An Exploration of the Effectiveness of Positive Behaviour Support in Unstructured Community Settings: A Systematic Review of Quantitative Literature

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DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed:  (Narelle McCaffrey)

Date: 01/04/2019

Supervisors' Certification

I confirm that that we have approved all aspects of the research project in this thesis, including the content of the literature review, data collection, analysis, reporting and data storage.

Primary Supervisor Signed:  (Dr Alinka Fisher)

Date: 01/04/19

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ABSTRACT

Background: There are a high occurrence of behaviours of concern among individuals with disabilities. These can manifest in a variety of ways (e.g. aggressive behaviours, property destruction, sexual behaviours, reduced initiation and symptoms of mood disorders), can have a significant impact on an individual's quality of life, and may pose risk of harm to themselves or others. Positive behaviour support (PBS) is an evidence-based framework for improving quality of life of individuals, through determining the purpose of behaviours of concern, which inform the implementation of data-based strategies that improve the environment, teach functionally meaningful skills, and reinforce desired behaviours.

Aim: To examine the evidence base of community- based PBS interventions in enhancing quality of life and reducing behaviours of concern for individuals with disabilities.

Method: A systematic review of literature reporting on quantitative outcomes. Six electronic databases relevant to disability and behavior support were searched between 1980 and 2018. Citation indexes and hand searches of identified articles were also screened for relevance, and articles selected for full-text review were independently considered by two reviewers. Papers included in this review were analysed using the McMasters critical appraisal tool for quantitative studies.

Results: Sixty-six articles were identified and after duplicates were removed and fifty-one were assessed for relevance, twenty were included for review. A majority of studies were weak in design, however critical appraisal determined that the articles were of good quality.

Conclusion: Due to limited research and high evidence studies, no conclusions can be drawn regarding the efficacy of community-based PBS interventions in unstructured community settings. It is suggested that effective interventions are those where comprehensive assessments were conducted to understand the purpose of BOC. This understanding informed person-centered PBS plans that were mindful of cultural differences and values held by the individuals and their families.

Chapter 1:

INTRODUCTION

1.1 Introduction and Statement of Need

Positive behaviour support (PBS) is a framework for addressing behaviours of concern (BOC), with the primary aim of increasing the individual's quality of life. Behaviours of concern are behaviours that cause or risk harm to self, others or property (Anderson, 2000). PBS uses methods to modify the environment (physical, social and psychological) and teaches new skills to enable meaningful community participation (Carr et al, 2002).

PBS is based on the premise that all behaviour is communication and serves a purpose (Dept for Communities and Social Inclusion SA, 2017). It is a way of communicating that one's needs are not being met. If that purpose can be identified, and needs met by making changes to the environment in which the behaviours occur, and teaching relevant skills, the need to engage in BOC is eliminated (Bisiani & Angus, 2013). Individuals who present with BOC are at risk of social isolation, community exclusion and ultimately institutionalization (Tam, McKay, Sloan & Ponsford, 2015).

There is a growing body of literature describing PBS frameworks and interventions (Carr, 2002; Hieneman, 2015; Hieneman & Fefer, 2017). The PBS literature primarily includes articles describing the PBS process (Carr et al, 1999; Anderson, 2000; Horner & Sugai, 2018) and evaluating outcomes of PBS in schools (Kurth et al, 2017; Nocera, Whitbread & Nocera, 2014; Simonsen et al, 2010), but few articles examining the effectiveness of PBS interventions and evaluating outcomes in unstructured community settings (Carr & Carlson, 1993; Jensen et al, 2001; Webber et al, 2017).

A comprehensive understanding of PBS is essential in the current Australian context for reasons that follow. First, PBS is the recommended framework for providing behaviour support under

the National Disability Insurance Scheme (NDIS). The NDIS has been established to provide Australians with disabilities, and their families, greater choice and control in their living arrangements and the way they are supported (Department of Social Services, 2016). The NDIS aims to improve levels of community engagement and quality of life (QoL) for Australians with disabilities. The values of the NDIS and PBS are both consistent with the United Nations Convention on the Rights of Person with Disabilities (UN, 2006). As such, PBS is a recommended framework for addressing BOC by the NDIS. Second, in Australia it is currently legislated (Department of Social Services, 2014) that services that use restrictive practices, must have them included in an individual's behaviour support plan. It is also stated in the Restrictive Practices Reference Guide (Dept for Communities and Social Inclusion SA, 2017) that those with approved restrictive practices must have a PBS plan. These then need to be reported according to the laws or guidelines of individual states.

Therefore, providing further insight into the effectiveness of PBS interventions to inform recommendations for best practice has implications for ensuring individuals, their families and communities are receiving the necessary support to live a quality life. Determining the effectiveness of positive behaviour support interventions, and what features add to the effectiveness is a must. Such knowledge could provide important insights for future PBS program recommendations and therefore the potential to allow for further evolution of best practice.

1.2 Aim and Research Questions

The aim of this thesis is to examine the evidence base of PBS for people with disabilities who engage in BOC in unstructured community settings. Specifically, the following research questions were addressed:

- What is the evidence supporting PBS interventions in enhancing quality of life and reducing BOC?

- What are the features of effective PBS interventions?

1.3 Structure of Thesis

This thesis is structured as follows:

Chapter 2 - Background information: This chapter provides information on behaviour, what BOC are, the impact BOC, and outlines the concepts of PBS. A historical perspective is presented, selected reviews critiqued and case studies of PBS interventions in community settings that embrace the concepts of positive behaviour support summarized.

Chapter 3 - Methods: This chapter describes the methodology used to conduct the systematic review. It details the search strategy, search terms, databases used and inclusion and exclusion criteria.

Chapter 4 – Results: This chapter presents results obtained from study selection (described in Prisma diagram), considers the quality of literature reviewed and the quality of the evidence presented. Data is extracted and tabulated.

Chapter 5 – Discussion and conclusion: This chapter discusses the results and how they relate to, or, answer the research questions. Limitations of the review are also identified/discussed.

A summary of the work carried out during the systematic review process and results obtained will be provided. Recommendations for future research are also made.

Chapter 2:

BACKGROUND INFORMATION

2.1 Introduction

This chapter presents an overview of current literature regarding treatment of and supports for individuals with disabilities presenting with BOC. A definition of BOC will be provided followed by an overview of the evolution of behaviour supports. The chapter then focusses on PBS and the characteristics that set it apart from other interventions or frameworks that aim to modify behaviour. Some case studies that examine characteristics of PBS are also presented to illustrate the PBS process.

2.2 Behaviour

2.2.1 Behaviours of Concern

BOC are defined as behaviours that have a negative impact on an individual's participation in the community (Bigby, 2010; Rogers, 2018; Osburn, 2006; Webber, McVilly & Chan, 2011). BOC undermine a person's rights, dignity and quality of life and can pose a risk to others (Rogers, 2018; Osburn, 2006). BOC may include verbal and physical aggression, property destruction, self-injury, absconding or socially sexually inappropriate behaviours (Rogers, 2018; Webber, McVilly & Chan, 2011).

BOC are often associated with developmental disorders such as intellectual disabilities (ID) and autism. Based on data collected in a meta-analysis, McClintock, Hall and Oliver (2003) it was suggested that severe ID, autism and poor communicative abilities could be markers for BOC. Others, like Lowe et al (2007) have estimated that 10%-15% of children with a developmental disorder engage in behaviours that might result in risk of harm to self or others. The prevalence of BOC

among those with disabilities is higher than in the general population (McClintock, Hall & Oliver, 2003; Lowe et al, 2007).

2.2.2 Impact of BOC

When a person engages in BOC they may be judged and devalued (Osburn, 2006). This places individuals at risk of being rejected, segregated and abused. BOC can also lead to social isolation, can be a barrier to employment (Schall, 2010; West & Patton, 2010) and can impede an individual's ability to live independently (Durand, Hieneman, Clarke, Wang & Rinaldi, 2012).

BOC can also have an impact on families (Buschbacher, Fox & Clarke, 2004). It is widely acknowledged that supporting someone with a disability who engages in BOC can cause significant levels of stress, symptoms of anxiety and depression (Durand, Hieneman, Clarke, Wang & Rinaldi, 2012; Lee, Poston & Poston, 2007; Lecavalier, Leone & Wiltz, 2006; Sloper, 1999; Tam, McKay, Sloan & Ponsford, 2015), which may result in families becoming socially isolated. For many years, parents of children with disabilities who present with BOC have faced difficulties in accessing behaviour support services, or even the knowledge of where to go to seek help (Sloper, 1999; Brown, MacAdam-Crisp, Wang & Iarocci, 2006). Not only can an individual's BOC impact a parent's mental health, but high levels of parental stress can have a negative impact on the individual's behaviour (Hastings, 2002). It is therefore important to support families when supporting an individual who engages in BOC. A PBS program developed via a parent-professional partnership is one way in which both the individual and their family receive support simultaneously (Smith-Bird & Turnball, 2005 and Lucyshyn et al 2015). PBS can help families understand BOC (Lucyshyn et al, 2015) and can contribute to improvements in family interactions and family QoL (Smith-Bird & Turnball, 2005).

2.3 Positive Behaviour Support

2.3.1 Historical Perspective

Perceptions relating to disability and BOC have evolved over time. For instance, it was once believed that individuals with intellectual disabilities were unable to learn and that BOC were a result of an individual's disability (Anderson & Freeman, 2000; Dunlap & Fox, 2011). Individuals with disabilities were seen as 'less than' human, institutionalised and largely forgotten about by the public (Deane, 2009). During the 1960's the unfavourable living conditions in many institutions and the treatment residents endured were brought to light, resulting in the disability rights movement and the disability discrimination act (Wiesel & Bigby, 2015). Since that time, there has been a shift in service provision for people with disabilities. Philosophies stemming from the civil and disability rights movement (Dunlap, Sailor, Horner and Sugai, 2009), which embrace concepts of normalisation, social role valorisation and person- centered planning have played a significant role in deinstitutionalisation and service provision. The United Nation's Convention of the Rights of Persons with Disabilities (UN, 2006) states that people with disabilities have the right to live independently in the community, the right to full inclusion as well as choice and control. PBS as a framework embraces these principles and can afford these rights to individuals presenting with BOC (Carr et al, 2002).

2.3.2 The evolution of PBS from ABA

PBS began evolving from Applied Behaviour Analysis (ABA) in the 1980's as people with disabilities moved from institutions and into the community (Anderson & Freeman, 2000). For many behaviourists, it was a move away from practices that could cause pain and removed freedoms that every person should be entitled to (Sanetti, Dobey & Gritter, 2012). While PBS has evolved from ABA, it still uses some of its methods, procedures and assessment such as environmental control, the

use of functional assessments and some teaching strategies. Unlike ABA though, PBS is much more person and family centered in that it uses individual or family values, lifestyle, strengths and interests to improve QoL (Davis & Gavidia-Payne, 2009). As suggested by Dunlap, Sailor, Horner and Sugai (2009) much of the research in this field of ABA was solely focused on extinguishing BOC. It did not meet the needs of those working with the individual engaging in BOC, nor did it consider what was beyond observable (Dunlap, Sailor, Horner and Sugai, 2009). According to Carr (1999), everyday support people (e.g. parents, carers, support workers, teachers) working with the person exhibiting BOC needed an approach that was more socially and ecologically valid, that would bring about lifestyle changes for the person with disability and promote meaningful community participation; an approach that reflected the values of the disability rights movement. PBS fulfils these gaps and reflects these values. It is a framework that is person-centered, it embraces social role valorisation and can improve the quality of life for the person with BOC. Most of the work carried out by Carr (1993, 1994) and Taylor & Carr (1992) focused on behaviour triggers and altering the environment in which the behaviour occurs rather than attempting to change the behaviour itself, supporting the development of the PBS framework.

2.4 Characteristics of Positive Behaviour Support

Positive behaviour support is premised on principles of normalisation (or social role valorization) and person-centered practice to improve an individual's QoL. There are nine characteristics of PBS (Carr et al, 2002). These include:

Lifestyle change to improve QoL. The main aim of PBS is to improve the quality of life of the individual and their everyday support people. This can be done through a comprehensive lifestyle change that addresses the dimensions of quality of life, such as, community inclusion, self-determination, personal satisfaction and social relationships.

Lifespan perspective. Long-term changes do not occur overnight. Meaningful change can take years, so interventions need to take this into consideration. Interventions need to change and evolve as the individual develops. For example, supporting transition to primary school will look different from supporting transition to employment.

Ecological validity. PBS is a framework for meeting the needs of the individual in real life settings. Any intervention, or approach taken, needs to be applicable to those settings.

Stakeholder participation. PBS interventions are based on person-centered practice. The individual, alongside family, friends and other support people are partners in the planning process, thus ensuring likes, interests, values, beliefs and culture are considered and included. Person centered plans are developed to improve opportunities for self-determination, social role valorisation, skill development and improved quality of life of the individual and their everyday support people.

Social Validity. Interventions need to be a good fit for the individual and their everyday support people.

Multicomponent interventions and system change. One of the main concepts of PBS is to "fix problem contexts, not problem behaviours" (Carr et al, 2002, p8). Interventions address settings and the way support people interact with the individual, they teach the individual new skills, making BOC unnecessary and they also address the consequence of the behaviour.

Emphasis on prevention. This means that focusing on making changes to settings that meet the needs of the individual is paramount. Secondly, the most productive time for any intervention is when the BOC is not occurring. The individual has a greater capacity to learn skills such as communication, self-management and self-regulation or will have a greater opportunity for choice making when they are in a calm state.

Multiple theoretical perspectives. PBS is bigger than the individual. It has evolved from a focus on the operant to a framework involving various systems and including different fields of psychology. PBS holds contexts within society responsible, hence focusing on setting changes, it is more than specific techniques and it sees a person's behaviour as a reflection of the interface between ability and context.

Flexibility with respect to scientific practices. Good science does not always equate to good practice. Historically, research has taken place in controlled settings, so controlled approaches were appropriate. However, the emphasis of PBS is in the natural environment, which is far from controlled nor predictable a lot of the time, so measurements and assessments need to be flexible.

2.5 Assessment and Plan Development

An underlying assumption of PBS is that all behaviours serve a purpose (i.e. have a function) (Dept for Communities and Social Inclusion SA, 2017). Determining what that function is requires a comprehensive assessment process, known as a functional behaviour assessment. A functional behavioural assessment (FBA) is a systematic method for determining the antecedents, consequences and settings that maintain BOC (Horner & Carr, 1997). The assessment process involves broad consideration of setting events, indirect assessments involving the collection of data indirectly from people who are most familiar with the individual (e.g. via interview), and where appropriate, reviewing previous records (e.g. medical, criminal, educational). This is followed by direct and systematic observation (direct assessment methods) of the individual within their natural environment, which involves recording events prior to behaviours occurring (antecedents), the operant behaviour, and events occurring directly after the behaviour (consequences). The recorded data is examined to

identify patterns and develop a formulation for why behaviour may occur (Martella, Nelson, Marchand-Martella & O'Reilly, 2012). An Antecedent – Behaviour – Consequence (A-B-C) chart is a commonly used tool for recording this data (Synapse, 2019).

Figure 2.1: Example of an A-B-C chart

Date	Time	Antecedent (what happened before)	Behaviour (what did it look like)	Consequence (what happened after)	Possible function

When conducting an FBA, it is also important to consider the individuals disability, and the impact this may have on the individual's cognitive abilities. The disabilities commonly associated with BOC are diverse, and whilst the overt behaviour might look the same, the underlying reason for such behaviour could be very different. This was highlighted in Moskowitz and Jones (2015) systematic review of behavioural interventions for Fragile X Syndrome (FXS). They found those with FXS only reacted differently to the same interventions than someone with both FXS and autism, or FXS and attention deficit hyperactivity disorder (ADHD), exhibiting the same behaviours with the same apparent functions. A collaborative team approach between everyday support people, the individual and professionals should ensure all these aspects are considered.

Having formulated the likely function of BOC, a PBS plan is developed. Strategies employed focus on proactive and preventative measures and inform multi-component plans. An environment that is conducive to behaviours that are functionally meaningful for the individual involved is created and new skills to build competency and positive behaviours are taught (DHHS, 2018). A plan to address any BOC that do occur is made. Any strategies employed must be individualized and designed to meet individual needs (Carr et al, 2002).

Prioritising behaviour for intervention is morally important. Dunlap and Fox (2007) mention repetitive behaviours like hand flapping, can become "socially noxious" but they do not result in harm to self, others or property. No matter how annoying a behaviour might be, careful consideration needs to be given, because intervening might prevent the individual from freedom of self-expression.

2.6 PBS in the Community

There is a growing body of literature describing PBS frameworks and interventions which have been applied in community settings (Magito-McLaughlin, Mullen-James, Anderson-Ryan and Carr, 2002; Vaughn, Wilson & Dunlap, 2002; Schall, 2010), however, there appears to be limited research determining the effectiveness of such interventions, which is needed to inform evidence-based practices. Determining the effectiveness of these interventions, and the features of what is effective, will provide important insight in the development of evidence-based PBS programs.

For the purpose of this thesis, the term 'community' is geographical in nature. It refers to the area in which one lives, participates in leisure, socialises, shops, works, learns and worships (MacQueen et al, 2001). Settings within the community are either structured or unstructured. For instance, schools would be considered structured community-based settings because they exist within a framework or larger system and have rules and regulations defined by a governing body that need to be followed, whereas home would be considered an unstructured setting. Given that individuals spend most of their time in community settings, and that PBS is a framework for supporting desired behaviour within an individual's natural environments, it is important that we examine the effectiveness of PBS across these various settings. This is the focus of this thesis.

There appears to be limited literature reviewing of PBS research interventions, and what has been published does not consider the effectiveness of PBS in natural settings, but rather, behavioural interventions are described, or the outcomes of staff training is explored. Clarke, Zakszeski and Kern

(2018) published a review of trends that have emerged regarding the types of empirical studies that have been published in the Journal of Positive Behavior Interventions (JPBI) since the growth of school wide positive behaviour support (SWPBS) and during the lifetime of this specific journal itself. The authors considered where interventions took place and target populations. Comparisons were made every 6 years between 1999 and 2016.

This systematic review (Clarke et al., 2018), revealed that over 18 years, 431 empirical studies were published. Out of these studies 46.95% were data-based interventions. The 6-11 year old age group was consistently the most represented (52.98%). The most common setting for interventions was general education, comprising 53.83% of all articles over 18 years. It is worth noting that interventions in general education settings increased from 41.19% of articles in the years 1999 - 2004, to 60.94% of articles between 2011 - 2016, while the reporting of home-based interventions decreased from 34.31% published between 1999 -2004, to 14.82% published between 2011 -2016. Interventions carried out in the community remained constant, making up 5.79% of all published interventions over an 18-year period.

Clarke et al (2018) found that types of interventions used remained consistent over time and across settings. The most widely used interventions used include antecedent-based strategies, consequence-based strategies and skills trainingWhile this study was concerned with reported PBS trends in JPBI across settings, including the community, the authors do not provide a definition for the term community. Given that education, employment and residential settings are all considered separately, as are activity centers and clinics, it may be assumed that the term ‘community settings’ equates to places such as shopping centers.

Moskowitz and Jones (2015) published a systematic review considering behavioural interventions for those with FXS. In their introduction they mentioned that this is a relatively new approach and that no reviews had been published prior. They found most interventions were

antecedent and/or consequence based and studies dealt with small participant numbers. As noted by the authors, there is some evidence to suggest positive outcomes of behavioural interventions, but the validity of these outcomes is difficult to comment on because of the small number of participants in studies. It is difficult to determine whether this study is describing PBS as the authors did not provide any evidence of the use of functional assessments.

Erturk, Machalicek and Drew (2018) published a systematic review of single-case studies looking at the effectiveness of behavioural interventions on self-injurious behaviours (SIB) exhibited by children with developmental disabilities. Most studies reviewed presented positive results, although some also included mixed results and others with negative results (where no reduction in SIB's were observed). After reviewing the data presented for the 100 eligible participants, the authors found some commonalities across the 46 studies. Multicomponent interventions produced more positive results than when antecedent, consequence or teaching interventions were implemented alone. The most popular interventions used were consequence based. More positive results (greater reductions in SIB) were observed when used in combination with antecedent or teaching interventions. The authors then concluded that for any intervention to yield positive results, it needs to match the purpose of the behaviour.

2.6.1 Implementation of PBS interventions in unstructured community settings

For the purpose of this thesis it is important to consider current literature examining PBS implementation in unstructured community settings so that recommendations to clinicians and those implementing PBS plans might be made. The databases; OVID gateway (psycINFO and MEDLINE), PubMed, Informit and ProQuest were searched using terms developed under the themes of disability, positive behaviour support and community. The four studies presented below are examples of PBS effectively being implemented (Magito-McLaughlin, Mullen-James, Anderson-Ryan & Carr, 2002;

Lobb, 2011; Keen & Knox, 2004 and Ziomek-Daigle and Cavin, 2015). They all describe work that is collaborative in nature, between researchers and key stakeholders, and they each demonstrate many of the characteristics of PBS. For example, the study discussed by Magito-McLaughlin, Mullen-James, Anderson-Ryan & Carr (2002) highlights important considerations in the application of PBS in unstructured community settings for Christos, a young man diagnosed with autism.

Magito-McLaughlin, Mullen-James, Anderson-Ryan and Carr (2002) describe ways in which they were able to develop and implement an effective PBS framework with the core PBS values at its heart, for supporting Christos, a young man who had been diagnosed with autism, a seizure disorder and bipolar disorder. Christos moved into a treatment center for children at the age of 19, and then an institution for adults at age 23. In both settings he was routinely restrained and secluded as a way of staff dealing with his BOC. He was seen as being non-compliant and in need of punishment for his BOC. No matter what staff tried, Christos' BOC were maintained or even increased. Christos was communicating that these interventions were not meeting his needs. It became necessary for a new approach. An FBA found the purpose of Christos' BOC was to escape crowds, impersonal relationships, invasions of privacy, physical restraint and undesired activities. With this information, a new support plan was developed.

The new strategies employed to support Christos were now considered best practice in PBS. They included;

- person centered planning with a team of valued people in Christos' life, including Christos himself, and members of his family
- customisation of environment - for Christos, this meant an individualised home and work in the community
- community membership
- meaningful, functional skill development (including communication skills)

- more natural supports, and
- scheduling that allows for self determination

These strategies were effective as they resulted in significant reductions in BOC and increased time spent in the community, which contributes to improved QoL.

One of the main themes that is evident in the literature is the importance of partnerships between everyday support people and professionals. Professionals are able to teach and support parents in understanding BOC and the reasons behind it, as well as ways to support their children and to prevent BOC from occurring. Partnerships can assist in PBS being used across settings, such as home and school and with whole families as clients. Table 2.1 summarises the findings of the three additional studies.

Table 2.1: Examples of PBS interventions that describe work that is collaborative in nature, between researchers and key stakeholders, and demonstrate many of the characteristics of PBS

Author (date of publication)	Key Findings
Lobb (2011)	- the close involvement of everyday support people - when behaviour teams work alongside families and help them to understand the function of behaviour and the need BOC fulfils for the individual, changes experienced can be life changing for all involved
Keen & Knox (2004)	- importance of involving everyday support people in developing PBS plans - person engaging in BOC does not exist in isolation - a family/professional partnership - family are the decision makers
Ziomek-Daigle and Cavin (2015)	- PBS across settings - school counsellor as facilitators and guides in the implementation of PBS at school and at home - school counsellor to form partnerships with both parents and with teachers; allowing all parties a contribution and sense of control.

2.7 Summary

Positive behaviour support is an evolving framework for supporting those who engage in BOC to improve their quality of life. There are nine characteristic of PBS that set it apart from interventions aimed at improving behaviour. Each of the nine characteristics are premised on the principles of person centeredness, social role valorisation and QoL.

Positive behaviour support was developed to be implemented in the natural environment, by everyday support people. The framework includes FBA and the development and implementation of socially and ecologically valid PBS plans that allow for real lifestyle change for the individual and their families to improve quality of life.

There is a small yet growing body of literature describing PBS interventions and/or reporting any changes in BOC and QoL. Most of what has been published is concerned with school wide positive behaviour support as opposed to interventions conducted in unstructured community settings.

Chapter 3:

METHODOLOGY

3.1 Introduction

This chapter describes the methodology used in conducting the systematic review, which aimed to examine the evidence base of PBS for people with disabilities who engage in BOC in unstructured community settings of PBS research in unstructured community settings. The search strategy will be presented, followed by study selection, and methods used to critically appraise and analyse data. The review was carried out according to the PRISMA guidelines for conducting systematic reviews and meta-analyses (Moher, Liberati, Tetzlaff & Altman, 2009). PRISMA is a set of evidence-based items that can guide the development of a review protocol to ensure transparency in the selection process (Moher, Liberati, Tetzlaff & Altman, 2009).

3.2 Search Strategy

Searches of peer reviewed literature were carried out using the following four electronic databases; OVID gateway (psycINFO and MEDLINE), PubMed, Informit and ProQuest. Subjects and keywords were developed under the following themes: disability (e.g. developmental disability, intellectual disability, autism, brain injury), positive behaviour support (including American/English spelling) and the community (e.g. community, home). These subjects and key words were then combined using relevant Boolean operators. For example, for psycINFO the final search term entered was; (disability OR 'developmental dis*' OR 'intellectual disability' OR autism OR autis* OR 'brain injuries' OR ASD OR ID OR ABI OR TBI) AND ('positive behavior support' OR 'positive behaviour support) AND (community OR home). The same combinations of keywords were used to search the

remaining databases. The search strategy is included in Appendix 1. Searches were limited to title and abstract only. Hand searches of the reference list of appropriate articles and the citation index, SCOPUS, were used to identify any additional papers.

3.3 Study Selection

Studies were included for systematic review if they:

- specifically reported on PBS strategies
- examined PBS interventions conducted in unstructured community settings (with *any* component of the PBS plan implemented in unstructured settings)
- reported on behavioural outcomes (any impact of PBS on BOC)
- were inclusive of PBS plans implemented by paid and/or unpaid support people
- included quantitative research methods (including mixed-methods)
- were published between 1980 – 2018
- were published in English

This review included peer-reviewed imperical research that met inclusion criteria. Theses and dissertations, literature reviews, book chapters and grey literature were not included for review. Research articles were also not included if they reported on PBS interventions conducted in structured settings (e.g. schools), without any component of the plan implemented in unstructured setting, and if they only utilized qualitative methods of data collection. Searches included research conducted between 1980 and 2018. This ensured first studies in PBS were captured, which appeared in the late 1980's – early 1990's. These inclusion and exclusion criteria were used at abstract and full-text screening levels.

Studies identified were uploaded into Covidence and two reviewers (student and Primary Supervisor) independently screened their titles and abstracts to determine inclusion for full-text review, with conflicts resolved during face-to-face meetings. The same two reviewers then screened the full text of relevant studies, with conflicts resolved through face-to-face meetings and agreement reached on the final articles to be included for systematic review.

Covidence is an online software package designed to improve the efficiency of conducting systematic reviews and can be used from title and abstract screening up until the point of analysis/summarising (The Cochrane Society, 2018). For this review, Covidence was used to manage the study selection process.

3.4 Critical Appraisal

Critical appraisal refers to the process of systematically looking at research to judge its credibility, relevance and value. Critical appraisals find strengths and weaknesses in research and help to determine whether results are reliable (Holly, Salmond and Saimbert, 2012).

The quality of the articles included in this review was assessed using the McMaster's Critical Appraisal for Quantitative studies form (Laws, 1998; see Appendix 2). This critical appraisal tool was chosen because it has been widely used in academic literature, comprises of a detailed user guide and its appropriateness for a range of research designs. The form contains 14 criteria and covers study design, purpose, sample selection, interventions and contamination, outcome measures and appropriateness of findings. Each criterion required a response indicating "yes", "no", "not addressed" or "not applicable". "Yes", responses were tallied, yielding a final score, with any "not applicable" responses reducing the highest score achievable. The level of evidence for each study being reviewed was also determined according to the National Health and Medical Research Council's (NHMRC) levels of evidence (Merlin et al. 2009).

3.5 Data Extraction and Synthesis

In order to determine the effectiveness, and the effective features of PBS interventions, the following features of PBS interventions were collated: study design; participant demographics; inclusion and exclusion criteria; intervention settings; methods; outcomes; and, main findings. The effectiveness of interventions were examined according to the significance of behaviour change reported.

The studies identified were heterogenous, so meta-analysis was not possible. Therefore, a descriptive synthesis was employed. Descriptive analyses incorporate narrative summaries and the tabulation of study characteristics (Evans, 2002). It is a subjective method of synthesis and there is no standard practice. As such, it is important to consider the reliability, validity and the quality of the evidence presented in the selected studies.

Chapter 4:

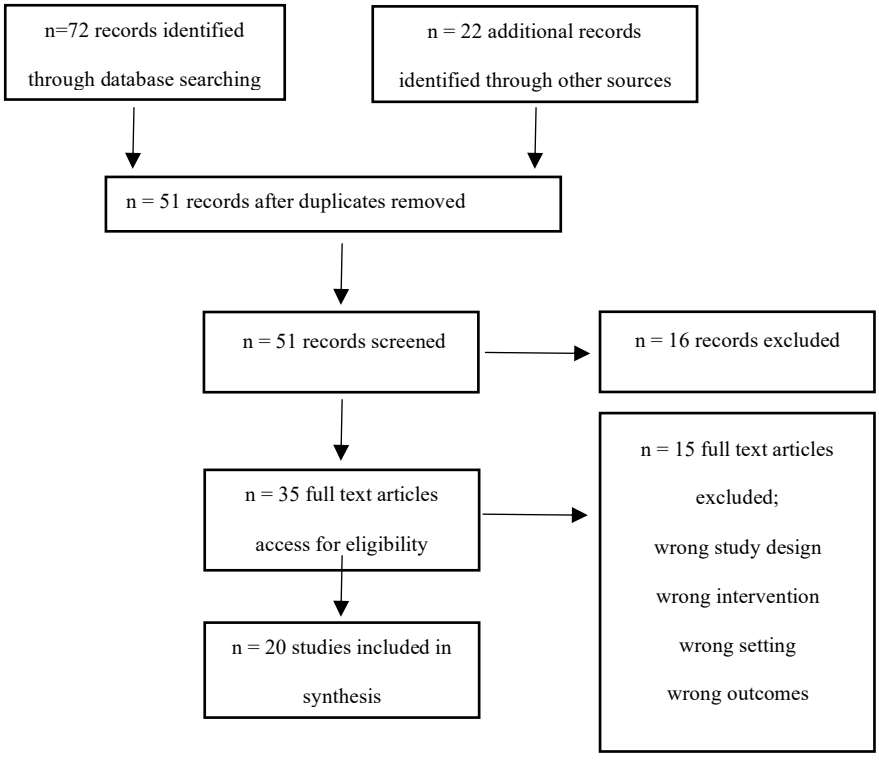
RESULTS

This chapter presents the results from the systematic review. An overview of studies is presented, including study selection, study characteristics, interventions, outcomes and methodological limitations. Common themes are also presented.

4.1 Study Selection

A total of 94 articles were identified for screening and 21 duplicates were removed (refer to Fig 4.1). Fifty-one articles were then screened at the title/abstract level and 16 were removed as they did not meet inclusion criteria. Full-text screening was then conducted for the remaining 35 articles, with a further 15 identified as not meeting the inclusion criteria. This included qualitative study designs, interventions conducted in structured settings, or examining the role of facilitators rather than participant outcomes.

Figure 4.1: Prisma flow diagram for articles identified through literature searches



4.2 Study Characteristics

4.2.1 Participants

Across the 20 studies included for review, there was a total of 417 participants (refer to Table 4.1). Of the 417 participants, 141 (34%) were female and 276 (66 %) were male and their ages ranged from three to 70 years of age. Diagnoses of the participants included autism, ID, mood disorders and mental illnesses, cerebral palsy, Rett syndrome, Landau-Kleffner syndrome, obsessive compulsive disorder and Tourette's. A majority (n=13, 65%) of the studies took place in the United States (Refer to Table 4.1), three (14%) took place in the United Kingdom (10, 14 & 15)), one (5%) study took place in Australia (1), one in Canada (5), one in Taiwan (6) and one in Korea (3).

Table 4.1: Overview of Studies Selected for Review

Authors (year) & location	**Design**	**Participants (Gender, Age/range (y), Diagnoses)**	**Outcome Measures**	**Facilitators & Intervention**	**Findings**
1. Arco & Bishop (2009) Australia	Single-subject case study	M = 3 12 – 43 ABI	- Observation	- researcher and parents (3 families) - assessments for each - plan development with each family - implementation (with parent training)	Family 1: BOC reduced by 40% and latency reduced by 16 min. Family 2: Time taken during getting dressed routine reduced by 10 min (from 16min to 6 min) Family 3: Independent behaviour during eating breakfast routine increased from 52% to 91%.
2. Binnendyk & Lucyshyn . (2009) USA	Single-subject case study	M = 1 6 , ASD	- Observation - goodness of fit assessment questionnaire - Family Qol survey	- Mum and researchers - Assessments (FBA, family ecology, food pref and reinforcer) - PBS plan development in partnership with mum, - child food training with therapist, - parent training - plan implemented by parents	Reduction in BOC = 100% Session 1-9 food refusal 100% of trials & food acceptance 0% Sessions 10-14 food acceptance rose to 100% Sessions 15-16 food acceptance dropped to 87% Sessions 17-22 food acceptance 100% At follow up; maintained high levels of food acceptance and gains in independence.
3. Blair, Lee, Cho & Dunlap (2011) Korea	Concurrent multiple baseline design	F = 1 M = 2 4.5 – 5.5 ASD & ID. ASD & CP.	- Observation -adapted Treatment Acceptability form - revised	- teachers and mothers facilitated intervention -Team building with researchers, teachers and parents and training. - FBA - Team develop PBS plan	F1: BOC decreased by 50% at school and 66% at home Appropriate behaviour increased by 49% at school and 53% at home. M1: BOC decreased by 46% at school and 60% at home Appropriate behaviour increased by 47% at school and 50% at home. M2: BOC decreased by 40% at school and 55% at home Appropriate behaviour increased by 46% at school and 48% at home.
4. Buschbacher, Fox and Clarke (2004) USA	Single subject case study	M = 1 7 autistic traits, Landau-Kleffner syndrome, food allergies	- Functional assessment interview - Observation	- Parents (& siblings), and researcher - FBA with parent involvement - Parents and interventionist developed plan - Parents implemented plan	Data indicative of supports and procedures put in place being associated with improvement in behaviour. Positive parent interactions increased, and negative interactions decreased.

5.Cheremshynski, Lucyshyn & Olsen (2012) Canada	Single subject, withdrawal design	M = 1 5 ASD, limited communication	- Observation - Cultural assessment tool	- Mum and researcher - Assessments (cultural and functional) - PBS plan developed (parent + interventionist) - Parent training - implementation of plan	Intervals of BOC – decreased from 87% to 16.7% of intervals during 1st implementation stage; increased to 45% during withdrawal phase and then further decreased to 2% during 2nd intervention stage. At follow up remained at 2.3% % of steps completed 1st Int =78% Withdrawal = 40% 2nd int = 95% Follow-up = 100% Latency increased.
6. Chu (2014) Taiwan	Single subject case study	M = 3 5 -6 ASD, ID, or CP	- Observation - Parenting stress index – short form -Treatment Evaluation Inventory- short form	- main carers (father for 1st child and grandmothers for the other 2) and researchers - FBA during targeted routines - PBS plan developed (parent + interventionist) - Behaviour intervention strategies implemented.	Off task behaviour: baseline – intervention – follow- up Yuan: 98% - 61% - 45% Cheng: 92% – 60% - 49% Kang:63% – 30 %- 25% Non-compliant behaviour Yuan: 93 – 58 – 49 Cheng: 71 – 45 – 40 Kang: 54 – 26 -27 PSI-SF: Total stress for all parents deceased from baseline to follow up Tei-SF: Results supported that the PBIS program involving families and outcomes was acceptable and effective
7. Clarke et al (2002) USA	Single subject case study design – multiple baseline	F = 1 12 ASD, ID, medical conditions	- Observation - child affect ratings, - QoL survey	- FBA (involving consultants, school staff and parents). - Behaviour plan then put together. - Implemented by classroom teacher	BOC – decreased from 75% during baseline to 31% during intervention and 29% in follow-up. Engagement – 12% during baseline, to 80% during intervention, up to 85% follow-up Adult interactions – positive interactions increased from a mean of 24% to 40% and then 45% over the 3 phases. Negative interactions decreased from 50% down to 12% and the 1%
8. Clarke, Dunlap & Vaughn (1999) USA	Single subject case study	M = 1 10 ASD, speech & language difficulties	- Observation	- Assessments (functional, with input from mother) - Parent/professional collaboration to develop PBS plan - Implemented by mother	BOC – decreased from an average of 68% of intervals to 13% during intervention conditions. Engagement – increased from 25% of intervals to an average of 80% during intervention The average time taken to complete the routine reduced from 27 min 5 sec to 10 min 50 sec.

9. Durand et al (2012) USA	RCT	F = 5 M = 30 Mean age = 4.3 ASD, ID	- Observation - QRS-SF (parent pessimism) - SIB-R (GMI) (behaviour) - PSQ	PBS parent training with therapist/researchers OR PBS + PFI parent training with therapist/researchers	Pessimism – post treatment scores were significantly lower than pre-treatment for all families who completed all sessions, no matter which intervention group they were in. GMI – PFI group improved significantly more in GMI scores than PBS only group. Behavioural Obs – On average, those who complete all 8 sessions showed reduction in BOC. Specifically, 10 children from PFI group showed reliable changes in BOC whereas only 5 in the PBS only group showed reliable changes. Attrition – there was no differences in attrition rates between groups. PSQ – difference in 2 questions (p139)
10. Hassiotis et al (2018) England	RCT	F = 88 M = 157 Mean age = 37 (range = 24 – 51) ID	- Observation - mini PASADD - Guernsey community participation & leisure scale - Uplift/burden scale - Family carer psychiatric morbidity (GHQ12)	- support staff - PBS training – 2-day workshop + manual OR TAU – treatment as usual.	There were no statistically significant differences in BOC between the intervention and TAU groups. Of 26 trained therapists, 8 left the study. Out of a possible 108 intervention reports only 33 included all elements. The available plans were rated as weak by an independent assessor.
11. Lucychyn et al (2007) USA	Single subject case study	F = 1 5 ASD, ID	- Observation - Resident lifestyle Inventory - Goodness of fit survey	- parents (mainly mother) and researchers - Assessments (functional and family ecology) - PBS plan developed - Plan implemented by parents -Training and support for parents provided	Data indicated the participant experiences a 94% reduction in rate of BOC Improvements were seen across all dependent variables being measured.

12. Lucyshyn, Albin & Nixon (1997) USA	Single subject case study	F = 1 14 severe ID, functional blindness, forefoot pronation	- Observation - Resident lifestyle Inventory - Goodness of fit survey	- functional assessment (and analysis), - plan development (including routine selection), - parent training, -implementation by parents	Rate of BOC: Total BOC showed statistically significant improvement in 3 out of 4 routines. Latency to termination or successful completion of routine: The leisure routine showed a statistically significant effect, the restaurant and grocery store routines only approached significance and there was no stat. significant change in the dinner routine. Frequency of parent reported indicator behaviours: statistically significant decreasing levels of indicator behaviours were observed. Child activity pattern: At baseline Helen participated in 98 community activities/month. After intervention they increased to 122 and 138 in each assessed month. Improvements maintained during follow-ups (3 and 9 month) Social validity: As rated by parents, was high Contextual fit with family ecology: Consistent with social validity.
13. Lee, Poston & Poston (2007) USA	Single subject case study	M = 1 17 ASD	- Observation	- mother and researcher - Self-reinforcement and self-monitoring explained. - encourage to reach target behavior	AJ became more independent during his night-time routine. The number of verbal prompts his mother made decreased, as did BOC.
14. Grey & McClean (2006) UK	Controlled trial (non-randomised)	F = 24 M = 36 3 – 70 Mean age = 35.5 ID	- Observation - Checklist for challenging behavior (CCB)	- Staff from service provider Intervention/target group - person focussed, training course - assignments (behaviour assessment report, behaviour support plan and quarterly progress review).	Significant reductions in frequency and management difficulty of BOC were seen for the target group. Essentially, pft is associated with significant reductions

15. McClean & Grey (2007) UK	Single subject case studies	F = 2, M = 3 22 - 38 ID, rapid cycling mood disorder. ASD, psychosis, depression, CP, mood disorder. paranoid schizophrenia?	- Observation - Mini PASADD - QoL questionnaire - Data from medication cardex - Periodic service review	- support staff, individuals themselves. - FBA - develop behaviour support plans. - implementation	For all plans, reductions to near zero levels in the monthly rates of behaviour were observed following the implementation of PBS. F1 -implementation of plan increased to 95% over 3 mo F2- 95% implanted by end of 10th mo M3 - implementation of plan increased to 80% over 5 mo M1 – max implementation rate of 74% M2 – max implementation of 48% QoL increased significantly for F1, F2 and M3. QoL did not change for M1 and M2. M1 refused 82% of activities offered to him (staff approached him with 2-way pic choice of preferred activities every 30 min). M2's plan needs more complete implementation.
16. Schall (2010) USA	Single subject case study	M = 1 25 ASD, non-verbal	- Observation	FBA – carried by job coach & a PBS facilitator. PBS plan developed and implementation in workplace	At baseline DJ had ~25-30 episodes of loud noises and 1 incident of pushing per month. On implementation – pushing incidents reduced to 0 and episodes of loud noises reduced to between 10 and 4 incidents across 5 months.
17. Sears, Blair, Iovannone & Crosland (2013) USA	Single subject case study	M = 2 4 – 6 ASD	- Observation	- parents (& researcher) - Initial PTR meeting; teaming and goal setting - Functional assessment (used PTR functional assessment form) and planning. - Developing support plans involved selecting interventions under Prevent, Teach and Reinforce interventions - Interventions implemented by parents	M1: Fidelity – during intervention, both parents scored 90% or greater. For the generalisation routine, there average dropped to 82% with some variability. Child behaviours – bathroom routine; % of independent steps increased from 14% to 53.3% - independent play; chewing inappropriate items decreased from ~93% to 3% of intervals per session. - mealtime; went from no bites of non-preferred food items to 3 bites per meal. M2: Fidelity – during intervention mother's fidelity was 89% for car routine, and 88% for morning routine.

					Child behaviour – car routine; repetitive behaviour went from 3.3 times/min to 0.04 times/min - morning routine; tantrums went from 75% of intervals to 19% and following instructions went from 25 to 81%.
18. Singh et al (2016) USA	RCT	F = 16 M = 32 24 – 57 Mean age = 40.77 ID, mental illness	- Observation - medication administration records - Perceived stress scale-10	- paid carers/support staff - 2 groups trained in PBS practice. - 1st group also trained in mediation and mindfulness techniques - All participants kept a log during the study	Perceived Stress; No difference between groups at time 1. At time 2, there was a significant difference, with a large effect size. ($p < 0.001$) Physical restraints; during training phase significant diff in physical restraint use per week b/n groups. Post treatment, use of physical restraints was lower in the MBPBS group. Stat Med; during post training phase, sig lower in MBPBS group Aggressive events; fewer in the MBPBS group post training

19. Vaughn, Wilson & Dunlap (2002) USA	Single subject case study	M = 1 7 ASD, severe ID, non-verbal.	- Observation	- mother and researcher - FBA across 3 subroutines (arriving, mealtime and leaving) - PBS plan developed; included 3 specific interventions - implementation	Arrival - Engagement; increased from 23.1% of intervals to 70.3% (47.2% improvement) - BOC; decreased from 69.3% of intervals to 28.1% (41.2% reduction) Mealtime - Engagement; increased from 41.3% to 92% of intervals (50.7% improvement) - BOC; decreased from 53% of intervals to 21.3% (31.7% reduction) Departure - Engagement; increased from 21% to 91.3% of intervals (70.3% improvement) - BOC; decreased from 78.6% to 15.3% of intervals with BOC (63.3 reduction)
20. West & Patton (2010) USA	Single subject case study	F = 2, M = 2 34 -41 ID, Rett syndrome, CP, used modified signs, limited language	- Observation	- lead trainer and agency trainer - individualised support plans - supported job training.	F1 – task analysis of 5 steps; completed independently and correctly @ session 15. F2 - task analysis of 5 steps; completed independently and correctly @ session 14. M1- task analysis of 6 steps; completed independently and correctly @ session 15. M2 - task analysis of 10 steps; completed independently and correctly @ session 15.

Key of Abbreviations: See Appendix 3

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4.2.2 Methodological Quality

Using the McMasters critical appraisal tool for quantitative studies, the studies included scored between 7 - 13 out of a possible 14, or 64%-93% (Table 4.2). The average overall score was 86%. These scores suggest the studies reviewed were relevant, reliable and valid. However, the overall level of evidence presented by these studies was low. Out of the 20 studies, three consisted of type II studies (randomized control trials) according to NHMRC guidelines (Durand, Hieneman, Clarke, Wang, & Rinaldi, 2012; Hassiotis et al., 2018; Singh, Lancioni, Karazsia, Chan, & Winton, 2016). These were the highest rating studies using the McMasters critical appraisal tool, scoring 12-13. One type III-1 (non-randomized control trial) study was included (Grey & McClean, 2006) and the remaining articles where type IV studies (case studies).

Table 4.2: Summary of McMasters University – Critical Review Form for Quantitative Studies

	Purpose clearly stated	Background lit reviewed	Sample described in detail	Sample size justified	Outcome measures reliable	Outcome measures valid	Intervention described	Contamination avoided	Cointervention avoided	Stat. significance reported	Methods of analysis appropriate	Clinical importance	Drop outs	Conclusions	Overall score
Arco and Bishop	Y	Y	Y	N/A	N	Y	Y	N/A	NOT AD	N/A	N	Y	Y	N	8/11
Binnendyk and Lucyshyn	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Blair et al	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Buschbacher, Fox and Clarke	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Cheremshynski, Lucyshyn and Olson	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Chu	Y	Y	Y	N/A	Y	Y	Y	N/A	N	N/A	Y	Y	Y	Y	10/11
Clarke et al 02	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Clarke, Dunlap and Vaughn	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Durand	Y	Y	Y	Y	Y	Y	Y	NOT AD	NOT AD	Y	Y	Y	Y	Y	12/14
Hassiotis	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	13/14
Lucyshyn et al 07	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Lucyshyn, Albin & Nixon	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	Y	Y	Y	Y	Y	10/12
Lee, Poston & Poston	Y	Y	Y	N/A	N	Y	Y	N/A	NOT AD	N/A	Y	N	Y	Y	8/11
McClean and Grey 06	Y	Y	Y	Y	N	Y	Y	Y	NOT AD	Y	Y	Y	Y	Y	12/14
McClean & Grey 07	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
Schall	Y	Y	Y	N/A	N	N	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	8/11
Sears et al	Y	Y	Y	N/A	Y	Y	N	N/A	N	N/A	Y	Y	Y	Y	9/11
Singh et al	Y	Y	Y	Y	Y	Y	Y	Y	NOT AD	Y	Y	Y	Y	Y	13/14
Vaughn, Wilson & Dunlap	Y	Y	Y	N/A	Y	Y	Y	N/A	NOT AD	N/A	Y	Y	Y	Y	10/11
West & Patton	Y	Y	Y	N/A	N	N	Y	N/A	NOT AD	N/A	Y	Y	Y	N	7/11

4.3 Interventions

All studies included an FBA consisting of indirect assessments and observation prior to developing behaviour support plans (refer to Table 4.1). Team approaches were taken and/or parent-professional partnerships developed at the beginning of the process, individualised behaviour support plans developed and interventions that included altering the environment in which the behaviour takes place, teaching and learning, positive reinforcements and plans for if or when behaviour escalated were implemented

All of the 20 studies included in this review consisted of those that were person and/or family-centered. The individual, their everyday support people, (e.g. family and friends) were partners in the intervention processes; from planning to implantation and follow up. The interests and needs of the individual and their families were central to support plans. Most plans were also multicomponent in nature (interventions addressed settings and the way support people interacted with the individual, they taught the individual new skills, and they also addressed the consequence of the behaviour; n = 18), and appeared to be ecologically valid (took place in natural settings; n = 19) and socially valid (were a good fit for the individual and their families; n = 18) (refer to Table 4.4). A majority of interventions also included training and support components (n = 18). There were also components that were not routinely incorporated. For example, only five studies provided evidence of having a life span perspective (refer to Table 4.3), five described the incorporation of multiple theoretical perspectives and four demonstrated flexibility (i.e. interventions could be altered or changed as needed).

The 20 articles included for review were categorised in to three major themes, including parent/professional partnerships, training and self-care and community participation.

4.3.1 Parent/Professional Partnerships

Eleven of the 20 articles (n=11) included, examined PBS interventions for children (Refer to Table 4.1). In each of these studies, parents (or primary caregivers) worked in parent-professional partnerships **w**ith researchers to develop family-centered PBS plans, addressing BOC that occurred during specific daily routines. After plans were developed by the parent-professional partnership, the primary caregivers were supported by the researchers to implement the plans. Arco and Bishop (2009) describe a similar approach for adults in which parent-professional partnerships were developed to carry out assessments, develop intervention plans and support parents in their implementation.

4.3.2 Training and Self-Care

While all of these studies (n=4) were concerned with PBS training for carers they reported outcomes for participants, hence the inclusion of these studies for review. The three RCT's (Durand, 2015; Hassiotis, 2018; Singh, 2016) and the non-randomised CT (Grey & McClean, 2007) all examined aspects of carer or support worker training in relationship to individual outcomes. Durand (2012) studied the benefits of incorporating positive family intervention (PFI) into PBS parent training compared to PBS training alone. PFI incorporates optimism training with PBS training for parents. Singh included mindfulness training into PBS training for paid support workers had on clients within their care and Grey

and McClean (2006) considered the impact of incorporating person focused training into the usual staff training. Hassiotis (2018) explored the impact of PBS training for disability support workers in urban rural areas

4.3.3 Community Participation

A number of studies (n=6) examined aspects of community engagement. Chu et al (2015) and Blair et al (2011) described interventions that relied, not only parent-professional partnerships, but with home-school collaborations.

West and Patton (2010) and Schall (2010) reported on the design and use of individualized PBS plans in the workplace and McClean and Grey (2007) and Lee, Poston and Poston (2007) explored PBS and the improvement of QoL as well as access to the community, in general.

4.4 Outcomes

A variety of assessment measures and outcomes were identified across the 20 studies included. Therefore, a meta-analysis of data was not possible, and a descriptive synthesis completed. Study outcomes relating to BOC and broader QoL issues are reported given their relevance to PBS. For example, feelings of pessimism have and impact of QoL.

The majority of studies reported reductions in BOC, and improved levels of engagement with set routines or task (refer to Table 4.3). Of the 20 studies reviewed, three explicitly meesured QoL (Binnendyk & Lucyshyn, 2009; Clarke et al, 2002: McClean et al, 2007).

4.4.1 Quality of Life

In Binnendyk and Lucyshyn's (2009) study, QoL and family well-being were assessed using the Family Quality of Life Survey (Hoffman, 2006). This survey consists of 41 items covering five family QoL domains including, family interactions, parenting, health and safety, family resources and support for family members with disability. The survey was conducted pre-intervention, six weeks and 26 months post-intervention. Although the overall family QoL had improved and was maintained, after the two years post intervention the parent's satisfaction level with the support for their child returned to its baseline level.

Clarke et al (2002) conducted a study using a number of measurements to assess the outcomes of an individualised PBS intervention within a school. This included the QoL survey, developed by Kincaid et al (2002). This survey contains 22 items using a Likert scale, which measures the students overall QoL, interpersonal relationships, self-determination, social inclusion, personal development and emotional wellbeing from the perspective of parent, classroom teacher aides, speech therapist and school staff (Clarke et al, 2002). The authors reported parents and teachers responded to survey questions more positively (higher ratings) post intervention than they did pre-intervention. More positive results would indicate a perceived improvement in the students QoL (Kincaid et al, 2002).

In their study describing the use of PBS to support five adults with ID's and significant BOC, McClean, Grey and McCracken (2007) measure changes in pre and post-intervention QoL, with the quality of life questionnaire (QOL-Q). The QOL-Q is a tool to measure QoL outcomes for people with intellectual and developmental disabilities that measures personal satisfaction, competence and productivity, empowerment and

independence as well as community participation and inclusion (Schalock, Verdugo, Gomez & Reinders, 2016). The QoL of three of the five participants improved significantly.

The QSR-F measures parent perceptions of family problems, pessimism, characteristics of the individual and physical incapacity. Durand et al (2012) administered this evaluation tool to determine whether there was a decrease in parent pessimism following optimism training and in turn, whether this had an impact on child behaviour. They did observe decreases in pessimism and these decreases seemed to have a positive impact on child behaviour. When compared to a group of parents who received PBS training, those who received optimism and PBS training observed greater reductions in child BOC. This may suggest that when parents have a more optimistic outlook, their family's overall QoL is improved.

The parenting stress index short form (PSI-SF) and the questionnaire on resources and stress (QSR-F) are both evidence-based measures of parental/carer stress. Chu et al (2015) administered the PSI-SF to gauge carer stress levels. The PSI-SF is a self-report tool that encompasses areas of parent stress, parent-child interactions and stress attributed to children engaging in BOC (or "difficult" child) domains. All families in the Chu et al (2015) study reported decreases in stress in the "difficult" child domain post intervention and two of the family's overall stress scores moved from high range stress to normal stress levels.

An increase in desired behaviours is often measured in addition to the reduction of BOC in PBS studies. Six of the studies identified for review included such measures (Clarke et al, 1999; Clarke et al, 2002; Lucyshyn et al, 2007; Lee, Poston & Poston, 2007; Sears et al, 2013 and Vaughn et al, 2002). Increases in desired behaviours might suggest an increase in levels of satisfaction and/or happiness, and therefore, improved QoL.

Table 4.3: Primary Outcomes and PBS Intervention Components

Authors / **Primary Outcomes**	Arco and Bishop	Binnendyk and Lucyshyn	Blair et al	Buschbacher, Fox and Clarke	Cheremshynski, Lucyshyn and Olson	Chu	Clarke et al 02	Clarke, Dunlap and Vaughn	Durand	Hassiotis	Lucyshyn et al 07	Lucyshyn, Albin & Nixon	Lee, Poston & Poston	McClean and Grey 06	McClean & Grey 07	Schall	Sears et al	Singh et al	Vaughn, Wilson & Dunlap	West & Patton
Significant reduction in BOC	*	*	*	*	*	*	*	*	*		*	*	*	*	*	*	*	*	*	*
Quality of life		*					*								*					
Intervention components																				
Person/family centred	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Multicomponent	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*		*	*
Focus on prevention				*	*	*	*	*	*				*		*	*	*	*	*	*
Lifespan perspective	*										*				*	*				*
Ecologically valid	*	*	*	*	*	*	*	*	*		*	*	*	*	*	*	*	*	*	*
Socially valid	*	*	*	*	*	*	*	*	*		*	*	*	*	*	*	*	*	*	
Multiple theoretical perspectives			*	*			*		*									*		
Flexible							*									*			*	*
Training/Support for carers	*	*	*	*	*	*		*	*	*	*	*	*	*		*	*	*	*	*

Note: Intervention Components are defined in Table 4.4

Table 4.4: Definition of Intervention Components

Intervention Components	**Definitions**
Person/family centered	PBS plans are developed to improve opportunities for self-determination, social role valorisation, skill development and improved quality of life of the individual and their everyday support people.
Multicomponent: Environment/setting Skill development Consequence	Interventions address settings and the way support people interact with the individual, they teach the individual new skills, and they also address the consequence of the behaviour.
Focus on prevention	Focus is on making changes to settings that meet the needs of the individual. New skills taught when behaviours are not present.
Lifespan perspective	Interventions take the notion that meaningful change can take years into consideration. Interventions need to change and evolve as the individual develops.
Ecologically valid	Takes place in real life settings.
Socially valid	Interventions need to be a good fit for the individual and their everyday support people. Likes, interests, values, beliefs and culture are considered.
Multiple theoretical perspectives	PBS is a framework involving various systems and including different fields of psychology.
Flexible	The emphasis of PBS is in the natural environment, which is far from controlled nor predictable a lot of the time, so measurements and assessments need to be flexible.
Training/Support for carers	Parent/Professional partnerships formed, or PBS training provided to carers (from assessment of behaviour through to review of plan). Additional training such as PFI or mindfulness provided. Active support provided.

4.4.2 Behaviours of Concern

Nineteen of the 20 studies identified for review reported reductions in BOC. Twelve of these employed parent-professional partnerships. Parents collaborated with, and received support from, professionals in the development and implementation of PBS plans (refer to Table 4.1). Follow-up periods ranged between two to twelve months post intervention. In one case, follow up data was collected seven years post intervention. The twelve studies reported reductions in BOC that were maintained until follow-up. For instance, Binnendyke and Lucyshyn (2009) reported 100% improvement in the eating habits of a young child, following a home-based PBS intervention. Vaughn, Wilson and Dunlap (2002) reported a reduction in BOC for one routine, from 78.6% of 10 second intervals measured at baseline, to 15.3% of 10 second intervals measured

at follow-up. Cheremshynski, Lucyshyn, and Olson (2013) reported a reduction in BOC from 87% at baseline to 2.3% at follow up, as well as an increase in engagement from 0% at baseline up to 100% at follow up.

4.4.3 Impact of Facilitator Training

Three studies examined the impact that facilitator training had on BOC (Durand et al, 2015; Hassiotis et al, 2018 & Singh et al, 2016). Two of the three studies that included PBS facilitator training also included a focus on self-care (Durand et al, 2015; Singh et al, 2016). These studies had positive impacts on reducing the BOC the individuals the facilitators care for. Singh et al (2016) found that as perceived carer stress reduced, so did BOC of those within their care and Durand et al (2012) found twice as many children's BOC reduced if their parents participated in PFI and PBS training, compared with those whose parents participated in PBS training alone. Hassiotis (2018) did not report any significant outcomes regarding the reduction of BOC after providing PBS training to staff in a residential facility in addition to their usual training programs.

4.5 Methodological Limitations

There were a number of methodological limitations noted. Two studies did not include any details of intervention/ behaviour plans (other than stating PBS) limiting ability to replicate or determine processes for review (Lucyshyn, Albin & Nixon, 1997; Sears, Blair, Iovannone & Crosland, 2013).

Aside from the RCT and CT studies, only one other study reported the statistical significance of results obtained (Lucyshyn, Albin & Nixon, 1997). The majority of studies included for review were class IV level studies, and sample sizes small, so generalisability is not

possible. Another limitation found across studies was the limited follow up. Only six of the 20 studies included for review collected follow up data 12 months or more post intervention. Determining long term benefits of PBS is therefore difficult.

Identifying specific components contributing to the effectiveness of PBS is difficult given it is multicomponent in nature. However, there is some evidence to suggest that the framework itself is effective. The studies reviewed have demonstrated that if the function of the behaviour has been determined and person-centered interventions implemented, then BOC are likely to be reduced.

4.6 Summary

This chapter has presented overviews of the study selection process used in this review as well as study characteristics. Twenty articles were identified for review. Across these studies there were a total of 417 participants within an age range of 3 – 70 years of age. Nineteen of the twenty articles reported reductions in BOC and three included measures of QoL. Results from the McMasters critical appraisal tool suggest themes that the studies reviewed were relevant, reliable and valid, yet most had a low class level of evidence.

Chapter 5:

DISCUSSION

5.1 Introduction

The aim of this systematic review was to explore the effectiveness PBS interventions have on enhancing quality of life and reducing behaviours of concern and, to explore effective features of PBS interventions. For the purpose of this review, effectiveness is determined by improvements in QoL and reductions in BOC. This chapter critically discusses results according to research objectives.

5.2 Methodological Assessment

Although the studies included in this review reported positive results concerning the reduction of BOC and improvements in QoL, the class level of evidence of most papers that met the criteria for inclusion is low (Merlin et al, 2009); however, their results revealed important findings. According to Balshem et al (2011), high levels of evidence do not imply strong recommendations, nor do low levels of evidence imply an intervention should not be considered.

There are difficulties with carrying out RCTs on interventions, like PBS, that are designed to improve the QoL of participants. The interventions used and support plans developed are highly personalised, so comparing them would probably yield unreliable results. Another difficulty is the question of how ethical it would be to designate (even randomly) vulnerable individuals or families to control groups when they and their everyday support people need help. This issue has been more acknowledged and work is being done to improve the rigour of single case study designs (Tate et al, 2016).

In all studies reviewed, the possibility of cointervention effects was not considered when assessing results. Given that 60% of the studies were concerned with children with disabilities it is possible that many of them were involved in other types of therapy/interventions in addition to PBS. This involvement could have an impact on behaviour, so is important to consider.

Five of the included studies also did not use reliable outcome measures. Results were based on observation without the inclusion of interobserver reliability measures. Many of the studies reviewed (n = 16) were single case studies. This meant sample sizes were small and the number measurements taken limited. One study (Sears, Blair, Iovannone and Crosland, 2013) did not provide enough information about strategies used and plans developed for their study to replicated.

The evidence supporting the effectiveness of PBS interventions in enhancing quality of life and reducing BOC is of low class, meaning that intervention generalisations can not be made.

5.3 Primary Outcomes

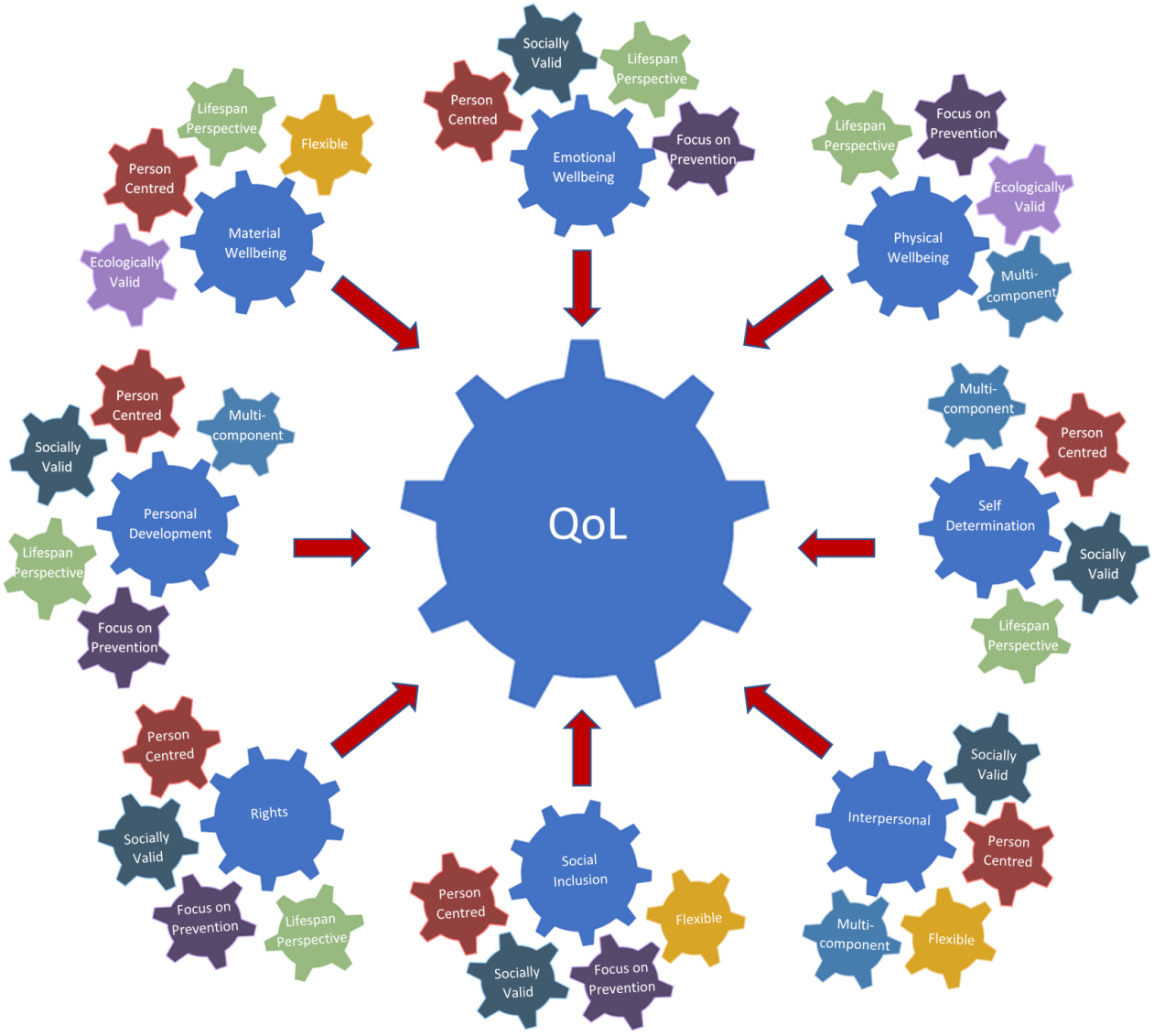
5.3.1 Quality of Life

QoL can be defined as the way an individual perceives their life in relation to their goals, values, and the things they believe will allow them to live a good life (WHOQOL group, 1995). Schalock, Verdugo, Gomez and Reinders (2016) described QoL as being multi-dimensional, comprising eight domains. The domains that QoL encompasses, include: material wellbeing, emotional wellbeing, physical wellbeing, self-determination, interpersonal relationships, social inclusion, rights and personal development (Schalock, Verdugo, Gomez & Reinders, 2016). Each of these domains contributes to the individuals overall QoL and can impacted by variables that are classed as mediators and moderators (Dardas & Ahmad, 2015 and Schalock, Verdugo, Gomez & Reinders, 2016). QoL can be improved if enhancement strategies are employed (Schalock,

Verdugo, Gomez & Reinders, 2016). It could be hypothesized that strategies embracing the principles of PBS could be considered QoL enhancement strategies. Figure 5.1 attempts to depict the interactions of PBS principles with QoL domains. Given that the primary goal of PBS is to improve the QoL of the individual engaging in BOC it could be posited that improving QoL measures ought to be central to all PBS plans. There does not appear to be any research examining this idea, so further investigation is warranted.

Interestingly, only three studies included in this review reported outcomes specific to QoL. Binnendyk and Lucyshyn (2009), Clarke et al (2002) and McClean, Grey and McCracken (2007) all reported improvements in QoL. However, if using the model (Figure 5.1), improvements in any of the QoL domains contribute to improvements in overall QoL. Hence, in reporting improvements in measurements pertaining to the wellbeing and inclusion domains of QoL, (Chu et al, 2015; Durand et al, 2012; Hassiotis, 2018; Lucyshyn et al, 1997), Lucyshyn et al, 2007; Singh, 2016; Clarke et al, 1999; Lee, Poston and Poston, 2007; Sears, Blair, Iovannone & Crosland, 2013, and Vaughn, Wilson and Dunlap, 2002) did provide evidence of making contributions to the improvement in overall QoL. According to this model (Figure 5.1) there is a possibility that the difficulties in measuring QoL in PBS interventions are circumnavigated. Clarke et al (2002) noted the lack of definitive tools that measure QoL changes resulting from PBS and any tool that could be used rely on assumptions. The fact that only three of the studies included in this review attempt to measure an overall QoL, and they each use a different measurement tool, supports this notion.

Figure 5.1: Interaction of PBS principles (coloured outer cogs) with QoL and QoL domains (based on Schalock, Verdugo, Gomez & Reinders, 2016)



Key: PBS principles = coloured outer cogs; QoL and QoL domains = blue cogs

5.3.2 Behaviours of Concern

The second goal of PBS is to reduce BOC. Ninety five percent (n=19) of the studies selected for review reported improvements in BOC during targeted routines, suggesting PBS as being effective in achieving this second goal. This suggests the presence of common effective features. Lucyshyn et al (2018) observed that (family-centered) PBS approaches had many features in common, including a FBA and the development of multicomponent intervention plans that include strategies that are preventative, that teach and encourage learning and reinforce positive behaviour. In additional, Lucyshyn et al (2018) noted that QoL was an important feature of PBS that was often missing in PBS studies. Not surprisingly, the common features observed by Lucyshyn et (2018) are the same as those in the studies identified for review. The positive correlation between observations made via this systematic review and the Lucyshyn et al (2018) paper extends to the lack of focus on QoL.

The one study that did not report any improvements in behaviour, or QoL, was conducted by Hassiotis et al (2018). The aim of this study was to compare client outcomes after staff received PBS training with outcomes of clients who received their usual treatment programs. A small percentage of service providers participating in the study had previously offered their staff training in PBS. Whether or not staff in the usual treatment group had any previous knowledge of PBS or used any PBS like interventions is unknown. Other possible reasons for this outcome may have been the focus on behaviour modification in the PBS training provided, rather than the improvement in QoL. As stated by the authors (Hassiotis et al, 2018) the goal of PBS was to help understand behaviour, and to apply personalized approaches to behaviour management. Another possible reason lies in the impact staff turnover has on a client's behaviour. During the course of the study 49% of the paid carers involved changed. Wallet (2016) observed that when support

staff left their place of employment (a supported living environment) clients experienced levels of distress as a result of the loss and disruption to routine and communicated this distress through BOC.

5.4 Principles of PBS and Intervention Components

The first step within the PBS framework is to gain an understanding of the individual and the BOC they present with. Factors contributing to the behaviour should be determined through a comprehensive assessment process. An FBA was incorporated into each of the studies reviewed, which included both indirect and direct assessment methods.

Indirect observations included interviews with primary carers and other support people in the individual's everyday lives. Aspects that are part of the HELP framework (Bradley & Korrossy, 2016) are considered during an indirect assessment;

H – health/medical (is the individual in any physical discomfort or pain?)

E – environment (are senses hyper- or hypo- aroused; do expectations match individuals capacity?)

L – lived experience/emotional wellbeing; mental wellbeing can be experienced by/in the body (is the individual able to articulate what is happening in their inner world. This can be difficult for the most articulate person. How well does the individual deal with daily stress? Any signs of emotional dysregulation?)

P – psychiatric disorder.

It is also important to consider the disability diagnosis the individual has, and the effect it has on the individual's cognitive abilities. The disabilities commonly associated with BOC are all

so different and while the outward behaviour might look the same, the underlying reason for such behaviour could be very different.

Direct observations were carried out in the individual's natural environments. Behaviours were recorded as where antecedent and consequential events. Data from these observations were then used to consider the events that could predict and maintain BOC (Fisher et al, 2018).

According to the findings of this review some of the intervention components contributing to the effectiveness of PBS, include person and family centered practices, the implementation of multicomponent PBS plans, training and support, interventions that are a good fit for the individual and their everyday support people and are ecologically valid. They also include multiple theoretical perspectives (Table 4.3). These components are exemplified in recommended PBS frameworks and are what helps reduce BOC.

5.4.1 Person/Family Centered Practice

All studies included in this review described (or included in training) person or family centered behaviour plans. Some studies provided strong evidence of person and family centered planning. For instance, Cheremshynski et al (2013) reported on developing a PBS plan that was culturally relevant to a Japanese family living in Canada; it placed the values and needs of the family at the centre of the planning process. A likely result from the effort in ensuring the plan was culturally appropriate and the intervention was a good fit for the family, was the significant reduction in BOC, and improved family QoL.

Other interventions included family-centered plans that seemed to limit the choice and control of the individual. For example, Lee, Poston and Poston (2007) described a self-managed intervention to build a young man's independence when following a night time routine. One of

the steps in the routine was tooth brushing, however the young man preferred to do this at other times of the day. Although the young man was able to successfully perform the steps of the routine independently, his preferences were not considered when developing or determining the success of the intervention. Not considering his preference when developing the intervention and could be seen as limiting the young man's self-determination. Self-determination is one of the QoL domains and something that self-managed interventions aim to enhance (Lee, Poston & Poston, 2007).

When an intervention diminishes the preferences of the individual, the essence of family-centered practice is lost. Family-centered practices are about building partnerships with family support workers and other professionals that may be involved with the family (Dunst & Dempsey, 2007). The partnerships developed are collaborative in nature, involve families at all levels and supports all family members so that family QoL is enhanced (Rolland, 2015; Dunst & Dempsey, 2007). Family centered practices recognize and respect the differences in each individual within the family unit (Institute of Human Services, 2008). Practices that diminish the preferences of the individual, or limit self determination are not consistent with key features of PBS and appear not to embrace the values of PBS.

5.4.2 Multicomponent Interventions

The multicomponent nature of PBS is an integral part of the framework. Multicomponent interventions have been implemented in a range of fields including, health (Wilson et al, 2010), mental health (Baker et al, 2018) and disability (Petrenko, 2013). When they involve preventative strategies to enhance QoL (e.g. parent training and strategies to improve parent-child interactions) resultant improvements in target behaviours have been promising (Petrenko, 2013).

All studies reviewed were multicomponent in nature. The PBS plan described by Lucyshyn, Albin and Nixon (1997) is one that clearly demonstrates what a multicomponent intervention looks like. That is, it demonstrates a plan that includes strategies that are preventative, that teach and encourage learning and reinforce positive behaviour (Carr et al, 2002). Their plan used participant family's knowledge of their child's triggers in detailing steps to prevent BOC, steps to prepare the child for participation in selected activities, skills to teach, reinforcements that were valued by the child and their family, and respectful strategies to implement if BOC escalate.

5.4.3 Training and Support

In the studies reviewed, training and support occurred in a variety of ways. When PBS was implemented with families, training and support for parents occurred within parent-professional partnerships (refer to Table 4.1). Parents/carers had input in all aspects of PBS plan development and implementation. They were equal partners with interventionists/researchers and shared their unique expertise, knowledge and understanding of their child and family values. Such partnerships contributed to the effectiveness of PBS; however, some families require longer term support than what these research studies can offer. Arco and Bishop (2009) acknowledged the limited time for training and support they were able to offer was insufficient for one family in their study. Longer term support can be facilitated through family-centered practices using a capacity building approach as they aim to support all family member. The shared expertise within family centered practice could empower some families to problem solve – i.e. apply knowledge of the PBS framework to different challenges as they arise (ECIA, 2016).

Other studies reported the provision of PBS training to support staff and some studies outlined the ways in which researchers worked directly with the individual and provided education

in PBS to job coaches and employers. One study worth mentioning was that conducted by Schall (2010), who reported on the implementation of PBS for an individual in their workplace. PBS in the workplace follows the same protocol as PBS implemented in any other environment; an FBA was carried out by the researcher and staff within the workplace and a PBS plan developed. This entailed the importance of a good job fit, antecedent strategies and skills to teach the individual to be successful at work. One of the antecedent strategies was teaching people with whom the individual worked about their communication differences and ways to communicate with them. When staff, peers or even the wider society become aware of, and embrace such differences the way the individual is perceived improves (Osburn, 2006). This contributes to social role valorisation and QoL. Social role valorisation is based on the premise that people are more likely to have an increased quality of life, if they hold socially valued roles (Osburn, 2006).

When a person engages in behaviours of concern they may be judged and devalued (Osburn, 2006). This places individuals at risk of being rejected, segregated and abused. Whereas, those who are feel valued are more likely to contribute to society in meaningful ways. PBS is premised on the principles of social role valorization (Carr et al, 2002). As such, any intervention needs to help the individual gain a socially valued role within their community. That might be through teaching new skills to build competency, by educating the community regarding various behaviours so that they may become more widely accepted; or altering the environment to reduce the likelihood of behaviours of concern occurring and providing opportunities for success in the workplace (Osburn, 2006 and Schall, 2010). Schall (2010) described the implementation of each of these strategies in their study on the support of an individual at work.

5.4.4 Ecological and Social Validity

The findings of this study suggest that implementing person-centered PBS plans in everyday settings can improve QoL and reduce BOC. West and Patton (2010) discussed the importance of FBA's and behaviour supports within the workplace for four adults that had consistently been isolated and left out of employment opportunities due to BOC. The community service organisation emphasised the need for a reduction in BOC to enable these opportunities, however, West and Patton (2010) demonstrated that a focus on improving the participants QoL achieved the desired outcome by providing employment and community access. As previously described, Schall (2010) also reported on the implementation of a PBS plan in a place of work. Hyman (2009) described the way PBS was implemented to prepare a Jewish boy diagnosed with autism for his Bar Mitzvah. They then went on to conclude that the implementation was successful as his QoL was enhanced through higher levels of inclusion in his community (Hyman, 2009).

5.4.5 Multiple Theoretical Perspectives

The inclusion of multiple theoretical perspectives in PBS interventions such as the theories underlying parent-child interactions and psychology influencing self-care practices are beginning to gain the attention of researchers. This research suggests that incorporating the theories underlying these practices as strategies that could improve QoL and reduce BOC (Smith, Greenberg, Seltzer and Hong, 2008; Lucyshyn et al, 2015; Lucyshyn et al, 2018; Durand et al, 2012 and Singh, 2016). However, only five of the 20 studies included in this review presented evidence of including multiple theoretical perspectives (e.g. the theories underlying parent-child interactions or self-care for carers) in their interventions. These studies did reveal positive outcomes relating to QoL and reductions in BOC.

Blair, Lee, Cho and Dunlap (2011) and Bauschbacher, Fox and Clarke (2004) collected data on the incidence of positive and negative parent/child interactions yet did not comment on the role these interactions potentially played in the reduction of BOC. Clarke et al (2002) collected data on positive and negative adult/child interactions. They commented that these interactions were more positive during intervention, but did not explore this further.

The hypothesis that positive parent/child interactions have a positive influence on behaviour directly correlates with the results reported by Smith, Greenberg, Seltzer and Hong (2008). They found that positive family environments had a positive impact on reducing BOC. More specifically, the warmth and praise extended by mothers to their autistic children and the quality of the mother/child relationships were related to the reduction of BOC. Exploring the impact of positive relationships within a PBS framework could add to the effectiveness of PBS.

Durand et al (2012) and Singh et al (2016) explored the use of different theoretical perspectives in their studies. Rather than focusing on the steps of 'preventing', 'teaching' and 'reinforcing', they examined the impact of including self-care strategies (optimism training and mindfulness) for carers on behavioural outcomes. Optimism training is a type of cognitive behaviour therapy that focuses on positive thinking (Riskind, Sarampote and Mercier, 1996), while mindfulness can be described as a state of present moment awareness (Donald, Atkins, Parker, Christie, & Ryan, 2016). Building optimism and practicing mindfulness both contribute to improving coping abilities and reducing stress (Segerstrom, Taylor, Kemeny & Fahey, 1998 and Donald, Atkins, Parker, Christie, & Ryan, 2016). When a person is more able to cope and can reduce stress, their emotional wellbeing is improved. Improvement in carer wellbeing can contribute to the enhancement of their own QoL and that of the individual, which, in turn, may have an impact on behavioural outcomes (Schalock, Verdugo, Gomez & Reinders, 2016).

5.5 Limitations

Although valid methodologies were used in conducting this systematic review, a number of limitations should be acknowledged. In the key word search only two terms pertaining to unstructured community settings (community and home) were identified. Including search terms such as natural environments or everyday settings may have led to more relevant studies being identified. The inclusion criteria meant that only studies written in English and published in peer reviewed journal were selected and limiting the databases used meant that some journals were not searched.

It is possible that giving equal weight to the items within the McMasters critical appraisal tool limited this review. This tool weights each question equally no matter how significant they were. For example, ecological validity and sample size justification are considered to be equal.

5.6 Recommendations for Future Research

This review has explored effective features contributing the improvement of QoL and the reduction of BOC. It has identified most studies report improvements in BOC without measuring QoL, despite QoL improvement supposedly being the primary outcome of PBS. Further research is needed in order to place QoL improvement at the forefront of studies. Some suggestions are presented below.

- Study the impact of using a mindfulness-based PBS (MBPBS) approach in family homes. Singh et al's study on MBPBS involving support workers in residential accommodation services, provides important insight into the impact self-care strategies have on the QoL of the individual.

However, more research is needed to determine whether using this practice in family homes would yield similar positive results.

- Early childhood intervention services have found family-centered practices using a collaborative teamwork model to be effective. This is where family member and professions work as a team to improve the QoL of the family. Team members can be anyone who supports the individual and their family such as teachers, therapists, support works and extended family members. Further research into the effectiveness of this model of practice, across the ages (not just early childhood) could yield some promising results.

- Determine whether other models used for understanding BOC and supporting those who present with BOC, e.g. Self-Reg. (Hopkins & Shepard, 2016 and Shanker & Francis, 2016), can be incorporated into the PBS framework. Simply, Self Reg views BOC as being a stress response. It recommends that stressors be identified and removed (or minimised) in order to reduce the response.

- At present there is no consistently applied tool for measuring and reporting QoL. Future research should examine appropriate measures of QoL for use to monitor PBS interventions to inform guidelines for best practice.

5.7 Conclusion

The aims of this systematic review were to explore the evidence supporting the effectiveness of PBS interventions in enhancing quality of life and reducing behaviours of concern as well as the features of effective interventions. Ninety-five percent of the studies reviewed reported improvements in BOC following intervention, however, the low class level of evidence and small sample sizes of most of the papers reviewed means that generalisations regarding

effectiveness of interventions cannot be made. Key intervention components that contribute to the effectiveness of PBS interventions include person and family centered practices, the implementation of multicomponent PBS plans, training and support for carers, interventions that are a good fit for the individual and their everyday support people and that are ecologically valid. They also include multiple theoretical perspectives. These components are steeped in the values underlying the PBS framework.

The primary goal of PBS is to improve the QoL of those presenting with BOC, their families and other everyday support people, yet the focus of much of the PBS literature appears to be on the reduction of BOC. When steps are taken to improve the QoL of families and carers by reducing parent or carer stress levels or by improving parent-child interactions as part of PBS, more significant reductions in BOC are observed. There is much work to be done to place QoL enhancements at the forefront of PBS planning and implementation.

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APPENDIX 1

	Key Word Search				
Subject Themes	**ScienceDirect**	**OVID (psychINFO and MEDLINE)**	**PubMed**	**ProQuest**	**Informit search**
Disability	disability	disability	disability	disability	disability
	"Developmental dis*"	'Developmental dis*'	"Developmental dis*"	"Developmental dis*"	"Developmental dis*"
	"Intellectual disability"	'Intellectual disability'	"Intellectual disability"	"Intellectual disability"	"Intellectual disability"
	autism	autism	autism	autism	autism
	Autis*	Autis*	Autis*	Autis*	Autis*
	"Brain injuries"	'Brain injuries'	"Brain injuries"	"Brain injuries"	"Brain injuries"
	ASD	ASD	ASD	ASD	ASD
	ID	ID	ID	ID	ID
	ABI	ABI	ABI	ABI	ABI
	TBI	TBI	TBI	TBI	TBI
Hits		**188545**	**208913**	**201042**	**11106**
PBS	"Positive behavior support"	'Positive behavior support'	"Positive behavior support"	"Positive behavior support"	"Positive behavior support"
	"Positive behaviour support"	'Positive behaviour support'	"Positive behaviour support"	"Positive behaviour support"	"Positive behaviour support"
Hits		**768**	**48**	**552**	**22**
Community	community	community	community	community	community
	home	home	home	home	home
Hits		**396585**	**532084**	**1005038**	**90220**
Combined search (Hits)	**0**	**47**	**4**	**20**	**1**

APPENDIX 2

Critical Review Form – Quantitative Studies
©Law, M., Stewart, D., Pollock, N., Letts, L. Bosch, J., & Westmorland, M.
McMaster University
- Adapted Word Version Used with Permission –

The EB Group would like to thank Dr. Craig Scanlan, University of Medicine and Dentistry of NJ, for providing this Word version of the quantitative review form.

Instructions: Use tab or arrow keys to move between fields, mouse or spacebar to check/uncheck boxes.

CITATION	Provide the full citation for this article in APA format:
STUDY PURPOSE Was the purpose stated clearly? ☐ Yes ☐ No	Outline the purpose of the study. How does the study apply to your research question?
LITERATURE Was relevant background literature reviewed? ☐ Yes ☐ No	Describe the justification of the need for this study:
DESIGN ☐ Randomized (RCT) ☐ cohort ☐ single case design ☐ before and after ☐ case-control ☐ cross-sectional ☐ case study	Describe the study design. Was the design appropriate for the study question? (e.g., for knowledge level about this issue, outcomes, ethical issues, etc.): Specify any biases that may have been operating and the direction of their influence on the results:
SAMPLE N = Was the sample described in detail? ☐ Yes ☐ No Was sample size justified? ☐ Yes ☐ No ☐ N/A	Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups?: Describe ethics procedures. Was informed consent obtained?:

<table>
<tr><td rowspan="2">OUTCOMES

Were the outcome measures reliable?
☐ Yes
☐ No
☐ Not addressed
Were the outcome measures valid?
☐ Yes
☐ No
☐ Not addressed</td><td colspan="2">Specify the frequency of outcome measurement (i.e., pre, post, follow-up):</td></tr>
<tr><td>Outcome areas:</td><td>List measures used.:</td></tr>
<tr><td>INTERVENTION

Intervention was described in detail?
☐ Yes
☐ No
☐ Not addressed
Contamination was avoided?
☐ Yes
☐ No
☐ Not addressed
☐ N/A
Cointervention was avoided?
☐ Yes
☐ No
☐ Not addressed
☐ N/A</td><td colspan="2">Provide a short description of the intervention (focus, who delivered it, how often, setting). Could the intervention be replicated in practice?</td></tr>
<tr><td>RESULTS

Results were reported in terms of statistical significance?
☐ Yes
☐ No
☐ N/A
☐ Not addressed
Were the analysis method(s) appropriate?
☐ Yes
☐ No
☐ Not addressed</td><td colspan="2">What were the results? Were they statistically significant (i.e., $p < 0.05$)? If not statistically significant, was study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis?</td></tr>
</table>

Clinical importance was reported? ☐ Yes ☐ No ☐ Not addressed	What was the clinical importance of the results? Were differences between groups clinically meaningful? (if applicable)
Drop-outs were reported? ☐ Yes ☐ No	Did any participants drop out from the study? Why? (Were reasons given and were drop-outs handled appropriately?)
CONCLUSIONS AND IMPLICATIONS Conclusions were appropriate given study methods and results ☐ Yes ☐ No	What did the study conclude? What are the implications of these results for practice? What were the main limitations or biases in the study?

APPENDIX 3

Key of Abbreviations for Table 4.1

ABI – Acquired brain injury

ASD – Autism spectrum disorder

ID – Intellectual disability

CP- Cerebral palsy

BOC – Behaviour of concern

FBA – Functional behaviour assessment

PBS – Positive behaviour supports

PBIS – Positive behaviour intervention and supports

QoL – Quality of life

QSR–SF – Questionnaire on resources and stress - short form

SIB-R – Scales of independent behaviour – revised

PSQ – Parent satisfaction questionnaire

PFI – Positive family intervention

PASADD – Psychiatric assessment schedule for adults with developmental disability

PFT – Person focused training

PTR – Prevent, teach, reinforce

MBPBS – Mindfulness positive behaviour support