are either restricted when infants weigh less than 900 g, or are not offered due to a lack of available space (Kalimba & Ballot, 2013) – which is not the case in developed countries such as Canada, Japan and America (Boyle et al., 2011; Cooke, 1996; Cooper & Sandler, 1997; Kalimba & Ballot, 2013; Velaphi et al., 2005). The low survival rates of ELBW infants born in South African public hospitals are therefore largely influenced by the availability of resources offered by these health-care facilities (Pistorius, 2011; Velaphi et al., 2005; Velaphi, 2011).

A study at the CHBAH's neonatal unit in South Africa between 2000 and 2002 shows that infants born at 1000 g were not offered mechanical ventilation except under exceptional circumstances (Velaphi et al., 2005). Infants weighing over 1000 g may gain access to ventilators, but were still likely to experience delays before admission to a neonatal care unit with available ventilators. In addition, survival rates differ from one South African hospital to the next and will ultimately depend on the resources available, and the quality of antenatal treatment (Matsuo, 2003; Velaphi et al., 2005). In December 2002, the survival rate of ELBW in CHBAH was 34%, and a similar study done at CMAH in July 2006 showed a survival rate of 34.9% (Kalimba & Ballot, 2013). It is interesting to note that - despite the restrictive treatment circumstances in South African public hospitals – improvement in technology, mothers taking corticosteroids, and medical teams gaining a more comprehensive understanding of the composition/bodily processes of immature infants, has ultimately lead to the increase in the survival rates of ELBW infants (Pistorius, 2011).

On the other side of the healthcare spectrum, a report published by The Little Life Hospital group indicates that their nation-wide private maternity care facilities throughout South Africa offer mechanical ventilation to infants born at 25 weeks plus and do not have a birth-weight restriction, except if infants are born with major impairment (Kristen, 2012). Therefore, in some private hospitals in South Africa, mechanical ventilation is not restricted based on birth weight (Kalimba & Ballot, 2013).

As a further example of the disparity in survival rates: The Neonatal Intensive Care Unit (NICU) in the tertiary academic hospital, Tygerberg Children's Hospital, is split into public and private facilities. In the private unit, the hospital provides advanced facilities and treatment modalities such as high-frequency oscillation, surfactant treatment and ventilation to infants born at ELBW. A recent study at that facility showed that advanced care yields a survival rate 62.9% for ELBW infants when receiving surfactant replacement treatment and nasal continuous-airways pressure (Kalimba & Ballot, 2013; Kristen, 2012). Surfactant is as a natural substance produced by the lungs. It breaks surface tension; without surfactant in the lungs, the alveoli have difficulty remaining open (Sharma & Mishra, 2013). Surfactant is usually produced in the foetus from about 24 weeks of pregnancy but reaches normal ranges by 37 weeks. ELBW infants are found to be born with low surfactant levels and therefore often suffer from respiratory distress syndrome. Surfactant therapy is then recommended (Cooke, 1996;

Sharma & Mishra, 2013). Surfactant therapy is the delivery of surfactant using artificial breathing tubes that are inserted into the trachea at birth for ELBW infants (Sharma & Mishra, 2013). However, in the public unit at Tygerberg, there is officially a 1000 g, 28-week gestational age cut-off guideline for admission to an NICU for ventilation (Velaphi & Rhoda, 2012). Unfortunately, the study did not report survival rates for the public part of the NICU (Kristen, 2012).

Admissions into public hospitals such as CHBAH, CMAH and Tygerberg Children's Hospital, do not mean that babies born under 28 weeks or that weigh less than 1000 g are left to die. The infants that do not meet the requirements for admission into NICU for ventilation are sent to high-care neonatal wards and offered alternative treatments such as kangaroo care (Cooper & Sandler, 1997; Kalimba & Ballot, 2013; Velaphi & Rhoda, 2012). The outcome of support from mechanical ventilation is much more effective than alternative modes of treatment, but alternative treatments have also contributed somewhat to the increase in survival rates of ELBW in South Africa (Kalimba & Ballot, 2013; Mokhachane, Saloojee, & Cooper, 2006).

The restrictions of the public NICUs are reportedly due to a lack of resources, financial constraints, and staff shortages. The worst prognosis is found in ELBW infants who are born in clinics without high-care facilities, or whose mothers did not attend an antenatal clinic or who did not receive antenatal steroids (Kristen, 2012; United Nations Children's Fund and World Health Organization, 2004).

Possible causes of being born at an ELBW

When considering possible causes of ELBW, the entire context within which foetal development occurs has to be reviewed. Factors such as maternal age, fertility treatment, multiple births, chronic and acute medical illness, and socio-economic status are all linked to ELBW.

Maternal age

Foix-L'Hélias and Blondel (2000) found that an increased percentage of women in developed countries such as France, Finland and Sweden are giving birth later in life relative

to women in the 1980s. They reported that a maternal age above 34 years is an important risk factor for preterm and ELBW infants (Matsuo, 2003). Tough, Newburn-Cook, Johnston, Svenson, and Belik (2002) report that:

It has been suggested that fecundability (the ability to conceive) and fertility decrease with maternal age, whereas conception delay increases. Concomitant with advanced maternal age may be an impaired functional capacity of the uterus, biological aging, and synergistic effects related to systematic disease. (p. 5)

In Spain, the Netherlands and Sweden there has been an increase in the proportion of live births for women above the age of 30. This proportion increased from 25.6% in 1980 to 45.0% in 2001 in Norway, and from 27.4% in 1980 to 54.3% in 2001 in the Netherlands, and reached nearly 60% in Spain in 2000 (Council of Europe, 2004).

According to Statistics South Africa (Lehohla, 2011), there has only been a slight increase in the proportion of live births for South African women above the age of 30. In 2007 the percentage of women giving birth above 30 was estimated to be around 17% (Lehola, 2009) compared to 17.6 % in 2011 (Lehohla, 2011). However, research by Willian (2013) reports that 18 % of adolescent girls in South Africa fell pregnant in 2013 - a larger percentage than women above the age of 30. South Africa has one of the largest concentrations of adolescent girls giving birth in the world (Willian, 2013). Sharma and Mishra (2013) suggest that there are biological mechanisms that increase risk of ELBW in adolescent girls too:

In adolescents the blood supply to the cervix and uterus has not developed completely in some adolescents which leads to poor supply of nutrients to the foetus. Poor blood supply to the genital tract leads to an increased risk of infection which triggers the onset of preterm births and possibly low birth weight. There is a higher incidence of unplanned pregnancies among adolescents which is a risk factor of adverse outcomes (p.41).

Therefore, it appears that maternal age can have an important effect on the birth weight of a child. Both very young (biologically immature) and older mothers run the risk of giving birth to an ELBW infant.

Fertility treatment and multiple births

Fanaroff and Wright (1995) report that there is an increase in the number of women that seek treatment for fertility and this has led to an increase in multiple births. Multiple births are a risk factor for infants to be born preterm and at ELBW (Fanaroff & Wright, 1995; Matsuo, 2003; Reichman, 2005; Sachdev, 2001). However, due to the high financial costs of fertility treatments, only a small number of women globally can afford them (Lehohla, 2011). This might therefore limit the rate of ELBW as a result of such treatments. For example, although *in vitro* fertilisation is found to be a contributing factor to ELBW, Stephen (2000) reported that due to the high financial costs of *in vitro* fertilisation treatment, only 3% of women on a global scale can afford ovulation drugs and only 1% utilise treatments such as *in vitro* fertilisation (Matsuo, 2003).

Medical illness

Women diagnosed with medical conditions such as diabetes, kidney diseases and heart defects are more at risk of having ELBW infants than their healthy counterparts (Askin & Wilson, 2007; Strang-Karlsson, 2011). Additional risk factors for ELBW are pre-eclampsia, which results in high maternal blood pressure and protein in the urine. This condition is more prevalent in older mothers and women expecting multiples (Tommiska et al., 2001). Maternal infection and abruption of the placenta are additional contributing factors to ELBW (Matsuo, 2003; Tommiska et al., 2001).

Socio-economic status

Low socio-economic status is another contributing factor to ELBW (Elgen & Sommerfelt, 2002; Indredavik et al., 2004; Saigal et al., 2007). Low socio-economic status is broadly indicative of a poorer QOL than is high socio-economic status. Associated poor nutrition, health and, at times, intense labour, all contribute to the development of preterm birth and ELBW (Matsuo, 2003; United Nations Childrens Fund and World Health Organisation, 2004).

The above considered, it is evident that there are an increasing number of infants that do survive despite multiple challenges. Therefore the medium-term and long-term outcomes of ELBW infants are increasingly important public health concerns.

Outcomes of ELBW infants

The health outcome of being born at ELBW is a multi-dimensional concept (Matsuo, 2003). Health is defined by the World Health Organisation (1948) as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (p.100). This emphasises a broad perspective of the outcomes of ELBW that will be referred to through the exploration of the biological, psychological and social factors affected by ELBW.

Birth weight is a good predictor of the outcome for ELBW infants. The higher the birth weight, the better the prognosis (Velaphi et al., 2005). The gestational age of the infant will contribute to birth weight and therefore the prognosis. Research done in South African public hospitals, such as CHBAH and CMAH, shows that there are distinct differences in survival rates of babies born between 600 g and 700 g in comparison to those born weighing >1000 g (Velaphi et al., 2005; Velaphi, 2011). Sweet et al. (2003), found that only 24% of infants born weighing < 600 g survive, and 90% of those that survive have severe impairments in developmental functioning, such as CP, IDD, blindness and gastrostomy. Every 100 g decrease in weight reflects increased organ immaturity and poorer prognosis. Doctors in developing countries such as South Africa, have to make ethical decisions whether a new-born infant should be put on mechanical ventilation or if the incubator should be given to a heavier infant based on the infant’s prognosis and the availability of resources (Simeoni et al., 2004).

The biological effects of being born at ELBW

The impact of biological effects on infants will largely affect their QOL and functioning in the world (Spenser, 2003). Infants born at ELBW are predisposed to biological impairments such as neurodevelopmental delays, chronic illness, and lung disease (Claas et al., 2011; Piecuch et al., 1997). For the purpose of this study the temperament of ELBW adolescents will also be explored, which will suggest how these infants relate to the world, and ultimately how this will affect their physical, mental and social well-being (Schmidt, Miskovic, Boyle, & Saigal, 2008).

Neurocognitive disorders found in ELBW adolescents

ELBW infants are estimated to have a 20-50% chance of being born with a neurocognitive disorder (Matsuo, 2003). A neurocognitive disorder is defined as impairment of growth and development of the brain or central nervous system, which affects emotion, learning ability, memory and self-control (American Psychiatric Association, 2013). Neurocognitive disorders commonly found in ELBW infants are CP, significant developmental delays, significant hearing impairment, or significant visual impairment (High Risk Follow-up Working group, 2008).

Neurocognitive impairment is largely affected by the gestational age at which an infant is born. The closer the pregnancy is to full term, the lower the percentage of impairment in cognitive development (Claas et al., 2011). The development of the brain structure, the neural maturation, synaptogenesis and myelination progress significantly towards the latter part of the second trimester – which leaves the brain vulnerable to impairment in earlier development (Strang-Karlsson, 2011). Neurocognitive symptoms are more common in preterm babies, but due to the significant overlap between preterm birth and ELBW, this often also applies to ELBW infants (De Souza Rugolo, 2005; Leholá, 2009; Strang-Karlsson, 2011; Zwicker & Harris, 2008). It has been shown through imaging of the cerebral cortices of ELBW infants at 38-42 weeks that there was less cortical surface area and cortical complexity than in full term, NBW infants. This means that the maturation of the brain is not completed for that growth period. Insults such as hypoxia and intracranial bleeding place the infant at further risk of physical and mental illness (Tekolste et al., 2004).

There has been a significant amount of research (Chan et al., 2008; Sweet et al., 2003; Tekolste et al., 2004; Vohr et al., 2000) that finds ELBW to be a risk factor for being born with CP. CP is diagnosed in 10-20% of ELBW infants. CP is defined as a non-progressive central nervous system disorder beginning in early childhood and persisting through the life span. CP is a chronic disorder of movement and posture, due to a defect or lesion of an immature brain. CP, like IDD, autism, and ADHD, is a recognisable pattern of negatively altered neurological development (Morris, 2007).

Another neurocognitive disorder that is commonly diagnosed in ELBW children is IDD. IDD is defined by the American Psychiatric Association (2013) as a mental disorder in which the individual's intellectual functioning falls at least two standard deviations below the mean (therefore an IQ < 79). Intellectual ability must also impact the individual's adaptive

functioning in three domains of functioning: 1) skills in language, reading, abstract reasoning and memory; 2) the social domain, which refers to social judgment, interpersonal communication skills and the ability to show empathy towards other; and 3) the practical domain, which refers to personal management, financial management, and occupational functioning (American Psychiatric Association, 2013). These symptoms must be confirmed by both a clinical assessment and in individualised psychometric intelligence testing. At school age, ELBW are more than nine times more likely than full-term controls to have an IQ below 70, thus indicating IDD (Tekolste et al., 2004).

In a study by Sweet et al. (2003), 21 ELBW infants weighing 600 g or less at birth were examined. Of the 24% surviving infants, 90% exhibited some form of neurodevelopmental abnormality. Developmental problems included CP, blindness, gastrostomy (surgical insertions of a tube for feeding) and ventriculoperitoneal shunts (Sweet et al., 2003). A ventriculoperitoneal shunt is a device used to relieve the pressure caused by fluid accumulation on the brain. This is usually necessary when there is an excess amount of cerebral spinal fluid collected in the ventricles (Askin & Wilson, 2007).

Research conducted in Canada, Australia and Japan by researchers such as Boyle et al. (2011) and Saigal et al. (2003) has identified common neurodevelopmental impairments associated with ELBW infants. Parents, doctors and school teachers are increasingly reporting cases of IDD, CP, and neurosensory abnormalities such as visual and auditory impairment (Olivieri et al., 2012; Schmidt, Miskovic, Boyle, & Saigal, 2008; Schmidt, Miskovic, & Boyle, 2010). These adverse outcomes occur in approximately 20 to 30% of ELBW survivors (Tekolste et al., 2004).

Developmental delays in ELBW children

Developmental delay is defined as an infant progressing through his or her developmental milestones substantially behind the average expectations for children of the same age, in two or more domains (Schendel et al., 1997). These domains include cognitive, intellectual, gross motor, fine motor, language, social, and adaptive development (High Risk Follow-up Working group, 2008).

A study by Picuch, Leonard, Cooper and Sehring (1997) investigated the long-term neurodevelopmental outcomes of ELBW over a 12-year period. Of significance was the finding

that – although birth weight alone could not be attributed to any significant developmental delays – several other risk factors associated with ELBW largely impact on the development of these individuals. Risk factors such as intracranial haemorrhage (bleeding within the skull), cystic periventricular leukomalacia (destruction of white matter usually due to lack of oxygen to the areas around the ventricles) and lung disease worsen the QOL of ELBW (Piecuch et al., 1997). ELBW children that have experienced prolonged respiratory insufficiency associated with ELBW, have delayed motor-functioning development, impaired growth, and increased morbidity. Their rates of re-hospitalised and post-neonatal morbidity are significantly elevated compared to their healthy peers (Farel et al., 1992; Piecuch et al., 1997).

Psychological disorders commonly found in ELBW adolescents

There is a small body of research about the long-term psychological well-being of ELBW adolescents (Mackay, Ballot, & Cooper, 2011; Mokhachane et al., 2006; Strang-Karlsson, 2011; Velaphi et al., 2005). ELBW adolescents are found to have more internalising disorders such as anxiety and social withdrawal, as well as externalising problems such as poor attention and concentration, learning disorders and psychomotor impairment than their NBW peers (Cooke, 1996; Msall & Park, 2008; Olivieri et al., 2012; Pistorius, 2011). Hack et al. (1994) studied children that weighed less than 750 g at birth and compared them to a control group that weighed 751-1,500 g at birth. They found that those weighing less than 750 g had poorer cognitive ability, psychomotor skills and academic achievement – as well as impaired social skills, adaptive behaviour and attention regulation. This supports the notions that an infant's birth weight will determine the occurrence of impairment, while the severity of the impairments improve with every additional 100 g (Bassler et al., 2009; Simeoni et al., 2004). In addition, feedback from parents and teachers indicate that they perceive adolescents born at ELBW as being lower achievers in academic functioning, attention regulation, QOL, and social competencies (Jones, Edwards, & Gifford, 2002).

ADHD

ADHD is a psychological disorder defined by the DSM-V (American Psychiatric Association, 2013) as affecting both children and adults. It is described as a persistent pattern of inattention and/or hyperactivity-impulsivity that affects behaviour and the ability to function effectively in two or more contexts – e.g. school and home environment. There are three presentations of ADHD: 1) inattentive; 2) hyperactive-impulsive, and 3) combined inattentive

and hyperactive-impulsive. Impairment in functioning is often located in the frontal cortex, specifically the frontal lobe in the brain. Impairment in functioning in this area causes individuals to have difficulties with executive functions, maintaining attention and with working memory. The brain's ability to begin an activity, organise itself, and manage the task is impaired in people with ADHD (American Psychiatric Association, 2013).

Zwicker and Harris (2008) report that VLBW children experience academic, motor, psychosocial and behavioural difficulties. The impairment in functioning is most evident at school age. VLBW children are 2.6 % more likely than their peers to develop psychological disorders like ADHD. Meanwhile, an increasing amount of literature by authors such as Anderson, Luca, Hutchinson, Spencer-Smith, and Doyle (2011), Davis, Harris, and Burns (2010), De Pauw and Mervielde 2010, Indredavik et al., (2004), and Strang-Karlsson (2011) illustrates the prevalence of ADHD in adolescents born at ELBW. It is important to note that not all ELBW survivors go on to develop ADHD; approximately 10% of ELBW adolescents are found to meet the criteria for ADHD (Tekolste et al., 2004). However, ELBW children are at greater risk for developing symptoms of the inattention and impulsivity subtypes of ADHD than their NBW peers. A large percentage of ELBW have attention regulation, concentration and social difficulties (Boyle et al., 2011; Lahey, 2004; Saigal et al., 2003).

ELBW adolescents are reported to have poor impulse control and shorter attention regulation, which may predispose them to ADHD and behaviour problems. A study by Strang-Karlsson (2011) reports that symptoms such as difficulty with concentration, emotional regulation, externalising symptoms (risk-taking behaviour) and executive dysfunctions are repercussions of the biological programming of the developing brain: ELBW infants are born premature and therefore their brains are not developed to optimal maturity. Below-par development or prematurity is associated with illness in the postnatal period, which may interfere with neonatal organisation and modify later psychological functioning (Strang-Karlsson, 2011). This is an example of how biological and psychological aspects of ELBW may mediate poor outcomes for ELBW adolescents.

Learning and intellectual disabilities

Learning disorder is defined in the DSM-V (American Psychiatric Association, 2013) as:

Persistent difficulty learning academic skills for at least six months despite intervention targeting the area(s) of difficulty. The affected academic skills are substantially below expectations given the individual's age and result in impairment in school, work and activities in daily living. The academic learning difficulties occur in the absence of any other significant stressor or intellectual disabilities. (p.87)

Rickards, Ryan, and Kitchen (1988), Roussounis, Hubley, and Dear (1993), and Vohr and Garcia-Coll (1985) report that adolescent ELBW children are at risk of developing learning disorders. Farel et al. (1992) and Vohr et al. (2000) report that children born at VLBW and ELBW experience learning difficulties – especially difficulty with memory tests, speech impairments, and language impairments. Vohr and Msall (1997) conducted a study on the neuropsychological and functional outcomes of VLBW infants at preschool and school age. This indicated that more than 55% of these children have severe reading disability by the age of 8 years, and 28% of children at the age of 12 years were reported to have learning problems in school (Vohr & Msall, 1997; Vohr et al., 2000).

The temperament structure found in ELBW adolescents

There is no consensus on the definition of temperament, but the definition that is usually accepted refers to temperament as an early pattern of observable behaviour that is presumed to be biologically based and which can be used to distinguish one child from another (Sturm, 2004). According to Kagan (1994) “temperament conventionally refers to stable behavioural and emotional reactions that appear early in infancy and are influenced in part by genetic constitution.” (p.40). Temperament traits and characteristics show cross-situational stability and some stability across time (although the behaviours that reflect the characteristic alter with development), and these characteristics have differing degrees of genetic basis (Rothbart & Derryberry, 2000). Temperaments comprise the subclass of personality traits that have been inherited - in other words, the basic building blocks of personality structures seen in adults (Halverson, Kohnstamm, & Martin, 1994).

The concept of temperament has been documented in history for many centuries (De Pauw & Mervielde, 2010). There are many diverse theories of temperament that date back at least to

the ancient Greek ideas formulated by the philosopher Hippocrates (Shiner & Deyoung, 2011). Hippocrates believed that an individual's typical mood and behaviour resulted from the balance of four humors in the body: blood, black bile, yellow bile and phlegm (Clark & Watson, 2008; Shiner & Deyoung, 2011; Zuckerman, 1995). Modern theories of temperament were developed by Eysenck, whose definition of temperament is based on genetic predisposition and physiology; by Chess and Thomas who formulated the nine categories of the 'Goodness-of-Fit' model, and by Cloninger (Cloninger, Svrakic, & Przybeck, 1993) who developed the biopsychosocial theory of temperament. For the purpose of this study, we will be focusing on Cheek and Buss's definition and understanding of temperament.

Cheek and Buss (1956) collaboratively found that there are stable traits in individuals that influence the way they deal with external stimuli and development throughout life. These formative traits are defined as temperament (Cheek & Buss, 1981). As stated above, the formative traits observed in the developmental years of an individual are hypothesised to be biologically based and stable across situations. Cheek and Buss particularly focus on two traits: shyness and sociability (Cheek & Buss, 1981; Hopko, Stowell, Jones, Armento, & Cheek, 2005). Research indicates that adolescents born at ELBW are more inclined to be shy and risk averse than NBW peers (Aron & Davies, 2005; Janson & Mathiesen, 2008; Ristvedt & Trinkaus, 2009; Schmidt, Miskovic, Boyle, & Saigal, 2008; Takai et al., 2011). Cheek and Buss's scale of temperament deals with shyness and sociability, and is applicable to this population.

Crozier (2001) reported on evidence that investigated whether shyness can meet the basic requirements for a temperament characteristic. Firstly, evidence showed that shyness appears early on in life. Shy infants were seen to show increased motor activity and signs of distress when confronted by novel sensory stimuli (Kagan, Reznick, Snidman, Gibbons, & Johnson, 1988). Secondly, Terblanche (2011) and Rothbart and Alansky (1990) reported that shyness is stable over time. A longitudinal study conducted by Kagan et al. (1988) found that 75% of inhibited 21-month-old infants were classified as shy six years later. Another study by Ramachandran & Kagan (2012) confirmed these results through a longitudinal study on temperament and individual differences – in which 450 four-month-old infants were assessed and classified into two groups: high reactive and low-reactive. Highly reactive infants were fearful and showed distress. One in four highly reactive infants was reassessed on a yearly interval basis to assess for any changes in their reaction to stimulation. The results showed that

children who were found to be highly reactive at 4 months were still highly-reactive at the age of 18 years. Highly reactive young adults were found to be worried about being exposed to large groups of people, interacting with strangers, fearful of social environments, and extremely shy in comparison to their peers (Kagan & Ramachandran, 2012). In addition, Schmidt et al. (2010) found that infants classified as being fearful or highly reactive had higher electroencephalography (EEG) activity in the right frontal area of the brain, as well as higher baseline heart rates.

Cheek and Buss (1981) see shyness and sociability as reliable predictors of both poor physical and mental health among adolescents (Briggs, Cheek, & Buss, 1981; Hopko et al., 2005; Peirson, Heuchert, Thomala, Berk, & Plein, 1999). Shyness is defined by Aron and Davies (2005) as “the fear of negative social evaluations that leads to discomfort and limitations on the desire for social contact (p.3)”. Shyness has a conceptual similarity to constructs such as social anxiety disorder. Social anxiety exists on a continuum from very mild, nonclinical social anxiety (i.e. shyness) to severe and clinical levels of social phobia (Cheek & Buss, 1981; Hopko et al., 2005; Janson & Mathiesen, 2008; Schmidt et al., 2008). Shyness is associated with a number of negative outcomes. These include: fear of negative evaluation by others, low self-esteem, difficulty initiating new relationships, problems establishing and maintaining close and satisfying relationships, depression, loneliness, fearfulness, social anxiety and neuroticism, as well as psychosomatic difficulties such as allergies and gastrointestinal problems (Aron et al., 2005; Buss & Block, 1980).

In contrast to shyness, sociability is defined as a tendency to affiliate with others and a preference for being with others rather than remaining alone (Rai, 2011). Sociability can also be defined as an aspect of extraversion and is characterised by being warm and friendly towards others and motivated towards frequent social interactions (Taylor, 2004). A study by Schmidt (2008) reports that adolescents born as ELBW without major physical impairment, seem to be more cautious, shy, risk averse and less extraverted than their NBW counterparts – possibly placing them at risk for future psychological and emotional problems (Schmidt et al., 2008).

Thus, temperament characteristics seem to be useful in understanding the factors contributing to the risk of developing psychological and emotional problems. The interaction between temperament and the environment where social learning occurs, influences the development of how an individual relates to the world (Snowden & Gray, 2010).

The relationship between temperament and psychopathology in adolescents

Psychopathology relates specifically to emotions and behaviours that are associated with functional impairment at a specific time in an individual's life (Lahey, 2004). Temperament can then be viewed as the basic socio-emotional behaviour that appears evident from infancy, and provides the developmental foundation for complex and differentiated behaviour to develop (Shiner & Deyoung, 2011). Psychopathology would be the extreme of socio-emotional behaviour that characterise impairment in functioning (De Pauw & Mervielde, 2010; Lahey, 2004; Sabet et al., 2009). According to research done by Muris and Ollendick (2005), temperament plays a role in aetiology and maintenance in the development of a psychological disorder (Calkins & Fox, 2002; Lonigan & Phillips, 2001). Whittle et al. (2006) report that temperament provides a reliable and measurable base for objectively characterising or assessing for psychopathology. There is accumulating evidence (Cloninger & Zohar 2010; Josefsson et al., 2011; Takai et al., 2011) that temperament is strongly related to affective-related disorders such as depression and anxiety. In addition, temperament dimensions are reported to have a biological basis that impacts those associated with psychopathology (Whittle et al., 2006).

As mentioned in the biological effects of ELBW section, temperament has a biological component that refers to stable behavioural and emotional reactions that appear early in infancy, and are influenced, in part, by genetic constitution (Kagan, 1994). Cheek and Buss (1956) found that there are stable traits in individuals that influence the way they relate interpersonally and deal with external stimuli and development throughout life. These formative traits eventually evolve into stable personality traits (Cheek & Buss, 1981). As previously stated, Cheek and Buss particularly focus on shyness and sociability – otherwise known as inhibited or uninhibited individuals (Whittle et al., 2006). Social inhibition is related to internalising problems, leading to social withdrawal and poor self-esteem; in-turn, these are manifested in symptoms of depression, anxiety and poor social functioning (Boyle et al., 2011). On the other hand, social disinhibition means that an individual is able to engage socially without restraint by mind or social convention. Whittle et al. (2006) researched the role of temperament as a vulnerability factor for the emergence of psychopathology. They conducted a longitudinal study where they tracked 79 adolescents that had been previously labelled by a psychiatrist as inhibited or uninhibited. The study reported that there was a significant relationship between early inhibited temperament (e.g. shyness) and later generalised social

anxiety. However, uninhibited temperament appeared to be a buffer against the development of social anxiety (Schwartz, Snidman, & Kagan, 1999).

Schmidt et al. (2008) and Kelly, Nazroo, McMunn and Marmot (2001) found that adolescents born at ELBW are more cautious, shy and risk averse than their NBW peers. They are found to be more introverted and socially withdrawn. The high probability of ELBW adolescents being socially withdrawn, subsequently increases the chance of experiencing loneliness and lower emotional well-being (Saigal, Ouden, Wolke, & Hoult, 2003; Schmidt et al., 2008).

Heiser, Turner, & Beidel (2003) report that the shyness temperament trait predisposes individuals to developing affective (anxiety and fear) related disorders such as social phobia, avoidant personality disorder, and selective mutism. Heiser, Turner, Beidel and Roberson-nay (2009) designed a study to understand the relationship between shyness and social phobia. The study suggested that shyness and social phobia are strikingly similar and can be viewed on a continuum. Shyness is a trait that does not significantly impair the individual's social or occupational functioning, whereas social phobia can be seen as extreme shyness (Marshall & Lipsett, 1994; McNeil, 2001; Stein, 1999). While many shy people do not meet the criteria for social phobia, individuals diagnosed with social phobia have a greater number of social fears, higher tendency to avoid social situations, more negative thoughts, and more somatic symptoms – than individuals that report being somewhat shy (on the lower end of the continuum). Shy individuals report symptoms of anxiety and fear, but do not always avoid social situations. Therefore, despite the shared features between shyness and social phobia, the exact nature of the relationship remains somewhat unclear (Carducci, Hutzel, Morrison, & Weyer, 2001; Heiser et al., 2009).

Contrary to the research reporting that ELBW adolescents exhibit inhibition, some research reports on disinhibited traits found in ELBW adolescents (Claas et al., 2011; De Pauw & Mervielde, 2010; Strang-Karlsson, 2011). Kelly, Nazroo, McMunn, and Marmot (2001) report that some adolescents born at ELBW appear to have behavioural problems similar to those seen in ADHD. According to De Pauw and Mervielde (2010) and Saigal et al. (2003) temperament affects the vulnerability to psychological problems – particularly related to inattention and hyperactivity at school age (Saigal et al., 2003). ADHD is found to be highly correlated with dimensions of temperament and there are correlations between temperament traits such as low

inhibitory control, poor attention, and all three subtypes of ADHD: hyperactive/impulsive, inattentive, and combined (symptoms of both inattention and hyperactivity/impulsivity). The relationship between temperament and ADHD reinforces the notion of a relationship between the biology and the psychological functioning of an ELBW individual (Jones et al., 2002; Rothbart & Derryberry, 2000).

While research clearly shows that an infant's temperament will play an important role in health and cognitive development, the influence of social systems such as the hospital he/she is born in and home environments should not be disregarded from a biopsychosocial perspective. Matsuo (2003) showed that the quality and amount of stimulation that children receive differs from one environment to the next and will impact on their psychological and social functioning. The most visible difference is between parents from different socio-economic classes, where children from lower socio-economic status families develop more slowly than individuals born into high socio-economic status families (Matsuo, 2003; Resnick et al., 1999). Factors such as nutrition and parents taking the time to stimulate their children, also play a role in development (Angelsen & Vik, 2001).

Social effects of being born ELBW

The QOL of ELBW adolescents is a good predictor of social functioning, which can be linked to physical health and mental well-being (Ho, 1995; Neubauer, Voss, & Kattner, 2008; Takai et al., 2011). QOL is a subjective and multidimensional concept that can be defined by the individual according to his/her physical and scholastic functioning, psychological state, and history of health impacting social or occupational functioning (Saigal et al., 2007; Zwicker & Harris, 2008).

There are contrasting research reports on the social effects of being born at ELBW. Saigal and Rosenbaum (1996) report that ELBW adolescents have significantly poorer physical abilities and a higher prevalence of chronic health conditions and functional limitations than their NBW; all of these have an impact on and are influenced by the social aspects of an individual's life. Zwicker & Harris (2008) report that the health-related symptoms diminish over time and as ELBW infants mature into adolescents, there is no significant difference in QOL compared to their NBW peers (Saigal & Rosenbaum, 1996; Zwicker & Harris, 2008).

Saigal & Rosenbaum (1996) have followed ELBW infants from birth to adolescence. The study cohort included 156 ELBW infants and 146 NBW controls, and they focused on assessing the sample's health-related QOL at 8 years, and then again in adolescence. At the age of 8 years the assessors interviewed parents and the quantitative data showed that ELBW children had more neurological impairments, functional impairments and poorer QOL than their peers. Subsequently, researchers reassessed the sample at adolescence, but asked the adolescents to complete the health-related QOL questionnaires. Adolescents reported that they experienced more limitations in cognition, self-care and pain compared to their NBW peers. Saigal et al. (2007) report that physical health and prevalence of chronic disease could also affect QOL. ELBW adolescents are observed to have more residual chronic health conditions such as seizures, recurrent bronchitis and asthma than their NBW peers (Boyle et al., 2011; Saigal, et al., 2003).

In contrast, Zwicker and Harris (2008) reviewed 15 journal articles that explored the health-related QOL of ELBW adolescents. Their analysis showed that parents of ELBW adolescent perceived their children as having a lower health-related QOL than their NBW peers. They reported that their children experienced academic, psychosocial, motor and behavioural difficulties at school age – but the ELBW adolescents perceived their QOL as being similar to that of their NBW peers.

According to UNICEF (United Nations Childrens Fund and World Health Organisation, 2004), 63% of children in South Africa come from families that live on a salary below the minimum wage and poverty line. More than 50% of South African children born at ELBW come from lower socio-economic classes. Resnick, Gueorguieva, Carter, Ariet, Sun and Bucciarelli (1999) argue that socio-economic and demographic factors have a large impact on QOL. This means that children born as ELBW in South Africa are more likely to have a poorer QOL than infants born in first world countries from higher socio-economic classes. The impact of having such a large percentage of children born as ELBW from lower socio-economic classes means that there is a larger percentage of infants with neurodevelopmental disorders and other health-related problems, that are unable to receive the required additional medical and emotional support. A long-term study on the neurodevelopmental outcomes of ELBW infants over a 12-year period showed children that experienced prolonged respiratory insufficiency associated with ELBW have delayed motor-functioning development, impaired growth, and increased morbidity. The rates of re-hospitalised and post-neonatal morbidity for

these children are significantly elevated in comparison to their healthy peers (Farel et al., 1992; Piecuch et al., 1997). The prolonged and recurrent hospitalisation impacts the individual's QOL negatively, due to impairment in development and physical functioning and the possible negative experience of being hospitalised many times.

Summary

ELBW is a phenomenon that provides developmental researchers with a model for understanding how exposure to adverse events early in life can impact on development across a variety of domains (Schmidt, Miskovic, Boyle, & Saigal, 2010). Individuals born at ELBW are the smallest and most at-risk infants, and are exposed to the greatest amount of pre- and perinatal risk. These stressful pre- and post-natal events are presumed to shape the developing brain and predict the development of the biological, psychological and social problems associated with ELBW.

Research on the long-term psychological impact of ELBW is lacking – possibly due to the only recent increase in long-term survival rates of ELBW infants. Nevertheless, the biological effects of ELBW include neurocognitive and functional impairments observed in CP, IDD, and developmental delays. Moreover, ELBW adolescents experience psychological problems such as anxiety, depression, low self-esteem and poor socialising ability. ELBW adolescents also appear to have a poorer QOL compared to their NBW peers given the effects of their biological and psychological outcomes on their social functioning.

Chapter 3: Method

The aim of the study was to explore temperament and psychopathology in ELBW and, to examine their links with QOL in adolescents born at ELBW. In order to answer the main research question (What is the relationship between temperament and psychopathology in adolescents born at ELBW?) and the sub-questions (What is the incidence of psychopathology amongst ELBW adolescents and in what ways are shyness, psychopathology and QOL related to each other in adolescents born at an ELBW?) – a quantitative method, underpinned by the positivist paradigm, was used. The method was chosen because objective and empirical data best served to establish the relationship between the tested factors (Kaboub, 2008).

Due to poor data-capturing techniques at public facilities, limited accessibility, and the denial of ELBW treatment, the population available for research was still very small in South Africa (Mackay et al., 2011). It was therefore decided to investigate only a small number of subjects to help later researchers decide on the feasibility of further and larger undertakings.

Research Design

For the purpose of this research a quantitative research method was adopted to answer the research question. Quantitative research seeks causal relationships between variables, and seeks to generalise the results of the study to a population group beyond that included in the sample (Cohen, Manion, & Morrison, 2005; Schrag, 1992). In this study, data from the RCBS was analysed and correlated to data on the SF12v2 and M.I.N.I in order to establish if there is a significant relationship between temperament and psychopathology in ELBW adolescents.

Glenshin and Peckshin (1992) state that quantitative research is “supported by the positivistic or scientific paradigm, which leads us to regard the world as made up of observable, measurable facts” (p.6). Augustus Comte (1797-1857), a French political and social activist, is considered to be the founder of positivism (Kaboub, 2008). Comte believed that science should be used to study those aspects of the human being that can be observed and measured. In this study there is an attempt to quantify temperament, psychopathology and QOL.

Positivism is defined by O'Boyle (2006) as "the assertion that only those aspects of the universe that can be publicly observed can be known for certain" (p.140). The positivist paradigm focuses on studying objective and empirical data that can be measured and quantified. This study made use of standardised questionnaires to obtain objective, empirical data. Four questionnaires were administered: 1) a biographical questionnaire, 2) the M.I.N.I., which was used to assess for psychopathology; 3) the RCBS to assess temperament; 4) and the SF12v2 to assess QOL.

Positivism suggests that reality can be observed empirically and explained with logical analysis (Kaboub, 2008). Positivist research requires a research setting that eliminates external influences that may contaminate the results. It is based on a scientific method, and a conclusion is derived from a causal explanation of the quantifiable data that have been gathered in an objective, controlled and valid manner (Kaboub, 2008; O'Boyle, 2006). This study is descriptive and not experimental, as it lacks a controlled environment and control group.

Sample size and selection

The sample was one of convenience due to the difficulty in accessing ELBW adolescents through public and private institutions. Request for access to patients' files were submitted to eight public and five private hospitals; however, permission to scan through hospital files to identify possible participants was only granted from Rahima Moosa Mother and Child Hospital (see Appendix C). This sample is therefore a restricted and isolated sample with a bias towards people in a socioeconomic group that cannot access private care. Individuals were also identified through advertisements on social media. Details of the study with contact numbers were posted on the following Facebook pages: "Support for mom's with premie babies" and on Dannita Borrageiro's personal Facebook page.

Adolescents born at a weight of less than 1000 g were invited to be part of this study. Adolescents older than 12 years and younger than 17 years and 11 months at the first meeting were included in the study. Of the 25 individuals contacted/that made contact with the researcher to participate in the study, 15 agreed to participate. The birth weights of participants were confirmed by recording the participant details from their hospital file or, alternatively, if they were contacted through social media - the parents of participants confirmed the child's weight.

Research setting and entrée

All questionnaires were administered at the homes of the subjects. On arrival at the home, the researcher explained the procedure to the parents and the ELBW adolescents. Written consent and assent were obtained from both parties, and the researcher completed each questionnaire with the participants.

Collection of data

Data were generated through the completion of four questionnaires. All four questionnaires were completed on the same day. The parents were asked to complete the biographical questionnaire and the SF12v2. Only one parent completed the questionnaires for each child. The ELBW adolescents were asked to complete the RCBS and M.I.N.I with the aid of the assessor. Due to physical handicap (CP-related impairments) three parents were required to fill out all four questionnaires on behalf of their ELBW adolescents.

Biographical questionnaire

The questionnaire was used to obtain socio-demographic information such as age, education, income and previous developmental history (including prenatal and perinatal development). The education of parents and the diagnosis of any family physical and psychological conditions were also recorded.

Mini International Neuropsychiatric Interview 5.0.0

The M.I.N.I is a structured interview questionnaire developed by Sheehan and colleagues in 1992. The questionnaire consists of 120 items with yes/no responses. It is used to diagnose 17 Axis I disorders (major depression, dysthymia, mania, panic disorder, agoraphobia, social phobia, generalised anxiety disorder, obsessive compulsive disorder, psychosis, alcohol abuse, alcohol dependence, drug abuse, drug dependence, anorexia, bulimia, post-traumatic stress) (Sheehan et al., 2010). The disorders are classified according to the Diagnostic and Statistical Manual of Mental Disorder (DSM)-IV-TR), (American Psychiatric Association, 2013; Mula et al., 2009).

The M.I.N.I has been translated into a number of languages. The English version and translations show sound psychometric properties (Amorim, Lecrubier, Weillerl, Hergueta, &

Sheehan, 1998; Cohen, Vardy, Weiner, Shvartzman, & Aviv, 2005). In a study by Bunevicus, Peceliuniene, Mickuviene, Valius and Bunevicius (2007) 503 primary health care users who were consecutively admitted into health care facilities in Kaunas, Lithuania were assessed for symptoms of depression and anxiety that met the criteria for the disorders. The M.I.N.I had a Cronbach's alpha coefficient of 0.78, indicating good reliability for a screening instrument.

The Revised Cheek and Buss scale (RCBS)

This inventory was developed by Cheek and Buss in 1983. It is a 13-item measure that is based on the original 9-item measure of shyness and sociability developed in 1981. It is designed to measure shyness and sociability. Items are rated on a Likert scale from 0-5 (Hopko et al., 2005). In brief, sociability "is a preference for affiliation or need to be with people", and shyness is "the discomfort and inhibition that may occur in the presence of others" (Cheek & Buss, 1981, p. 330).

According to research by Hopko et al. (2005), the RCBS has high validity and reliability scores. The RCBS was found to have strong internal consistency ($\alpha=.90$), an excellent 45-day, test-retest reliability and correlation with original nine-item version (Hopko et al., 2005). The 13-item scale measures the tendency to behave awkwardly in social situations (e.g. "I find it hard to talk to strangers") and to experience unpleasant affect in the presence of others (e.g. "I feel tense when I am with people I don't know well"). The scale is internally consistent, with an alpha of .79 ($n = 913$) (Cheek & Buss, 1981).

Total scores on the RCBS range from 13 to 65. Cheek and Buss (1983) propose that individuals scoring over 49 should be considered very shy, those with scores over 39 should be considered shy, and individuals scoring below 39 should be recognised as non-shy or sociable.

The Medical Outcome Study 12-Item Short-Form Health Survey version 2 (SF12v2)

The second version of the SF12 is a 12-item questionnaire that measures QOL based on an individual's physical and mental health over the last four weeks. It was developed by RAND Corporation and Medical Outcome Study (MOS), in 2002, as a subset scale of the SF-36 health-related quality of life measure. The SF-12v2 includes a 12-item summated rating scale, which measure the original eight domains of health: 1) limitations in physical activities because of

health problems; 2) limitations in social activities because of physical and emotional problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities, because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions (Ware & Sherbourne, 1992). These domains are used to calculate two component scores. Firstly, there is the Physical Component Summary (PCS) which is defined as the grouping of scores that reflect the individual's physical well-being. It comprises the total of the scores derived from the physical functioning, role functioning-physical, bodily pain, and general health domains. Secondly, there is the Mental Component Summary (MCS), which is defined as the grouping of scores that reflects the individual's mental well-being. It comprises the total of the scores derived from the vitality, social functioning, role functioning-emotional, and mental health domains (Güthlin & Walach, 2007; Saigal et al., 2007). The scoring of the questionnaire uses norm-based scoring. Each scale is scored to have the same mean of 50 and standard deviation of 10. If a scale score is below 50, health status is considered to be below average relative to the general population (Ware, Kosinski, Turner-Bowker, & Gandek, 2002).

According to research by Ware, Kosinski, Turner-Bowker and Gandek (2002), the SF12v2 has a good test-retest reliability. The reliability of the summary measures was high, with a Cronbach's alpha of 0.89 for PCS and 0.86 for MCS (Cheak-Zamora, Wyrwich, & McBride, 2009; Ware et al., 2002).

Data analysis strategies

Data was captured in an Excel spread sheet and transferred to SPSS 22. Given the small sample ($N = 15$) the median and not the mean values are focused on, in the descriptive statistics. Correlation analysis was conducted using the non-parametric Kendall-tau-b statistic. The Kendall-tau-b is used to measure associations between two variables. Specifically it is a measure of rank correlations to establish if two variables may be regarded as statistically dependent and is considered appropriate for small samples (Field, 2000). Kendall-tau-b was used to correlate variables derived from the four questionnaires. Guidelines from Cohen and Cohen (1983) were used in the discussion of strength of correlation: when $r = .1$ to $.3$, it indicates a small effect; if $r = .3$ to $.5$, it indicates a moderate effect; while an $r > .5$ indicates a large effect. The Mann Whitney U Test was used for comparing the RCBS scores and the SF12v2 scores (continuous data) and The Fisher's Exact test was used for comparing M.I.N.I

results (categorical data) across specific groups (Field, 2000). The level of significance was set at $p \leq .05$ for all calculations.

Validity and reliability of the questionnaires used in the study

In order to ensure that each parent and participant understood each questionnaire fully the interviewer was available to assist with any language problems or difficulty understanding any questions throughout completing the questionnaires. Furthermore, each questionnaire was carefully chosen by assessing its applicability and reliability within the South African context. Each questionnaire was screened for high reliability and validity scores. The questionnaires were also chosen based on previous research conducted on similar topics with a sample of similar ages.

The MINI has been proved to have acceptable validity and reliability scores according to multiple studies the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10 (A. D. Cohen et al., 2006; DV Sheehan et al., 1998). It has been used in a variety of studies focusing on the diagnosis of psychiatric illnesses and identifying symptoms of disorders such as ADHD, depressions, PTSD, bipolar mood disorder and anxiety. Based on the literature review on common psychiatric illnesses found in ELBW individuals, the previous studies good reliability and validity scores indicate it is a valid tool in assisting with the diagnosis of psychiatric illness in ELBW adolescents. Although it does not have norms for the South African population, the M.I.N.I is the most widely used psychiatric structured diagnostic interview instrument in the world and is used by mental health professionals and health organizations in more than 100 countries. The M.I.N.I has also been used in multiple studies conducted in the South African context, it has been found to be reliable and valid in research associated to the measurement of symptoms of psychiatric disorders in patients that suffer from PTSD, depression, substance abuse and anxiety (Bunevicus et al., 2007; Dannatt, Cloete, Kidd, & Weich, 2014).

The RCBS was chosen because it has high validity and reliability scores (Hopko et al., 2005). It also has high validity scores when correlated with the original 9- item Cheek and Buss Scale (Cheek & Buss, 1981). Hopko et al. (2005) did a comprehensive review of the RCBS and found that it has a strong internal consistency of .86 and strong 2-week test-retest reliability of .88. Currently there is no available data on South African norms for the RCBS. However

based on its extensive research world-wide and extensive use in a South African population it was seen to be a good measure for assessing anxiety and shyness in ELBW adolescents (Hopko et al., 2005; Terblanche, 2011).

The SF12v2 has been found to have high validity and reliability scores (Ware et al., 2002). The questionnaire has been used in multiple studies to measure QOL and physical and mental health of patient (Andersen, Mühlbacher, Nübling, Schupp, & Wagner, 2007; Chin et al., 2011; Landgraf, Vogel, Oostenbrink, Van Baar, & Raat, 2013). Currently there are no South African norms developed for the SF12v2, but this questionnaire has been researched for its cross-cultural vulnerability, the results from the study indicate that it yields satisfactory validity and reliability scores to be used cross-culturally (Obtel et al., 2013).

Ethics

Ethics clearance for the original study was obtained from the University of South Africa's Department of Psychology. Permission was also obtained from Rahima Moosa Mother and Child Hospital to scan through records to obtain contact details for ELBW adolescents (see Appendix G). Parents were contacted and invited to attend a scheduled session.

At the outset of the study, the parents of the ELBW adolescents were informed of the research aim and process, and they received a clear explanation of what would be expected of them and their children. The parents were allowed to ask questions and raise any concerns pertaining to participation in the study. Parents were informed about the disclosure of their identifying information, the reason for the study and how this study could assist in ELBW research. The information allowed them to make an informed decision about participating in the study and deciding if they wanted their children to participate. Parents were asked to provide written informed consent to participate in the study once they understood what would be required of them and their children (see Appendix A). The ELBW adolescents were then approached and asked to be part of the study. Written assent was obtained from the minors (see Appendix B). The option of deciding to retract their participation if they felt the need later in the study was also given.

Confidentiality and anonymity were explained to the parents and ELBW adolescents. All the information collected during the course of this research study is protected against

unwarranted access. Participants were given the option to leave out their names and remain anonymous or withdraw from the study if any unforeseen circumstances were to arise. Identifying information will not be released publicly. The electronic data are kept on a password-protected computer. Written data are stored and kept under lock and key with the researcher for five years (for auditing purposes). The researcher and the supervisor are the only people with access to the data.

Upon terminating the interview process, the interviewer's contact details were shared with the participants. Participants were informed that the results of the study would be reported back to them through informal feedback, a face to face feedback session or email, depending on the availability of the participants and their personal preferences.

Chapter 4: Results

This chapter presents the results of the study. The aim of the study was to explore temperament and psychopathology in ELBW, with additional exploration of QOL in relation to temperament and psychopathology. The descriptive results are reported according to the specific questionnaires used in this study. This is followed by correlations and then comparisons of questionnaire outcomes across various sub-groupings.

Description of the sample

From the descriptive information, a context is formed to answer the first research sub-question (What is the incidence of psychopathology amongst ELBW adolescents?). Table 4.1 (below) presents the biographical data. The gender distribution was slightly biased towards male children ($n = 9$; 60%). The median age in years was 13 $SD = 2.526$. The race of the sample was biased towards Caucasians ($n = 10$; 67%), while three (20%) were coloured and two (13.3%) were Indian. All participants spoke English as a first or second language, while nine participants (60%) also spoke Afrikaans and two (13.3%) were exposed to a third language.

All participants had attended some form of schooling: three (20%) of the sample attend a school for special-needs children, while one (6.7%) has a Grade 4 level of education, two (13.3%) attained a Grade 5 level of education, *one* (6.7%) attained a Grade 6 level of education and three (20%) have completed Grade 7. All ELBW adolescents attending a mainstream school had attained the appropriate number of years of education in relation to their ages.

Table 4.1. Biographical data

Variable	Frequency (n; %)
Gender: <ul style="list-style-type: none">• M• F	9; 60 6; 40
Race: <ul style="list-style-type: none">• Caucasian• Coloured• Indian	10; 66.7 3; 20.0 2; 13.3
Highest level of education: <ul style="list-style-type: none">• Grade 4• Grade 5• Grade 6• Grade 7• Grade 8• Grade 10• Special-needs school	1; 6.7 2; 13.3 1; 6.7 3; 20.0 2; 6.7 3; 20.0 3; 20.0
Languages spoken at home: <ul style="list-style-type: none">• English• Afrikaans• Other	15; 100 9; 60 6; 40

Birth

As shown in Table 4.2 (below), nine (60%) of the sample was born in a private hospital, whereas six (40%) were born in public hospitals. Currently, eleven (73.3%) of the sample have medical aid and make use of private hospital services, whereas four (26.7%) of the sample do not have medical aid. Parents reported that ten participants (66.7%) in the sample were born between 25 and 30 weeks and five (33%) of the sample was born between 30 and 35 weeks, requiring them to be admitted into NICU in respective hospitals. Parents were also asked to report on the weight at which their child was born: four (26.7%) of the sample weighed 701-800 g at birth, six (40%) 801-900 g and five (33.3%) of the sample 901-1000 g.

Table 4.2. *Hospital and medical aid status of ELBW infants*

Variables	Frequency (n; %)
Hospital born in: <ul style="list-style-type: none">• Private• Public	9; 60 6; 40
Gestational age group: <ul style="list-style-type: none">• 25-30• 31-39	10; 66.7 5; 33.3
Birth weight (grams): <ul style="list-style-type: none">• 701-800• 801-900• 901-999	4; 26.7 6; 40 5; 33.3
Medical aid <ul style="list-style-type: none">• Yes• No	11; 73.3 4; 26.7

Psychological impairments

In Table 4.3 (below) a summary of the adolescents psychological functioning is reported by their parents– as well as any previous diagnosis of a mental illness. Parents reported that nine (60%) of their children experience concentration problems on a daily basis, two (13.3%) reported such problems four to five times a week, two (13.3%) reported concentration problems two to three a times week, and two (13.3%) reported only once a week. Parents also reported that three (20%) of adolescents had previously been diagnosed with ADHD, two (13.3%) had been diagnosed with IDD, and one (6.7%) had been diagnosed with bipolar mood disorder, most recent episode mania.

Parents were asked if they thought that their children appeared to be different to their peers. As shown in Table 4.3 (below), six (40%) were reported to be different by their parents. Two of those parents reported that their children had been diagnosed with CP. Parents explained that CP limits the physical movement of their children and subsequently delayed their basic developmental milestones significantly. One mother reported that her daughter was introverted and that her child was not like her peers because she enjoyed being alone, and when in a group of people she would be very quiet, and she avoided any activities that would attract attention. Two children (13.3%) were reported to be hyperactive. One mother reported that, as a baby,

her child was diagnosed with hydrocephalus. The doctors inserted a drainage pipe into the child's left hemisphere to drain the additional cerebrospinal fluid accumulated on the brain, and, unfortunately, she has never been able to attend a regular school and her daily activities need constant monitoring.

Table 4.3 *Psychological problems reported by the parents of ELBW adolescents*

Variable	Frequency (n; %)
Parents' perception of their child's concentration problems at school <ul style="list-style-type: none"> • One a week • 2-3 times a week • 4-5 times a week • Daily 	2; 13.3 2; 13.3 2; 13.3 9; 60.0
Parents' perceptions of whether or not their child is different <ul style="list-style-type: none"> • Yes • No 	6; 40 9; 60
Parents' perceptions of how their child is different from their peers <ul style="list-style-type: none"> • CP • Hyperactivity • Introverted • Hydrocephalus 	2; 13.3 2; 13.3 1; 6.7 1; 6.7
Previous diagnosis of a psychological disorder <ul style="list-style-type: none"> • ADHD • IDD • Bipolar Mood Disorder 	3; 20 2; 13.3 1; 6.7

Parent demographics

Table 4.4 (below) presents the employment status and the education levels of the parents. Eleven (73.3%) of the parents are employed whereas four (26.7%) unemployed. Only one (6.7%) of the parents did not complete any formal schooling, while five (33.3%) had completed tertiary education, five (33.3%) had completed secondary education, and four (26.7%) parents had completed primary school.

Table 4.4 *Parent demographic details*

Variable	Frequency (n; %)
Parent employment status <ul style="list-style-type: none">• Employed• Unemployed	11; 73.3 4; 26.7
Highest level of education achieved by primary care giver <ul style="list-style-type: none">• Primary school• Secondary school• Tertiary education• Never completed any level of schooling	4; 26.7 5; 33.3 5; 33.3 1; 6.7

The Revised Cheek and Buss Scale

The scores on the RCBS range from 13 to 65. As suggested in literature, a cut-off score of 39 was used for this study to differentiate the shy from the sociable individual (Hopko et al., 2005). Figure 4.1 (below) illustrates the scores obtained from the participants on the RCBS. The results show that four (26.7%) participants were classified as sociable and 11 (73.4%) were classified as somewhat shy. There were no participants classified as very shy. The median score was 41, $SD = 2.71$.

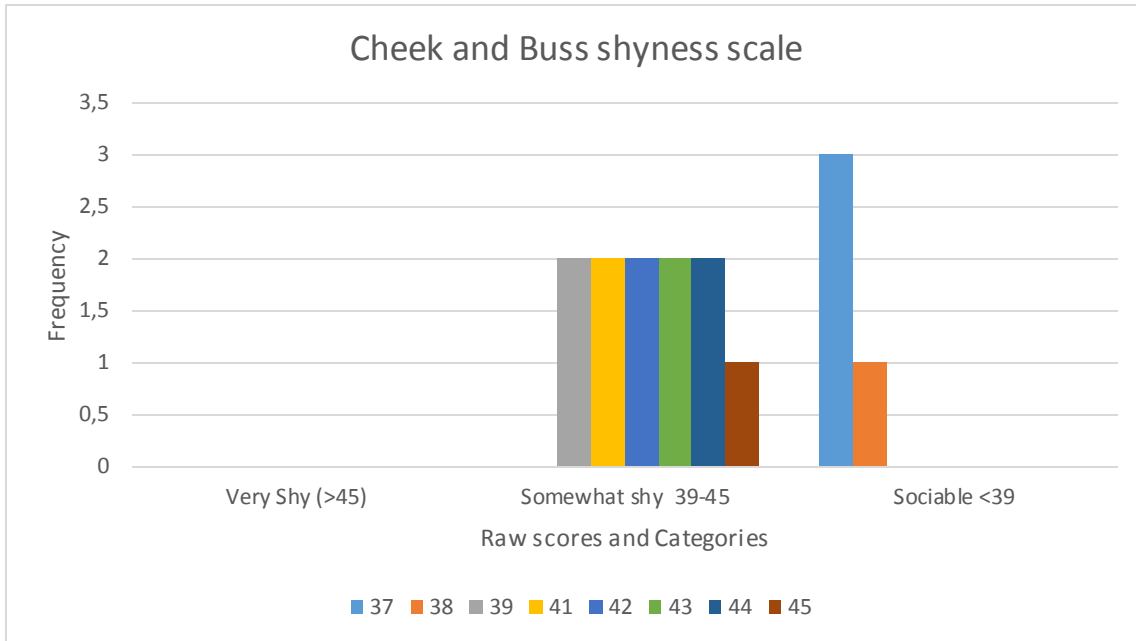


Figure 4.1. The frequency of shyness and sociability on the RCBS

M.I.N.I.

The results of the M.I.N.I. indicated positive results for three categories. One (6.7%) of the ELBW adolescents met the criteria for bipolar mood disorder 1, most recent episode manic. Six (40%) adolescents reported symptoms of social anxiety that met the criteria for social phobia disorder. One (6.7%) participant met the criteria for generalised anxiety disorder. None of the other psychological disorders indicated positive results and therefore are not reported.

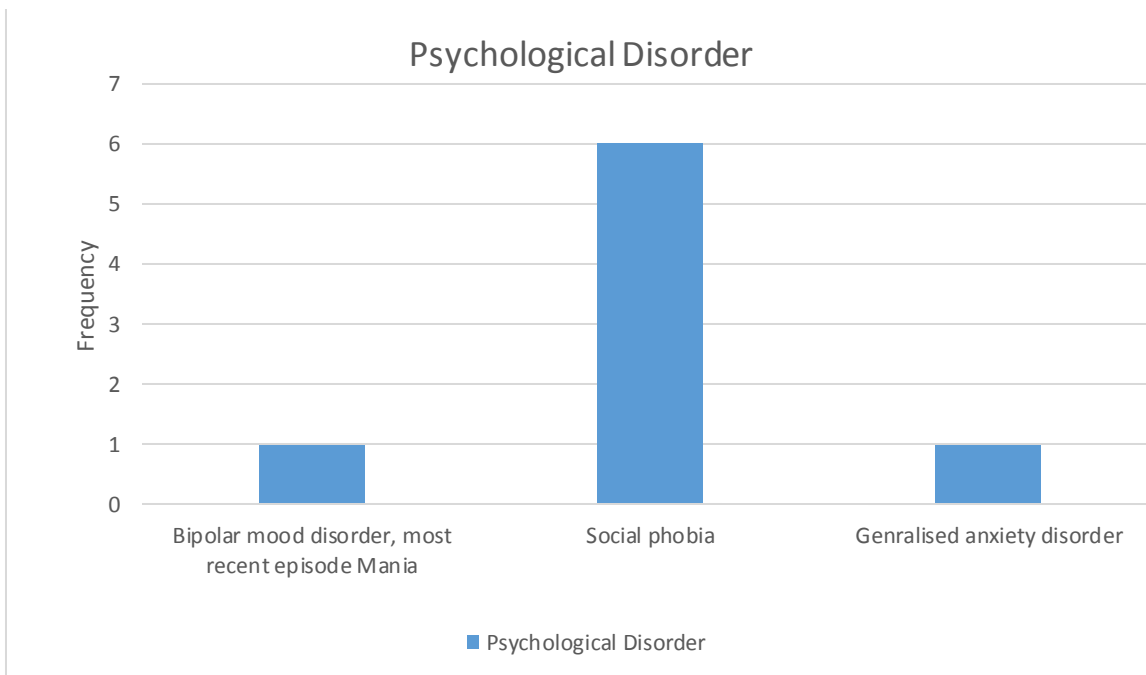


Figure 4.2. Significant results found on the M.I.N.I.

Short Form 12 version 2

The parents of ELBW adolescents were asked to report on the current functioning of their children over the past four weeks. Table 4.5 (below) illustrates the parents' reported views of their children's current QOL. The median physical functioning of the sample was 50.00 with a $SD = 33.806$; the median score for role functioning (physical) was 0.00 with a $SD = 11.764$. Bodily pain yielded a median score of 100.00 with $SD = 22.887$; the general health median of the sample was 60 with $SD = 24.485$; vitality median was 50, with $SD = 26.502$; the social functioning median of the sample was 75, with $SD = 30.178$; the role functioning-emotional median was 12.50, with $SD = 7.420$; the mental health median 62.50, $SD = 15.285$; and the physical component median was 48.83, with $SD=10.628$ and mental component median at 36.84, with $SD = 4$. Although the emphasis is on the median scores for this small sample, the general guidelines for the SF12v2 indicate a mean score of 50 as the norm, with a standard deviation of 10 (Ware et al., 2002). Normative data for median scores could not be obtained. Therefore, it was considered practical to examine the mean scores for descriptive purposes – to view emerging patterns. Low mean scores (< 40) are noted on the role functioning (physical and emotional) and on the mental component. High mean scores (> 60) are noted on Bodily pain and mental health.

Table 4.5. Descriptive statistics of SF12v2 domains of functioning (N = 15)

Variables	Physical Functioning	Role Functioning (Physical)	Bodily Pain	General Health	Vitality	Social Functioning	Role Functioning (Emotional)	Mental Health	Physical Component	Mental Component
Median	50.00	0,00	100.00	60.00	50.00	75.00	12.50	62.50	43.83	36.84
Mode	50	0	100	60	25 ^a	75	13	50	21 ^a	30 ^a
Mean	60.00	10,00	86.67	49.33	46.67	55.00	15.83	65.83	44.73	37.77
Std. Deviation	33.806	11.764	22.887	24.485	26.502	30.178	7.420	15.285	10.628	4.613
Range	100	25	75	100	100	100	25	38	41	15
a. Multiple modes exist. The smallest value is shown										

Correlations

The correlations and comparisons in the next section provide information to answer the main research question (What is the relationship between temperament and psychopathology in adolescents born at ELBW?). These correlations also ultimately allow the answering of the second sub-question, i.e. in what ways are shyness, psychopathology and QOL related to each other in adolescents born at an ELBW?

Correlations were explored by using Kendall-tau-b correlations to assess the degree of association between variables (Field, 2000). Correlation was explored between the following variables to answer the temperament-psychopathology research question: RCBS score; whether or not the caregivers perceived a concentration problem; how often the adolescent was perceived as having concentration difficulties; family history of psychological problems; the three M.I.N.I categories that were represented (i.e. bipolar disorder with most recent episode manic, GAD and social phobia) and whether or not the adolescent has a previously diagnosed psychological disorder. To answer the sub-question involving QOL, the SF12v2 domains of functioning were added to the previous list. To provide some contextual information, gender, race, the gestational age and the weight at which the adolescent was born were also investigated.

Kendall-tau-b correlations of the above-mentioned variables yielded a number of significant results. There are strong negative correlations between: The previous diagnosis of a childhood psychological disorder in the adolescent and social phobia ($r = -.667, p = .013$), the diagnosis of a childhood psychological disorder in the adolescent and shyness ($r = -.594, p = .011$), shyness and physical functioning ($r = -.662, p = .003$); shyness and role functioning-physical ($r = -.637, p = .004$); bodily pain and vitality ($r = -.572, p = .008$); gender and the gestational age ($r = -.577, p = .027$) and between physical functioning and general health ($r = -.527, p = .031$). Moderate negative correlations are found between physical component and mental health ($r = -.480, p = .022$) and shyness and age ($r = -.463, p = .029$). Meanwhile, a weak negative correlation was found between the mental health component and physical health component ($r = .390, p = .042$).

There are strong positive correlations between the diagnosis of a psychological disorder and physical functioning ($r = .570, p = .026$); between the diagnosis of a psychological disorder and role functioning-physical ($r = .603, p = .019$); between role functioning-emotional and race

($r = .557, p = .027$); role functioning-physical and physical functioning ($r = .818, p = .001$); general health and bodily pain ($r = .501, p = .040$); between general health and the physical component ($r = .676, p = .002$); physical functioning and bodily pain ($r = .603, p = .007$); vitality and physical functioning ($r = .680, p = .004$); physical functioning and physical component ($r = .793, p < 0$); role functioning-physical and bodily pain ($r = .571, p = .020$); vitality and role functioning-physical ($r = .544, p = .021$); social functioning and bodily pain ($r = .492, p = .036$); mental health component and bodily pain ($r = .742, p < 0$); physical component and physical functioning ($r = .793, p = .001$); role functioning-physical and physical component ($r = .697, p = .001$); bodily pain and physical functioning ($r = .659, p = .002$); vitality and physical functioning ($r = .604, p = .004$). There is a moderate positive correlation between general health and role functioning-physical ($r = .481, p = .049$); and physical functioning and social functioning ($r = .471, p = .045$). When examining patterns of correlations as illustrated in Figure 4.2 (below), temperament appears to have more significant correlations with physical components of QOL in comparison to mental components.

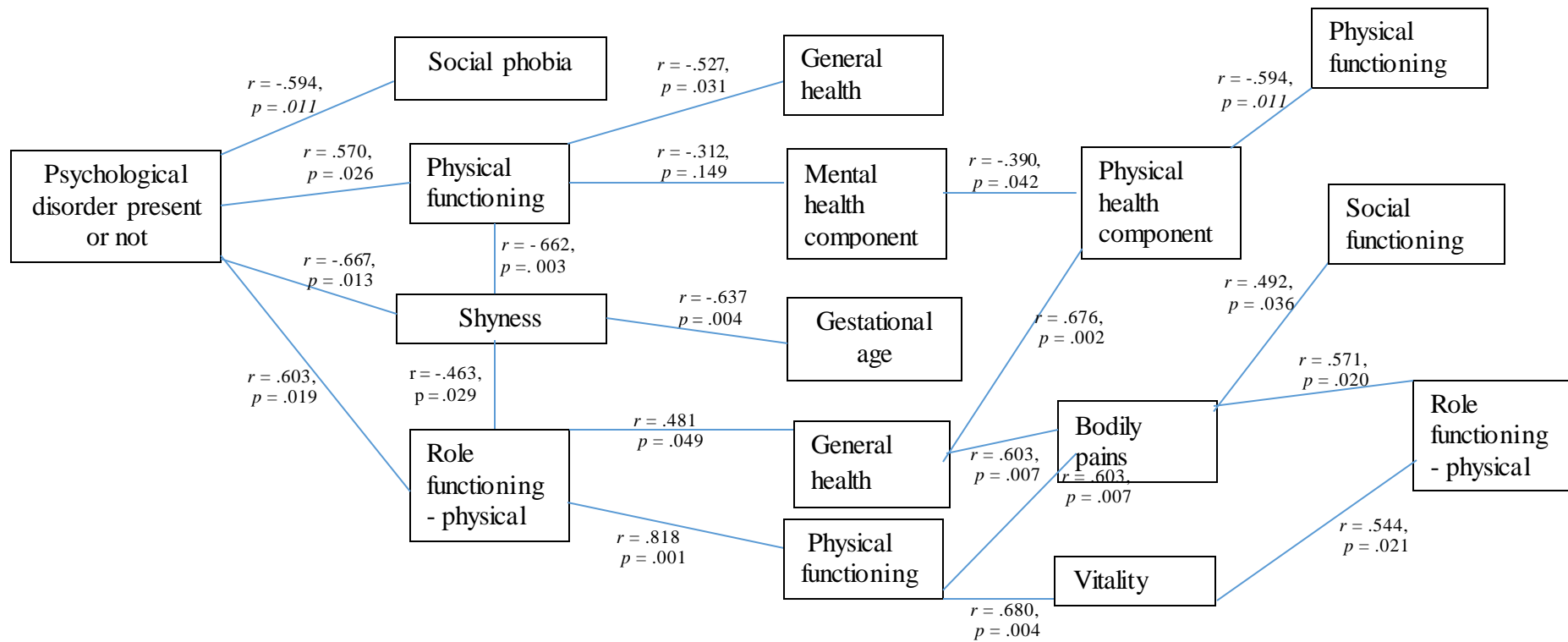


Figure 4.3. Significant correlations between variables

Comparisons across groups

The comparisons across groups help provide further understanding around the relationship between temperament and psychopathology in adolescents born at ELBW. Using Fisher’s Exact Test, comparisons were conducted for three positive M.I.N.I categories that were represented (i.e. manic episode, GAD and social phobia) across the following groups: gender, race, type of hospital in which the adolescent was born, employment status of the primary caregiver, whether or not the family has medical aid, gestational age, birth weight category, whether or not the adolescent has a concentration problem, family history of physical illness, family history of psychological disorders, and whether or not the adolescent has been diagnosed with a psychological disorder. No significant differences were found. RCBS scores and SF12v2 domains were compared across the same groups (with the addition of comparisons for whether or not the adolescent met the criteria for GAD, social phobia or manic episode on the M.I.N.I.) using the Mann-Whitney U-Test. Only significant data is reported in this section, but Appendix D illustrates all results of the Fisher’s Exact Tests and Mann-Whitney U-Tests. Significant differences (shown in Table 4.6. below) were found when comparing RCBS and SF12v2 scores across:

- Absence and presence of a diagnosed psychiatric disorder in the child; and
- Absence and presence of social phobia as diagnosed on the M.I.N.I.

Table 4.6.

Significant ($p < .05$) results for comparisons of shyness and QOL domain scores across groups

Group	Variable	RCBS Score	Role functioning (physical)	Mental health
	Absence vs presence of diagnosed childhood psychological disorder	p = .007	p = .041	
	Absence vs presence of social phobia (on the M.I.N.I)	p = .041		p = .041

The diagnosis of a child psychiatric disorder

The RCBS scores were significantly higher in adolescents with a diagnosed psychiatric disorder ($p = .007$) than for those without. This means that there is a significantly higher degree of shyness in adolescents with the diagnosis of a psychological disorder than those without.

When comparing SF12v2 domains amongst children with or without a psychological disorder, role functioning (physical) was significantly different ($p = .041$). This demonstrates that the role functioning (physical) scores of ELBW adolescents with a previous diagnosis of a psychological disorder is significantly higher than those without a previous diagnosis of a psychological disorder.

Social phobia

When comparing the children with and without social phobia according to the M.I.N.I., RCBS scores were significantly higher amongst those qualifying for the diagnosis than amongst those who do not ($p = .041$). Mental health scores of adolescents with social phobia are also significantly lower than in those without the disorder ($p = .041$).

Summary

Effects of ELBW in this sample included CP and hydrocephalus. Effects noted later in life by the adolescents and their parents included concentration problems, ADHD, social phobia, GAD and bipolar mood disorder. Of note from the psychological functioning of the sample, was that only two individuals in it have a formal diagnosis of ADHD, but more than half the sample reported symptoms of concentration difficulties and symptoms of mania that appear to overlap with ADHD symptoms.

Though the parents report that their children are generally healthy, they also report that the same adolescents experience high degrees of body pain, physical and emotional role limitations and poor mental well-being. There are indications of some discrepancies in the parents' reporting of their children's QOL.

Correlation analysis using Kendall-tau b correlation identified significant results pertaining to the relationship between a few variables. Though no significant correlations are noted between shyness and any diagnoses on the M.I.N.I., a previous diagnosis of a psychological disorder score is significantly related to lower shyness scores. Further investigation of this relationship shows that shyness scores differ significantly in adolescents with or without a diagnosis of a psychological disorder. The degree of shyness was also found to differ significantly in those with social phobia in comparison to those without. Furthermore, there is a significant difference in the mental health scores of children with and without social phobia

and in role functioning for those with or without a diagnosis of a psychological disorder. This implies a pattern of significant relationships between temperament, psychopathology and QOL. The results are discussed in more detail in chapter 5.

Chapter 5: Discussion

This chapter presents a discussion of the findings – in which the theory, results and literature reviewed are integrated. The dissertation concludes by discussing the study's findings. This is followed by a description of the strengths and limitations of the study and the recommendations for future studies.

The aim of conducting this research study was to explore temperament and psychopathology in adolescents born at ELBW, with the secondary aim of examining their links with QOL in these individuals. The research questions centred on the incidence of psychopathology, the relationship between the shyness temperament and psychopathology and the relationship of temperament and psychopathology to QOL in ELBW adolescents. The rationale for the study was underpinned by the increased survival rate of ELBW infants and the lack of research on the longer term outcomes for survivors in South Africa. Over the past 40 years there has been a global increase in the survival rates of ELBW infants due to increased offerings of intensive care; maternal steroids; surfactant therapy; and alternative medical advances in treating ELBW (Cooke, 1996; Lorenz, 2001; Simeoni et al., 2004; Strang-Karlsson, 2011). The objective was to examine shyness on the RCBS, psychopathology using the M.I.N.I. and QOL using the SF12v2 in South African adolescents aged 12 to 18 years and born at ELBW. After obtaining ethics clearance, approaching eight local hospitals in Gauteng and advertising the study on social media, a sample of 15 ELBW adolescents was realised. These subjects and their guardians were interviewed in their homes.

Immediate effects

Research in Canada, Australia and Japan by researchers such as Boyle et al. (2011) and Saigal et al. (2003) has identified common neurodevelopmental impairments associated with ELBW infants. Parents, doctors and school teachers are increasingly reporting cases of IDD, CP, and neurosensory abnormalities such as visual and auditory impairment (Olivieri et al., 2012; Schmidt, Miskovic, Boyle, & Saigal, 2008; Schmidt, Miskovic, & Boyle, 2010). These adverse outcomes occur in approximately 20-30% of ELBW survivors (Tekolste et al., 2004).

In this study, two (13.3%) of the subjects were reported to be diagnosed with CP. CP was found to limit their physical movement and it has delayed their basic developmental milestones significantly. CP begins early in childhood and persists through a life span –leading to a poorer QOL due to physical impairments and developmental delays. A large body of research (Chan et al., 2008; Sweet et al., 2003; Tekolste et al., 2004; Vohr et al., 2000) reports that ELBW is also a risk factor for being born with CP: CP is diagnosed in 10-20 % of ELBW infants and this comparable to 13.33% in this study.

In this study it was also found that one of the respondents had been diagnosed with hydrocephalus. At birth, the ELBW adolescent had water on the brain, and the doctors inserted a drainage pipe into her left hemisphere to drain the additional cerebrospinal fluid that had accumulated on the brain. The child was unfortunately never able to attend a regular school and her daily activities need constant monitoring. The individual has been diagnosed with IDD and has severe impairment in her adaptive functioning.

Outcomes in adolescence

The longer-term effects of being born at ELBW are largely unexplored in the literature and in South Africa, in particular, there has been scant relevant research. In order to gain a holistic view of the outcome of ELBW in adolescents, a biopsychosocial approach was taken. This approach allows us to explore the biological, social and psychological factors that play a significant role in the outcome of being born at ELBW – in a circular and holistic manner (Goodman, 1991; Smith, 1961). This approach allows for a broader multidimensional approach to the relationship between mind and body, and, ultimately, this examines how both nature and nurture might jointly influence the outcome of an ELBW adolescent. The high prevalence of neurocognitive impairments and CP may hamper the development of ELBW individuals into adolescence. This may be due to the infant's delayed developmental milestones – leading to a lag in autonomic movement, functioning in school and social performance, to mention a few. In addition, ELBW infants are found to have a more shy/risk-averse temperament compared to their peers, which puts them at risk of developing avoidant interactional styles and psychological disorders such as anxiety (Schmidt, Miskovic, Boyle, & Saigal, 2008). Socio-economic status, parental support and involvement relating to intellectual stimulation and development, and the development of a psychological disorder and temperament – all contribute to QOL in the ELBW adolescent (Zwicker & Harris, 2008).

Globally, an estimated 15.5 % of babies are born at LBW, but more than 90% of those babies are born in developing countries (Wielligh, 2012) – indicating a large percent of ELBW infants born to families of low socio economic status. Associated with low socio-economic status is poor nutrition, unavailability of parents due to intense labour and low wages, and minimal time for intellectual stimulation of children – thus impacting on their prognosis negatively (Elgen & Sommerfelt, 2002; Indredavik et al., 2004; Saigal et al., 2007).

In the current study, most participants were born in private hospitals in South Africa at a gestational age between 25 and 30 weeks (i.e. very preterm), and weighing 701-800 g. The closer infants are born to full-term (30-40 weeks), the better the prognosis of the outcome of the ELBW infant – due to the development of the infant's lung capacity and organs (Lorenz, 2001). Birth weight has also been found to be an important indicator of health status and better QOL later on. The lower the birth weight, the more health problems are experienced immediately after birth through to later in life (Matsuo, 2003). For example, Hack et al. (1994) conducted a comparative study of ELBW adolescents with birth weights under 750 g and those weighing 750-1499 g. They found that adolescents weighing less than 750 g at birth had more cognitive impairments, difficulty with academic functioning, and poorer psychomotor/social skills and adaptive functioning and behaviour than adolescents who were born weighing more than 750 g.

Recent research indicates that infants born in private hospitals have an increased chance of survival in South Africa, in comparison to those born in public hospitals due to availability of hospital resources like mechanical ventilators, surfactant steroid therapy and medical technology (Cooper & Sandler, 1997; Mokhachane et al., 2006; Partridge et al., 2005). The majority of the subjects in this study ($n = 9$; 60%) were born in a private hospital. In addition, the majority of parents were employed ($n = 11$; 73.3%) and educated to high school or tertiary training level ($n = 10$; 66.6%). This may have led to better outcomes for this sample than may otherwise be expected in developing country contexts and should be taken into account when generalising findings.

The incidence of psychopathology amongst ELBW adolescents

ELBW individuals are at higher risk of developing psychological problems such as poor attention and concentration, learning disorders, psychomotor impairment, shyness and social

phobia – in comparison to their peers (Cooke, 1996; Olivieri et al., 2012; Pistorius, 2011). In the current study, 40% of the respondents reported symptoms of social anxiety that met the criteria of social phobia disorder, 6.7% for bipolar mood disorder 1, most recent episode manic, and 6.7% for GAD – according to the M.I.N.I criteria. Interestingly, 40% of ELBW adolescents reported symptoms of mania in bipolar mood disorder that did not meet the criteria for a manic episode. Reports by parents indicated that 40% of the adolescents were previously diagnosed with ADHD.

Anxiety disorders

ELBW are the smallest and most at-risk infants that are exposed to pre- and post-natal risks. From a biopsychosocial perspective, research has found that ELBW adolescents experience psychological problems such as anxiety – due to the interactions of genetic predisposition, low self-esteem, shyness and poor socialising ability (Indredavik et al., 2004; Ristvedt & Trinkaus, 2009; Saigal, et al., 2003). ELBW is found to be associated with internalising problems related to anxiety, such as social phobia and GAD (Strang-Karlsson, 2011).

Social phobia is described as an intense fear of social situations, where one fears being watched or judged – and the situations may be so anxiety provoking as to force one to try and avoid them (Carducci et al., 2001; Schmidt & Fox, 1995; Schwartz et al., 1999). Six of the fifteen individuals (40%) of the current sample reported symptoms of social phobia that met the criteria for social phobia disorder. One (6.7%) participant met the criteria for GAD. This is similar to the report that 8-10% of ELBW adolescents suffer from some form of anxiety disorder or the symptoms thereof (Carducci et al., 2001; Indredavik et al., 2004).

Bipolar Mood disorder

One (6.7%) of the adolescents met the criteria for bipolar mood disorder 1, most recent episode manic. This individual was also previously diagnosed with bipolar 1 disorder, most recent episode manic – by a mental health practitioner. Although research has reported ELBW adolescents exhibiting inhibition and affective-related disorders in the anxiety cluster, there is a small amount of research reporting on disinhibited symptomatic behaviour related to affective disorders such as bipolar mood disorder (Claas et al., 2011; De Pauw & Mervielde, 2010). Hillegers et al. (2003) found that birth weight is associated with mood disorders such as major depressive disorder and bipolar mood disorder, as well as non-mood disorders. However, there is also a significant amount of research that has assessed for bipolar mood disorder in ELBW

adolescents, and which has not found any significant correlation between the two variables (Hillegers et al., 2003; Strang-Karlsson, 2011).

When evaluating for mood disorders such as bipolar mood disorder, Hillegers et al. (2003) and Nomura et al. (2007) recommend that one must consider the association of familial loading of mood and substance-use disorder with mood- and non-mood disorders in bipolar offspring. Research by Hillegers et al. (2003) indicates that bipolar mood disorder is found in ELBW adolescents with a family history of psychopathology such as depression and bipolar mood disorder, and it is not highly prevalent in ELBW adolescents without this additional variable contributing to the genetic loading (biological affects) of developing bipolar mood disorder. To date, no direct link between bipolar mood disorder and ELBW adolescents has been found (Strang-Karlsson, 2011).

ADHD

ADHD was not a category investigated on the M.I.N.I and therefore none of the subjects could be classified using this questionnaire. Parents of three (20%) adolescents reported that their children had been previously diagnosed with ADHD and 60% of parents reported that their children experience concentration problems on a daily basis. The severity of the loss of concentration varied from once a week, to five times a week. In particular, parents stated that their children struggle to concentrate on multiple tasks.

There is an increasing amount of literature on the prevalence of inattention problems in ELBW adolescents (Boyle et al., 2011; Claas et al., 2011; Olivieri et al., 2012; Saigal, 2003). ELBW children have attention regulation, concentration and social difficulties – and parents report symptoms of ADHD (Boyle et al., 2011; Lahey, 2004; Saigal et al., 2003). However, the co-occurrence of the symptoms is often insufficient to meet the DSM criteria for ADHD. One possible explanation provided by Saigal, Ouden, et al. (2003) and Strang-Karlsson (2011) is a discrepancy between parent and child reporting of ADHD symptoms. Parents are overly concerned about their preterm babies as they mature into adolescents and over-report symptoms, or, conversely, the ELBW adolescents under-report symptoms due to misunderstanding or denial (Saigal, Ouden, et al., 2003).

An interesting finding of the current study is that some symptoms of bipolar mood disorder – as assessed on the M.I.N.I – might have been better explained by the diagnosis and symptoms

of ADHD (Geller et al., 2002; Sachs, 2000). Symptoms such as irritability, difficulty concentrating, increased energy levels, and behaviour problems were reported, but Geller et al. (2002) noted that irritability, hyperactivity, accelerated speech, and distractibility are frequent symptoms in both bipolar and ADHD, and are therefore difficult to differentiate between these two diagnoses. Rather, symptoms must be looked at in relation to the environment and additional affective states. When parents were asked in what ways their children were different to their peers, they reported symptoms of hyperactivity, being easily distracted, and jumping from one task to the next. The prevalence of mania-related symptoms, together with the findings of concentration problems reported in this study, may therefore indicate a high prevalence of ADHD amongst ELBW adolescents.

IDD

Research by Vohr and Garcia-Coll (1985) indicates that parents and teachers report that ELBW adolescents experience more cognitive deficits related to IDD than their peers (Ho, 1995; Neubauer et al., 2008; Reichman, 2005; Vohr & Garcia-Coll, 1985; Whitfield, Grunau, & Holsti, 1997). At school age, ELBW are more than nine times more likely than full-term controls to have an IQ below 70, which is the indicator for possible IDD (Tekolste et al., 2004). Parents reported that two (13.3%) subjects had been diagnosed with IDD; however, it is unclear if any others had been tested for IDD or related symptoms. What can be stated, is that three (20%) sample members attend schooling for children with special needs – indicating intellectual deficit – but the remainder of the sample is in mainstream school and in the appropriate grade for the age, indicating that they are coping with their academic demands.

Relationship between the shyness temperament and psychopathology in adolescents born at an ELBW

The shyness temperament is defined by Aron and Davies (2005) as “the fear of negative social evaluations that leads to discomfort and limitations on the desire for social contact (p.3)”. Cheek and Buss (1981); Hopko et al. (2005), Janson and Mathiesen (2008) and Schmidt et al. (2008) found that shyness increases the probability of developing an affective-related disorder such as social anxiety. Social anxiety is seen as existing on a continuum from a very mild, nonclinical social anxiety (i.e. shyness) – through to severe and clinical levels of social phobia. Heiser et al. (2003) and Nigg (2006) indicate that social phobia and shyness increase the probability of being diagnosed with an alternative psychological disorder such as avoidant

personality disorder and selective mutism. In this study, avoidant personality disorder and selective mutism were not investigated for, but based on the current research it may have been fruitful to explore further.

In this study, shyness scores were significantly different in adolescents that have a previous diagnosis of a psychological disorder versus those that do not ($p = .007$). This supports the literature indicating that the severity of shyness may impact the diagnosis of a psychological disorder (Aron et al., 2005; Cheek & Buss, 1981; Schmidt & Fox, 1995). Schmidt et al. (2008) and Kelly, Nazroo, McMunn and Marmot (2001) found that the more shy adolescents are the lower their self-esteem, and this leads to an increase in their experiences of social withdrawal, loneliness and decreased emotional well-being. This could possibly exacerbate the chances of developing a psychological disorder. According to the National Comorbidity Study, shy individuals are about two times more likely to develop a psychological disorder, particularly an anxiety and mood disorder, than those in the general population (Kessler et al., 1994). However, the Kendall-tau-b correlation analysis between shyness and whether or not there was a previous diagnosis of a childhood psychiatric disorder (“No” was coded as 1 and “Yes” as 2), is strongly negative ($r = -.667$ $p = .013$). This means that the more shy the adolescent, the less likely it is that he or she would have been diagnosed with a psychological disorder. The findings of this study differ from those of Heiser, Turner, Beidel and Roberson-nay (2009) and Kessler et al. (1994) – who found the more shy the adolescent, the more likely they were to have a comorbid psychological disorder. A possible reason for this is that shyness is seen to be on a continuum from a little shy through to extreme shyness. The more severe the individual’s shyness is, the lower their self-esteem, and the more fearful, self-isolating and inhibited they are relative to their peers, The increase in shyness predisposes the individual to develop a psychological disorder such as social phobia, avoidant personality disorder, anxiety and mutism (Heiser, Turner, Beidel, & Roberson-nay, 2009).

When examining whether or not a subject met the criteria for social phobia on the M.I.N.I (“No” was coded as 1 and “Yes” as 2), it emerged that the level of shyness was significantly different between the two groups ($p = .041$). Thus, the severity of shyness is related to the diagnosis of a social phobia disorder, as has been shown in previous studies (Cheek & Buss, 1981; Hopko et al., 2005; Janson & Mathiesen, 2008; Schmidt et al., 2008). While many shy people do not meet the criteria for social phobia, individuals diagnosed with social phobia have a greater number of social fears, a higher tendency to avoid social situations, more negative thoughts, and more somatic symptoms – than individuals who report being somewhat shy (on

the lower end of the continuum) (Marshall & Lipsett, 1994; McNeil, 2001; Stein, 1999). A possible reason for this is that shy individuals may not overtly present with impairments in behavioural or emotional problems, and thus psychological disorders in this population may be under-reported (Beidel, Turner, & Morris, 1999).

Shyness may be a predisposing factor to the development of a psychological disorder such as social phobia (Heiser et al., 2003; Matsuda, Okanoya, & Myowa-Yamakoshi, 2013; Saigal et al., 2003; Schmidt et al., 2008). The relationship between shyness and psychopathology in ELBW adolescents would need to be explored on a larger scale to clarify if shyness plays a role in helping to conceal the development of a psychological disorder or in predisposing the ELBW child to the development of a phobia

Quality of life of ELBW adolescents

QOL is a subjective and multidimensional concept that can be defined by the individual according to their physical and scholastic functioning, psychological state, and the history of their health impacting their occupational and social functioning (Saigal et al., 2007; Zwicker & Harris, 2008). Therefore, poor-health-related QOL could be characterised by impairment in physical functioning (e.g. poor motor development, neurocognitive impairment, developmental delays), difficulties in scholastic functioning (e.g. learning disorders, ADHD) and a current or previous diagnosis of a psychological disorder or symptoms of psychological impairment [e.g. anxiety disorders, depression, social phobia, shyness] (Ho, 1995; Msall & Park, 2008; Ristvedt & Trinkaus, 2009; Saigal & Rosenbaum, 1996). The individual may also have a history of limitations in social and occupational functioning due to these impairments.

There are contrasting research findings on the QOL of ELBW adolescents. Saigal and Rosenbaum (1996) found that ELBW are found to have a poorer QOL than their NBW peers due to chronic health conditions, functioning impairments, and emotional difficulties. Zwicker and Harris (2008), on the other hand, found that ELBW adolescents have a similar QOL to their NBW peers, and that their functioning impairments and emotional difficulties diminish over time. Based on the literature and the findings of this study, QOL is a subjective variable that is interpreted from the individual's personal or observed experiences. Zwicker and Harris (2008) found that the discrepancies in research findings of QOL in ELBW is due to parents and adolescents reporting on ELBW QOL interchangeably (Saigal & Rosenbaum, 1996).

Therefore, QOL of ELBW is based on biological, psychological and social functioning. There appears to be a high prevalence of neurodevelopmental disorders, CP, IDD and lung disease that impacts the ELBW individual's life negatively. Psychological disorders such as ADHD, social phobia, affective-related disorder, and learning disorders are commonly found in ELBW adolescents. Lastly, 90 % of ELBW infants are born in developing countries where they are exposed to low socio-economic status, poor intellectual stimulation and poor hospital resources. The mutually dependent variables may ultimately cause ELBW to have a high chance of a poor QOL in comparison to their NBW peers.

Quality of life reported by the parents in the sample

In the current study the parents of the sample were asked to report on the health-related QOL of their children over the past four weeks (SF12v2). The scoring of the questionnaire used norm-based scoring: each scale was scored to have the same mean of 50 and standard deviation of 10. When a scale score was below 50, health status was below average relative to the general population (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). Some anomalies in the reporting of QOL domains are noted in Chapter 4 and these scores should therefore be interpreted with more caution. Of significance from the QOL domains of the assessment, was that parents perceived ELBW adolescents as experiencing difficulty in the role functioning-emotional domain in comparison to their peers. This means that a person's typical role activities (e.g. school, sports) are limited by the emotional problems they may have experienced. Parents also reported a lower role functioning-physical – which means that the adolescent's typical role activity (e.g. socialising, school) is limited due to physical health problems. They also reported an overall lower mental health component score for their children in comparison to the normative data. This means that the adolescents are perceived to experience frequent psychological distress, substantial social and role disability caused by emotional problems. The long term outcome of experiencing frequent long psychological distress is that ELBW adolescent health was generally rated as poorer than their peers.

There are contrasting research opinions on the QOL of ELBW survivors. Zwicker and Harris (2008) noted that ELBW individuals initially experience academic, psychosocial, motor and behavioural difficulties when starting school, but by adolescence they have a similar QOL to their NBW peers. On the other hand, Saigal and Rosenbaum (1996) found that ELBW adolescents have more neurological impairments, functional impairments and poorer QOL than

their peers. Furthermore, previous research studies have also reported that ELBW experience difficulty in internalising and externalising emotions and behaviours that affect their daily functioning (Cooper & Sandler, 1997; M. Hack et al., 2004; Lorenz, 2001; Neubauer et al., 2008). For example, ELBW adolescents are found to be more shy, socially withdrawn and risk averse than their NBW peers (Schmidt et al., 2008). They are also found to have motor difficulties impacting their physical performance, which ultimately impacts their physical functioning and ability to engage in sports and physical activity (Cooke, 1996; Saigal et al., 2007). Therefore, although there are differing opinions on the QOL of ELBW adolescents, looking at the results and previous research from a biopsychosocial perspective, there is a significant amount of data illustrating that according to parents of ELBW adolescents they have a higher chance of experiencing biological, psychological and social impairments – that may ultimately impact their QOL negatively – in comparison to their peers (Boyle et al., 2011; Claas et al., 2011; Olivieri et al., 2012; Saigal, Frpc, et al., 2003; Schmidt et al., 2010).

The correlation patterns shown in Figure 4.2, indicates that temperament correlates significantly with a number of physical components of QOL. To recapitulate, the physical component scale is defined as the grouping of scores that reflect the individual's physical well-being. It is composed of the totality of scores derived from the physical functioning, role functioning-physical, bodily pain and general health domains. A negative correlation between this domain and the shyness temperament indicates that the more shy an individual is, the fewer physical functioning difficulties or impairments are noted by the caregivers. This could link to reports that shy individuals are socially more isolated, and less likely to report any difficulty than their less inhibited peers, and are therefore more likely to under-report symptoms than their peers (Aron et al., 2005; Schmidt et al., 2008). On the other hand, the adolescents that had previously been diagnosed with a psychological disorder scored higher in their parent reports of physical functioning than those ELBW without a diagnosed childhood disorder ($p = .041$). A sufficient explanation for this could not be found in the current study and it would be useful to try and unpack this phenomenon in further work.

Shyness influencing QOL

The RCBS results indicate that the sample is somewhat shy. Shyness temperament affects the individual's QOL, because it limits the ability to function socially in the world and leads to loneliness, isolation and low self-esteem – predisposing to psychopathology (Vasey & Dadds, 2001). However, the shyness temperament was negatively correlated to a previous diagnosis

of a psychological disorder. This could have a significant impact on QOL. As stated above, shyness could prevent the individual from seeking professional help due to anxiety and fear of judgment – which would circumvent a diagnosis (Beidel et al., 1999; Nigg, 2006). Furthermore, when comparing the previous diagnosis of a psychological disorder to the levels of shyness, it appears that the severity levels of shyness are significant. The more marked the shyness levels, the more likely the individual is to have a diagnosis of a psychological disorder (Saigal, Ouden, Wolke, & Hout, 2003).

Social phobia impacting QOL

In the current study, there is a significant difference in the mental health domain functioning of QOL in individuals diagnosed with social phobia. This indicates that individuals diagnosed with social phobia will experience more frequent psychological distress, substantial social and role disability due to emotional problems – and their health-related QOL is generally rated as poorer than those without social phobia. Heiser, Turner and Beidel (2003) report that anxiety related to social phobia negatively influences the mental health of individuals and increases their chances of experiencing loneliness and lower emotional well-being (Saigal, Ouden, Wolke, & Hout, 2003; Schmidt et al., 2008).

There was, however, a strong negative correlation between the diagnosis of social phobia on the M.I.N.I (“No” was coded as 1 and “Yes” as 2) and a previous diagnosis of a psychological disorder – which may indicate that children that were found to meet the diagnostic criteria for social phobia are less likely to have been previously diagnosed with a psychological disorder. Hitchcock, Chavira, and Stein (2010) report that social phobia and other psychological disorders are often undiagnosed, as these individuals do not overtly display symptoms or report these symptoms to their parents to seek treatment – and therefore any comorbid disorders will at times remain undiagnosed (Heiser, Turner, & Beidel, 2003). In a recent epidemiological survey on social phobia, 10.2% ($n = 235$ out of 2319) university students met the diagnosis of social phobia, but only 0.8% ($n = 2$) have been formerly diagnosed by a health practitioner and treated (Hitchcock et al., 2010). It was found that the defining characteristics of social phobia such as anxiety, especially when feeling judged, may keep people from seeking help or treatment (Beidel et al., 1999). The negative correlation between social phobia and a previous diagnosis of a psychological disorder, in the current study, indicates that these individuals were not formally diagnosed. Despite symptoms of social

phobia such as anxiety, fear of judgement, low self-esteem, loneliness and social difficulties with peers, they remain untreated. This is likely to impact their QOL negatively (Wolke, 1998).

Strengths of the study

One of the strengths of this research is its novelty. There has been scant research on the long-term effects of ELBW from a psychological perspective in South Africa. This study has identified significant possible outcomes of ELBW. This makes a case for further research in this field. The exploration of various domains of an ELBW adolescent's life (biological, psychological and social) provides information for a wide range of professionals on the longer-term impact of ELBW on survivors, particularly in adolescents. This allows for varying inputs on the intervention level to be considered, using the results of this study.

Furthermore, the research made use of standardised questionnaires that are also used in international research on ELBW. Although the sample is smaller than that in the international studies the trends can be useful in comparison to the international data.

The use of self-report questionnaires such as the RCBS and the M.I.N.I has a number of strengths and limitations. Some strengths of the self-report questionnaires are that they allow the respondent to report on personal experiences and to share their perspectives directly. Robins, Paulhus, Vazire, and Paulhus and Vazire (2007, p. 227) report that “no one else has access to more information” than oneself, and that this information is rich with motivational and other introspective details that others might not be aware of”. Furthermore, self-report questionnaires allow the researcher to obtain information about situations that are not always observable and not necessarily easily available – e.g. reporting on family histories of mental illness. Self-report questionnaires are one of the most commonly used data-capturing measures in the social sciences and humanities, making it easier to compare data from other studies using similar methodologies (Van Berkel, 2009). A limitation of the use of the self-report questionnaires is that the results are subject to perceptual bias.

Limitations of the study and recommendations for future research

The small sample ($N = 15$) may not represent the larger ELBW population. Although a small sample study is a trend in ELBW literature (Saigal et al., 2003; Streiner et al., 2000; Saigal, Rosenbaum, Feeny, Burrows & Furlong, 2000) – generalising the findings is

questionable in such cases. The small population is more problematic when a researcher attempts to carry out a longitudinal study, due to a high dropout rate, which then yields conflicting results across studies (Streiner et al., 2000; Saigal, Rosenbaum, Feeny, Burrows & Furlong, 2000). Future studies could plan to use a larger sample size. A longitudinal design can be used to determine if changes over time are predictable, is also recommended.

All questionnaires were administered in English. This may have affected the response and the overall understanding of the questions for three (20%) respondents. Additional variables such as age, level of education and disability may have also limited the respondent's ability to report accurately on questionnaires. Parents were required to fill out questionnaires in cases where the respondent could not read or was physically disabled. For example, two respondents had CP, and their guardians needed to assist in answering the RCBS and the M.I.N.I. Zwicker and Harris (2008) found that parents of ELBW adolescents are more cautious and over-report medical and psychological symptoms related to their ELBW adolescent, which has shown to affect their congruency of reporting with that of the adolescent's subjective experiences. As a result, the reporting of symptoms on the RCBS and M.I.N.I may have been skewed by the perception of the parents. It is recommended that for future studies that health-related QOL is reported by both parents and adolescents to ensure a more holistic picture of the ELBW QOL.

The use of the SF12v2 yielded limitations with the sample of adolescents, as its normative data are only reported from the age of 18 years. The children's version SF10 would yield more valuable data for this sample. The SF10 could be used to assess the QOL of adolescents, and this may enable the researchers to compare data across studies.

The M.I.N.I. 5.0.0 used in the assessment did not identify symptoms of ADHD commonly found in ELBW adolescents (De Pauw & Mervielde, 2010; Foley, McClowry, & Castellanos, 2008; Strang-Karlsson, 2011). Thus, parents were not able to report on attention and concentration symptoms reported on the biographical questionnaire. The Mini International Neuropsychiatric Interview for Children and Adolescents (M.I.N.I.-KID) could be considered for future studies, as it is a shorter, structured diagnostic interview and does examine ADHD symptoms.

Conclusion

The aim of this study was to explore temperament and psychopathology in ELBW adolescents. The biopsychosocial approach was used as a framework for trying to understand temperament and psychopathology in ELBW adolescents – with reference to their impact on QOL (Spenser, 2003). The biological factors that emerged as important in this study were CP, hydrocephalus and gestational age. Shyness temperament, social phobia, ADHD symptoms, bipolar mood and GAD emerged as key descriptors of the sample. However, the influence of race and socio-economic markers did not present significantly in this sample.

This study provides a unique insight into the longer term effects of being born at ELBW and suggests that ELBW is linked to an inhibited temperament, and inhibition and disinhibition-related psychological disorders such as ADHD, GAD and social phobia. Increased shyness temperament and the presence of social phobia impacts the ELBW individual's QOL negatively with regard to both physical and mental well-being. These results are highly significant for future planning around the management of ELBW individuals and therefore also for the allocation of physical, mental and social health resources. In striving to improve the QOL of ELBW individuals, researchers, caregivers and intervention providers should aim to provide support for their holistic care and not focus solely on the physical or psychological or social impacts of ELBW in isolation.

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Appendix A

PARTICIPANT INFORMATION LEAFLET AND INFORMED CONSENT

Exploring the quality of life and psychological functioning of extreme low birth weight survivors.

Good day

My name is Dannita Borrageiro, I am a Masters student at UNISA, Pretoria. As part of the programme for completing my master's degree I have to do research in the field of Psychology. I have chosen to research the long term effects of being born at an Extremely Low Birth Weight (ELBW). An adolescent's personality, psychological status and quality of life will be assessed to gather this information. I will discuss what this all means in more detail a little later in this form.

The aim of this study is to identify the effects of ELBW and possibly develop risk profiles for survivors of ELBW. The results of this study will give medical professionals such as psychologists, doctors, and even families a clearer picture of what the long term effects of ELBW are. This could lead to further research to improve the quality of life of children like your own. This research could also be used to put together protective plans that could act as possible safeguards for some of the long term problems associated with ELBW.

Children that were born at ELBW in the Gauteng area are invited for this study. We have gathered information of survivors of ELBW through both government and private hospital records, and are inviting you and your child to participate in our research project. **PLEASE READ AND UNDERSTAND THIS DOCUMENT BEFORE YOU AGREE TO BE APART OF THE STUDY.** If you have any questions or concerns, please don't be hesitant to ask.

WHAT WILL YOUR CHILD BE EXPECTED TO DO?

Your child will be asked to fill out four questionnaires. If your child is not able to fill out the questionnaires on his or her own, we ask that you, as the legal guardian, accompany your child to help him/her complete the questionnaires.

The first questionnaire begins with questions about your child's biographical details such as age, school, grade, and gender. Please remember that your child does not have to put his/her name on the questionnaire, so the investigators will not know which child is yours. You and your child can therefore feel free to be honest. The second questionnaire is called the Mini International Neuropsychiatric Inventory; it consists of 120 short questions that help us identify any possible psychological problems that your child may have. The third questionnaire is called the Temperament and character inventory. This focuses on how your child may react to different situations. Lastly, the fourth questionnaire is the SF36, which measures quality of life.

WHO WILL HAVE ACCESS TO MY/ MY CHILD'S INFORMATION?

If you agree to give consent for your child to be part of this study and your child agrees to be a volunteer in the study, you and your child have the right to leave as a participant at any time. When the child is asked to fill out the questionnaires, he/she can remain anonymous and not add his/her name to the questionnaires.

Confidentiality

All the information that is gathered during the course of this research study is strictly confidential. This means that all the personal information that you share with us is kept private. If the findings are reported in journals, or published scientific articles, no names or information which identifies your child as a participant in the study will be released. The electronic data will be kept on a password protected computer. This data will be stored and kept under lock and key for five years (for auditing purposes). The researcher and the supervisor will be the only people who have access to the data. We will not show your information to anyone without your permission, except in the case where a law requires us to do so.

HAS THE RESEARCH RECEIVED ETHICAL APPROVAL?

The research has been approved by Unisa's Department of Psychology.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS RESEARCH?

Your child will be a voluntary participant in this research study, and therefore will be free to leave or refuse to participate at any time, without giving a reason. You and your child will not be punished in any way for this. The researcher retains the right to withdraw your child from the study if it is considered to be in your child's best interest.

ARE THERE RISKS INVOLVED IN THIS RESEARCH? CAN ANY OF THESE RESEARCH PROCEDURES RESULT IN DISCOMFORT OR INCONVENIENCE?

It is possible for some people to feel uncomfortable about some of the questions in the questionnaires. However, we are not trying to judge or disrespect you and we encourage you and your child to be honest. If there are any concerns or discomfort that you would like to discuss, please make the researcher aware of your discomfort.

INSURANCE AND FINANCIAL ARRANGEMENTS

There will be no financial requirements for the assessments carried out (by participant or medical aid). The participant will also not receive any gift or payment for participating in this study.

Informed consent for the project entitled

Exploring the quality of life and mental status of Extreme Low Birth Weight survivors

ALL PARENTS MUST PLEASE COMPLETE THIS SECTION:

Tick the best answer for you, please tick ONE.

I would **like** my child to participate and therefore give consent.

I would **not like** my child to participate and therefore do not consent.

INFORMED CONSENT FOR PARENTS/GUARDIANS (ON BEHALF OF MINORS UNDER 18 YEARS OLD)

I hereby confirm that I have been informed by the investigator about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information regarding the investigation. I am aware that the results of the research may be anonymously processed into a research report. I may, at any stage, without prejudice, withdraw my consent and participation in the research. It has been explained to me that I will be free to withdraw my child from the research at any time, without any disadvantage to future care. I have understood everything that has been explained to me and I consent to my child participating in this research.

Parent/Guardian(s) name: (Please print) _____ Signature _____ Date _____

My child's name: (Please print) _____ Child's signature * _____ Date _____

****Minors competent to understand must participate as fully as possible in the entire procedure***

The investigator herewith confirms that the above participant has been informed fully about the nature, conduct and risks of the above research.

Investigator's name: **Dannita Borrageiro** Investigator's signature _____ Date _____

Witness's name: (Please print) _____ Witness's signature _____ Date _____

Thank you for your time.

The Investigator: Miss Dannita Borrageiro

Supervisor: Ms C. Govender

Appendix B

Assent Form

My name is Dannita Borrageiro. I am a student that is trying to learn about people who were born at an extremely low birth weight, just like yourself. Extremely low birth weight means that when you were born you were very small, and you did not weigh more than 1000g. This study may help doctors, parents, psychologists and many other people help young children to grow up healthy and happy. If you would like, you can be part of my study.

If you decide you want to be part of my study you will have to fill out a few questionnaires for me. You don't have to worry about how you answer the questions or what you say in your answers because I will put the things I learn about you, with the things I learn about all the other children who decide they also want to be part of my study. When I speak to people about my research and everything I have learned from all the different people, I will not use your name, so no one will know that I am talking about you. Other people won't even know you were part of my study, unless you want to tell them.

We need to ask your parents or guardian if it will be okay for you to be in the study. If they say it is ok, then you get to choose if you want to do it. If you decide you want to be a part of the study and later you decide you have changed your mind that is okay too, no one will be mad at you. It is your choice.

My telephone number is 0827868998. You can call me if you have questions about the study or if you decide you don't want to be in the study any more. I will give you a copy of this form in case you want to ask questions later.

Agreement

I have decided to be in the study even though I know that I do not have to do it. Dannita Borrageiro has answered all my questions.

Signature of Study Participant (child)

Date

Signature of Researcher

Date

Appendix C



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA



RAHIMA MOOSA MOTHER AND CHILD HOSPITAL
Enquiries: Mrs. S. Jordaan
Tel: (011) 470 9030/4
Fax: (011) 477 4117
Email: sjordaan@icon.co.za

Department of Psychology
University of South Africa
P.O. Box 392
PRETORIA
0003

Re: "Exploring the quality of life and psychological functioning of Extreme Low Birth Weight survivors"

Dear Dannita Borrageiro,

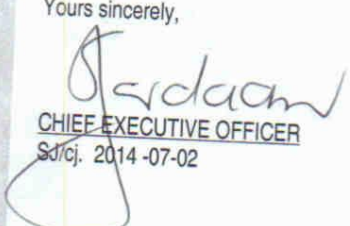
Permission is granted for you to conduct the research as indicated in your request as per the title above.

The terms under which this permission is granted is contained in the Researcher Declaration form that you signed. Failure to comply with these conditions will result in the withdrawal of such permission.

Note that it is imperative that you notify the hospital of the actual start and end dates of your study by notifying the CEO's secretary preferably by email or fax.

Should the study commence more than 12 months from receipt of this letter then the Researcher Declaration form needs to be re-signed prior to commencement of the research. You are strongly advised to keep a signed copy of the declaration form so as to ensure that the terms of this agreement are complied with at all times.

Yours sincerely,


CHIEF EXECUTIVE OFFICER

Sd/cj. 2014 -07-02

ADDRESS: cnr. FUEL & OUDSTHOORN STREET CORONATIONVILLE 2093 / PRIVATE BAG X20 NEWCLARE 2112 JHB

Appendix D

Table D.1.

Non-Significant results of the Fishers Exact and Mann-Whitney

Variables	Physical Functioning	Role Functioning (Physical)	Bodily Pain	General Health	Vitality	Social Functioning	Role Functioning (Emotional)	Mental Health	Physical Component	Mental Component
Race	p = .059	p = .262		p = .117	p = .653	p = .765	p = .153	p = .675	p = .675	p = .262
Gender	p = 1.000	p = .315		p = 1.000	p = .235	p = .400	p = .580	p = 1.000	p = .315	p = 1.000
Parent employment status	p = .077	p = .282		p = .267	p = 1.000	p = 1.000	p = .560	p = .077	p = .282	p = .077
Medical aid	p = 1.000	p = 1.000		p = .267	p = 1.000	p = 1.000	p = 1.000	p = .569	p = .569	p = .569
Highest level of education level of care giver.	p = .682	p = .720		p = .543	p = .636	p = .400	p = .453	p = .720	p = .720	p = .400
Hospital born in.	p = .329	p = .315		p = .400	p = .604	p = 1.000	p = .329	p = .119	p = 1.000	p = .119
Weeks born at.	p = .251	p = .608		p = .333	p = 1.000	p = 1.000	p = .251	p = .282	p = .608	p = .282
Birth weight	p = .509	p = .669		p = .343	p = .681	p = .343	p = .638	p = .405	p = .405	p = .935
Concentration difficulties	p = .432	p = .175		p = .870	p = .587	p = .870	p = .682	p = .998	p = .561	p = .400
Child psychiatric disorder	p = .329	p = .315		p = .400	p = .604	p = 1.000	p = 1.000	p = .119	p = 1.000	p = 1.000
Different from other children	p = .580	p = .608		p = 1.000	p = 1.000	p = 1.000	p = .329	p = .608	p = .608	p = 1.000
Manic episode	p = .333	p = .467		p = .067	p = .267	p = 1.000	p = 1.000	p = 1.000	p = .467	p = 1.000
Social phobia	p = .580	p = .608		p = 1.000	p = .604	p = .400	p = .580	p = .041	p = .608	p = .315
Generalised anxiety	p = 1.000	p = 1.000		p = 1.000	p = 1.000	p = 1.000	p = 1.000	p = .467	p = 1.000	p = .467

a. Asymptomatic significance are displayed, The significance level is $p < .05$.

