

**UNIVERSITY OF THE WESTERN CAPE**

**Faculty of Community and Health Sciences**

**MINI THESIS**

**Title:** A systematic review of psychosocial interventions for families of child burn survivors

**Student Name:** Shani Senekal

**Student Number:** 3165259

**Type of Thesis:** Mini-thesis

**Degree:** MPsych (Clinical Psychology)

**Department:** Psychology

**Supervisor:** Professor R. Ahmed

**Co-Supervisor:** Professor A. Van Niekerk

**Date:** 28 February 2020

**Key words:** burns, psycho-social interventions, systems interventions, support, families, child burn survivors, paediatric burns, systematic review, low-income countries

Submitted in partial fulfilment of the requirements for the degree MPsych at the University of the Western Cape

## TABLE OF CONTENTS:

<b>AKNOWLEDGEMENTS</b>	<b>iv</b>
<b>DECLARATION</b>	<b>v</b>
<b>ABSTRACT</b>	<b>vi</b>
<b>CHAPTER 1: INTRODUCTION</b>	<b>1</b>
1.1 Background & Rationale	1
1.2 Aims	2
1.3 Research questions	2
1.4 Definitions	2
<b>CHAPTER 2: LITERATURE REVIEW</b>	<b>4</b>
2.1 Introduction	4
2.2 Epidemiology in LMIC	4
2.3 Impact of burn injuries	5
2.3.1 Impact on the child	5
2.3.2 Impact on parents	6
2.3.3 Impact on the family	7
2.4 Interventions	8
2.4.1 Child interventions	8
2.4.2 Parent/Family interventions	9
2.4.3 Community interventions	11
2.5 Conclusion	11
<b>CHAPTER 3: METHODOLOGY</b>	
3.1 Introduction	13
3.2 Research Design	13
3.3 Study Protocol	14
3.4 Eligibility Criteria	14
3.4.1 Inclusion Criteria	14
3.4.2 Exclusion Criteria	15
3.4.3 Study Selection	16
3.5 Search Strategies and information sources	16
3.6 Data extraction process	17
3.6.1 Selection of databases and searching key words	17

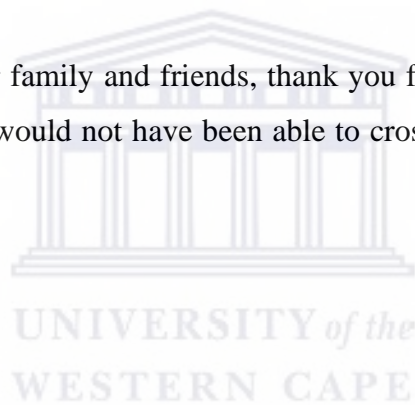
3.6.2 Title Screening, abstract screening, full article reading process and reference mining	19
3.6.2.1 Title screening	19
3.6.2.2 Abstract screening	19
3.6.2.3 Full text reading	20
3.6.6.4 Reference mining	20
3.7 Application of critical appraisal process	23
3.8 Outcome of critical appraisal process	25
3.9 Studies examined but not eligible for review	26
<b>CHAPTER 4: RESULTS AND DISUSSION</b>	<b>27</b>
4.1 Results	27
4.1.1 Search findings and study characteristics	27
4.1.2 Summary of interventions table	28
4.1.3 Intervention categories	33
4.1.3.1. <i>Medical Interventions with psycho-educational/psycho-social components</i>	33
4.1.3.2. <i>Interventions aimed at providing support</i>	36
4.1.3.3. <i>Burns Camps</i>	40
4.1.4 Reported limitations of studies	41
4.1.5 Reported implications for practice	43
4.1.6 Reported research recommendations of studies	44
4.1.7 Studies examined but not eligible for study	45
4.2 Discussion	47
4.2.1 Main findings	47
<b>CHAPTER 5: RECOMMENDATIONS &amp; CONCLUSION</b>	<b>55</b>
5.1 Summary of key findings	55
5.2 Recommendations for future research	55
5.3 Implications for practice	56
5.4 Study Limitations	57
5.5 Concluding comments	57
<b>REFERENCE LIST AND APPENDIXES</b>	

## AKNOWLEDGEMENTS

I would like to thank my supervisor, Professor Rashid Ahmed, for his guidance, support and encouragement through each stage of my thesis writing process. Thank you for going above and beyond to ensure that I finish this thesis in time. For this I am extremely grateful. I would also like to thank my co-supervisor, Professor Ashley Van Niekerk, who played a key role in identifying this crucial research topic, sharing his wealth of knowledge in the field and assisting with my writing process. I would also like to thank Shelley Vickerman, for patiently guiding me throughout my systematic review process. Your time and valuable input in the evaluation process was greatly appreciated.

I would also like to thank my editor, Brenda Burgess, for taking on this project with a limited time frame and being so accommodating.

Last, but not least. To my dear family and friends, thank you for your continuous emotional support and encouragement. I would not have been able to cross the finish line without your care.





## DECLARATION

I declare that *A systematic review of psychosocial interventions for families of child burn survivors* is my own work, that it has not been submitted for any degree or examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged as complete references.



Full name: Shani Vici Senekal

Date: 28.2.2020

A handwritten signature in black ink on a grey background, reading "S. Senekal".

Signed : \_\_\_\_\_

## **ABSTRACT:**

Burns are a major problem in Low-Income Countries (LIC) and Low-Middle Income Countries (LMIC). Children in LIC have been identified as a burn injury at-risk group. Individuals experience severe psychological and physical distress as a result of burn injuries. However, burns are a systemic problem and their impact is not limited to the individual but impacts the family system as a whole. Therefore, effective post burn interventions for families of child burn survivors are key in order to assist the child burn survivor's well-being and recovery. The present study hopes to 1) address some of the gaps in knowledge in burn interventions for families of child burn survivors and 2) identify promising psychosocial interventions. A systematic review of literature was conducted that focused on identifying burn interventions for families of child burn survivors. These interventions were evaluated in order to establish which interventions showed promise. This systematic review was conducted following the guidelines of the PRISMA Statement for Systematic Reviews. An integrated quantitative and qualitative appraisal tool was used to review the identified studies. All the available English-medium literature between 1990 and 2019 was reviewed for this study. A literature search was performed in EBSCOhost, Academic Search Complete, PsychArticles, CINAHL plus, Medline, ERIC, SocIndex and Health Source: Nursing/Academic edition. Five studies were identified which included psychosocial interventions for families of child burn survivors. Of these studies only two were of quantitative nature and indicated sufficient evidence with regards to outcomes and efficacy. Three studies were of qualitative nature and indicated subjective evaluation measures to assess efficacy. Interventions identified included a family burns camp, a support group for parents, a support website, a parent participation program during acute paediatric burns management, and a teaching manual. All five studies indicated a degree of efficacy however, support groups in conjunction with psycho-education groups with systemic focus appeared to show the most promise. It is recommended that researchers focus on using quantitative measures in future intervention studies to assist in measuring efficacy. Furthermore, context specific interventions for LIC should be considered.

## CHAPTER 1: INTRODUCTION

### 1.1 Background and Rationale

Burn injuries are a major global health threat. This threat is evident as annually 180 000 deaths can be ascribed to fire-related burn injuries (WHO, 2019). Millions more experience extreme psychological and physical distress as a result of disabilities and disfigurement from burn injuries (Blakeny & Creson, 2002; Mock et al., 2008). Children are particularly vulnerable to burns; such injuries are widespread and the related consequences impact the family system (Heath, 2016).

The rationale elaborates on the current focus of burns research, identifies a gap in burns research and explains the significance of this research study. Researchers have highlighted the need for health professionals to commit to interventions that assist burn patients in improving their long-term health (Al-Mousawi et al., 2009). However, there is a paucity of research on interventions for burn survivors and even less research has been conducted on evidence-based burns interventions. Most burns research has focused on high-income countries (HICs), however the risk for burns is mainly in Low-Middle Income countries (LMICs) and Low-Income Countries (LICs) (Peden et al., 2008; Van Niekerk et al., 2012). Research within LMICs and LIC's has been limited and has mainly focused on the epidemiology and risk factors associated with burns. In recent years, burns researchers started to focus their attention on post-burn interventions in LMICs and LIC's, but this type of research has mainly focused on clinical interventions such as mortality management and injury reduction (Van Niekerk et al., 2012).

The need for burns intervention research for a LMIC like South Africa becomes more apparent when looking at statistics on the extent of burns. Within the South African context children have been identified as an at-risk group for burn injuries (Wesson et al., 2013) as approximately 1,300 South African children's lives are lost annually due to burn injuries (Bradshaw et al., 2003). Of these, thousands sustain serious injuries that often have life-long consequences (Van Niekerk et al., 2012). Researchers have emphasised the importance of and the need for child interventions in LMICs and LICs (Hornsby et al., 2019).

Globally and nationally the focus has been on interventions for children, rather than systemic interventions. Although there is a need for child intervention research, Heath (2016) states that the mental health of parents of burn survivors is key to the effective recovery and healing

process of the child burn survivor. He emphasises the need for parental support in order to prevent psychosocial difficulties within the family. For this reason, the family system needs to be treated as a whole in order to effectively treat child burn survivors (Blakeney & Creson, 2002), thereby highlighting burn recovery as a systemic issue. However, it is evident that there is a disjuncture between intervention needs and current burns research. Van Niekerk et al. (2012) states that very little South African research has focused on the effect of burns on the individual, child, home, family and community.

Therefore, the family system needs to be a priority for burns intervention research, to better inform the management of burn injuries of child burn survivors and their families. Specifically, it is vital to identify evidence-based acute and post-discharge psycho-social interventions for parents of child burn survivors that shows promise or has demonstrated an impact, and can potentially be applied within burn care units, hospitals, clinics as well as other LMIC and LIC community settings in order to improve the psychological well-being of these parents.

## **1.2 Aims**

The present study sought to 1) address some of the gaps in knowledge in burns interventions for families of child burn survivors, 2) identify evidence-based psycho-social interventions aimed at the child burn survivor and their family, 3) evaluate the efficacy of these interventions.

## **1.3 Research Questions**

- 1) What are the available psycho-social interventions for families of child burn survivors?
- 2) Which evidence-based interventions are the most effective?

## **1.4 Definitions:**

*Psycho-social Interventions:*

Psychosocial interventions are defined as any non-pharmacological interventions aimed at addressing various problems which may be associated with mental health disorders. Such problems may include relational, psychological, social or vocational problems. These may include interventions with psychotherapeutic, skills, individual-, social- and peer support, as well as psycho-educational components with the outcome of maintaining the recovery process (Turton, 2014).

*Family system:*

The family system is defined as the nuclear family system eg. parents, child, siblings as well as the extended family system e.g. grandparents, aunts or uncles (other caregivers) (Dallos & Draper, 2015). Extended family has been included to accommodate the non-western family system often found within LMICs and LICs.

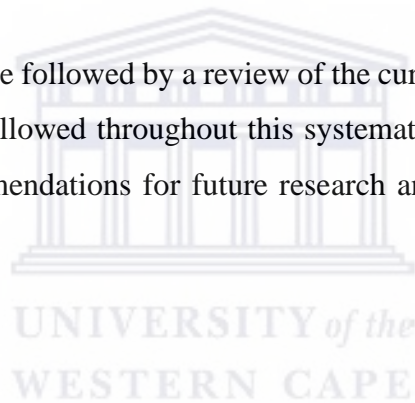
*Burns:*

Burns can be defined as any traumatic burns injury ranging from first to third degree burns with various causes. These may include scalding from hot liquids, electrical burns, fires and flammable liquids or gasses (NIH, 2018).

*Child:*

The child is defined as a child aged 0 months to 18 years of age (Kaneshiro et al., 2019).

This introduction chapter will be followed by a review of the current literature on this topic, an explanation of methodology followed throughout this systematic review process, results and discussion of findings, recommendations for future research and practice and will end with concluding comments.



## CHAPTER 2. LITERATURE REVIEW

### 2.1 Introduction

Child burn injuries are a major health problem in LMICs and LICs and impact the well-being of child burn survivors as well as their families. This literature review begins with an explanation of the epidemiology of burns in LMICs and LICs. It then focuses on the impact of burns on the child, parents and the family as a unit. Lastly, it identifies a few existing burn support interventions for the individual, family and the community.

### 2.2 Epidemiology in LMICs

Burn injuries and burn mortality is a major health threat in LMICs and LICs. Globally, it has been found that over 95% of all burn injuries predominantly occur within these countries (Mock et al., 2008; WHO, 2019). Specifically, the majority of burn deaths occur in LMICs and LICs in regions such as Africa, South-East Asia and the Eastern Mediterranean region (Peden et al., 2008).

Burns have been identified by the WHO as a dominant contributor to disease for children of LICs and LMICs (Peden et al., 2008). The unequal distribution of this phenomenon in LICs in comparison to HICs is evident as current statistics indicate that fire mortality rates for children are approximately seven times higher in LICs than in HICs (WHO, 2019).

Within South Africa, statistics echo a similar phenomenon to other LMICs and LICs. Each year approximately 1300 South African children lose their lives due to burn injuries (Bradshaw et al., 2003 and Van Niekerk et al., 2011). Therefore, it is no surprise that burns have been classified as one of the top three causes of fatal injury among urban South African children between birth and 14 years (Burrows et al., 2010). Within this population group, children aged between one to four years have been identified as particularly at-risk and vulnerable (Seedat et al., 2009; Bradshaw et al., 2003). The vulnerability of this group is highlighted by statistics reported by Red Cross War Memorial Children's Hospital in Cape Town, South Africa, which annually admits 650-900 child burn survivors. 50% of these child burn survivors are under the age of two years (Albertyn et al., 2006).

When child burn mortality statistics in LMICs are compared to those of adults, one sees a very different picture. It is estimated that annually 180 000 adult lives are lost prematurely due to fires (WHO, 2018). Comparing these statistics to the statistics from the much smaller population age group of children aged one to four years, it is evident that child burn mortality and injury is a concerning issue which requires research and intervention focus.

### **2.3 The impact of burn injuries**

Many families experience psychosocial difficulties as a result of burn injuries (Heath, 2016). Various studies have specifically commented on the significant impact of child burns on the child burn survivor as well as their parents. In order to understand the complex and longitudinal impact of burn injuries this literature review will categorise the burns injury process into: 1) the acute phase and 2) the recovery phase. The acute phase refers to the onset of the incident, intake and treatment in hospital. The recovery phase begins when the child burn survivor has been discharged from hospital and the family starts the recovery process at home. Both these phases pose different threats to the family system.

In order to gain insight to the systemic and complex dynamic within the family system as a result of child burns, systems theory will be used as a theoretical framework. According to systems theory families or other person(s) in relationship's actions exist interdependently. One person's response can influence the behaviour of another person, and their behaviour in turn may impact the other's behaviour. This can almost be seen as a circular motion of action-reaction responses within relationships (Dallos & Draper, 2015). This is evident within the family system of the child burn survivor. In order to make sense of the debilitating systemic impact of burns within the family system, the impact of burns on the child, the child's parents as well as the impact of burns on the family system will be unpacked.

#### **2.3.1 Impact on the child**

Burn injuries are seen as one of the most distressing and debilitating forms of trauma for children (Delgado et al., 2002). If children survive the injury, they are often left with visible disfigurement and scars and need to undergo excruciating physical treatment (Blakeny & Creson, 2002). These physical scars can lead to great psychological scars (Barrs et al., 1998 as cited in Van Niekerk et al., 2004).



A review study by Bakker et al. (2013) found that many child burn survivors experience acute and post-traumatic stress after the injury which can manifest in internalising behaviours such as anxiety and withdrawal, as well as externalising behaviours such as aggression and opposition. This indicates that children are extremely vulnerable during this critical phase and emphasises the importance of child and family intervention during the acute phase (Bakker et al., 2013).

The impact of burn injuries continues to affect child burn survivors long after the acute phase. Rivara (1995, as cited in Petridou et al., 1998) found in his study that burn injuries can cause developmental problems for children due to the child's body experiencing deformities as a result of the burn injuries. In addition to physical and developmental complications, burn survivors need to endure the reactions of society toward their disfigurement. This may often lead to re-traumatisation and embarrassment for the survivors (Blakeny & Creson, 2002). It is clear that the impact of burns on children is multi-dimensional and intricate and continues to influence the child long after the acute phase.

### **2.3.2 Impact on parents**

The focus on children needs to be complemented by a focus on other systems. The acute phase of child burns can be traumatising to parents and have an impact on their psychological health. A study conducted by McGarry et al. (2013) highlights the importance of the acute phase in burn injury as it was found that parents experienced significant distress within the first seven days of their child's burn incident. This severe level of distress has an impact on parents' functioning. A study conducted by Hall et al. (2006) found that parents of child burn survivors who developed Post Traumatic Stress Disorder (PTSD), initially experienced dissociation during the child's acute hospitalisation period. Ironically, it is during this acute phase that important information regarding post-care and treatment is shared with parents. However, due to their lack of adequate functioning, resulting from psychological distress, parents are not able to absorb such important information (McGarry et al., 2013).

The psychological distress and feelings experienced by parents during the acute phase of their child's burn injury is multi-dimensional. This is evident in a study by Bakker et al. (2013) who found that "...parents may experience profound guilt and depressive feelings, anxiety, traumatic stress, and many worries about their child's health and future appearance" (p.368). Therefore, it is evident that parents are vulnerable during the acute phase of the child's burn



incident. Proper acute phase management and early treatment of psychological distress is extremely important in order to prevent parents of child burn survivors from developing mental illness (McGarry et al., 2013). During the recovery phase the parent's psychological health is still at risk. Hall et al. (2006) found that 47% of parents in their study sample showed clinically significant symptoms of PTSD three months after their children were hospitalised for burn injuries. Egberts et al. (2017) focused on the longitudinal impact of child burn injuries on parents and found clinically significant PTSD prevalent in 26 % of fathers and 48% of mothers within the first month of their child's burns injury. Additionally, clinically relevant symptoms were found in 4% of fathers and 19% of mothers 18 months post-burn injury.

The physical health of parents of child burn survivors are also a cause for concern. Dorn et al. (2007) studied the physical and mental health of parents of children who survived a massive burn incident. The study found that parents of child burn survivors with burns experienced higher prevalence of mental as well as cardiovascular health problems. These parents were more likely to experience mental and cardiovascular health problems within the first two years post injury than their counterparts.

These findings emphasise the acute as well as the longitudinal impact on parents' mental and physical health and highlight the importance for continued psychosocial support for parents of child burn survivors post-discharge to ensure the health of the family system as a whole. The absence of such support will undermine the essential role that is played by parents in the recovery of the child (Bakker et al., 2013)

### **2.3.3 Impact on the family**

In addition to burn injuries impacting children and their parents, burn injuries also impact the family system as a whole. Hall et al. (2006) found that parents who developed acute anxiety during hospitalisation were more likely to experience conflict with their children post-discharge. These conflicts may be related to anxious parents becoming overprotective and restricting their children to avoid any further injury (Hall, 2006). Horridge et al. (2010) proves this possibility as their study found that the parent's emotional reactions lead to a loss of self-confidence. In an attempt to manage their feelings, parents would become overprotective of their children.

Concerns expressed by parents of burn survivors during interviews conducted by Oster et al. (2014) included worries about the child's burn injuries; feeling unsure about home treatment procedures and struggling to manage their children's reaction to treatment at home; adjusting to a new routine; and the impact on family relationships. Parents also disclosed that the adjustment process at home was a difficult and lonely experience and expressed that they needed more support. In a study conducted by Willebrand and Sveen (2017), a fifth of parents of child burn survivors did not receive adequate psychosocial or medical intervention post-burn injury. Their study highlights the need for professionals in the caring field to shift intervention focus to a multi-disciplinary approach and emphasises the importance and consideration of the parent's needs.

From these struggles it is evident that families of burn survivors need multi-dimensional interventions during the acute phase and post-discharge phase to address the continuously changing needs of the family system. However, the changing family system additionally finds itself within a broader ecological system (Bronfenbrenner, 1994) which in turn bi-directionally impacts the family system (microsystem). For example, families who live in LMICs and LICs (chronosystem) may experience lack of resources (macrosystem) which in turn may impede their ability to access psychological resources within a hospital setting (exosystem). This in turn may perpetuate a traumatised parent's functioning which may indirectly impact the healing process of their child (microsystem). Additionally, medical professionals in hospital who are functioning from a purely bio-medical perspective (meso-system) may consequently lack insight with regards to the needs of such parents and may indirectly perpetuate the dysfunction of the family system. Therefore, it is hypothesized that for burns interventions to effectively address family needs, practitioners should treat families within their ecological systems. This section reviews the current available interventions for child burn survivors and their families. These include interventions for the child, parent and the community.

## **2.4 Interventions**

### **2.4.1 Child interventions**

For the purpose of this study, child interventions will be defined as any psychosocial treatment e.g. educative, supportive or therapeutic skills aimed at supporting the child, while addressing the specific psychosocial issues which may be impeding the child's effective functioning.

These include interventions which are directly aimed at the child as an individual or child interventions which integrate the family.

A study by Van Niekerk et al. (2012) has identified a variety of child-centred rehabilitative intervention methods for child burn survivors in international literature. In their study they identified social support interventions which included burn camps as well as survivor and family support groups; psycho-educational interventions which include school or community re-entry programs using story books or animated video interventions; psychological interventions which include social skills training, psychological assessment and psychotherapy which included psychological treatment and behavioural techniques; and creative interventions such as art and play therapy. These interventions showed potential.

Several other interventions for children have been identified. One such intervention includes a psycho-educational intervention method identified by Lehna (2015) called 'The Body Image Work Book' (2008) to assist child burn survivors in developing a stronger body image, and 'Barbara Kammerer-Quayle's Behavioural Enhancement Skills Training document' to assist the child burn survivor with social skills and self-confidence development.

While several types of interventions exist, evidence with regards to efficacy of interventions varies (Van Niekerk, et al., 2012). It appears that this was due to the identification of quantitative and qualitative studies. Examples of effective interventions highlighted by Van Niekerk (2012) included the social skills training group (Blakeny et al., 2005 as cited in Van Niekerk, 2012), and individualized CBT which included social skills training and problem solving (Maddern et al., 2006 as cited in Van Niekerk, 2012). However, the efficacy of creative interventions such as play therapy still needs to be objectively assessed and this intervention type remains subjective. Therefore, although the intervention methods identified by Van Niekerk et al., (2012) may prove to be popular intervention strategies, a lack of empirical evaluation indicates a gap in burns intervention research.

#### **2.4.2 Parent/Family interventions**

For the purpose of this study parent/family interventions will be defined as any psychosocial treatment e.g. educative, supportive, therapeutic skills aimed at supporting the parent, caregivers and family while addressing the specific psychosocial issues which may be impeding the parent's/family's effective functioning. These include interventions which are

directly aimed at the parents/caregivers as individuals or systemic family interventions which aims to address the needs of the family as a whole.

There appear to be far fewer interventions for families. Internet support (Sveen et al., 2017) and group psychotherapy (Frenkel, 2007) have been identified as two intervention studies for families of child burn survivors and have been found to show potential.

Sveen, et al. (2017) reported on a Swedish internet-based support program for parents of child burn survivors. This programme focused specifically on psycho-educating parents about burns and assisted parents with developing coping skills through online Cognitive Behaviour Therapy (CBT), mindfulness and Acceptance and Commitment Therapy (ACT) modules. Weekly therapeutic feedback (in text format) was provided on participant's homework assignments. Results from this study indicated that parents found the program helpful. The program had a significant decline with regards to Post Traumatic Stress 3 months post-intervention. However, parents still experienced stress after completion. Researchers concluded that the program could easily be accessed and applied in other burn care units.

Frenkel (2007) reported on a more unstructured psychotherapy support group approach used in a South African burn unit. The program incorporated a psychological approach and focused primarily on providing a space for parents to express their emotions as well as facilitate a process where parents could provide each other with support. The success of this support group has not been evaluated due to financial constraints. Yet reflection of the parent's feedback from the support group, although subjective, suggests a degree of efficacy.

It appears that there are more interventions available for children than for families. Of the limited interventions available for families there appears to be a similarity between interventions for children in terms of social support and psycho-educative interventions for parents and families. However, there appears to be less focus on parent interventions with regards to adjustment in terms of community support and work support, in comparison to child interventions which address school and community reintegration. Like child interventions, evidence for efficacy for parent or family interventions does not appear to be strong. Lastly, family interventions were identified in one LMIC (South Africa) and one HIC (Sweden).

### **2.4.3 Community Interventions**

For the purpose of this study, community interventions will be defined as interventions which occur at community level and aim to address ecological systems which may impede effective functioning of the child or family.

One such intervention was identified by Lehna (2015) who recommends the use of ‘The Journey Back Programme’; this focuses on preparing the child burn survivor, their families as well as their class mates for the school reintegration process. However, Lehna does not refer to the efficacy of these programmes. Other researchers echo Lehna’s recommendation. Pan et al. (2017) identified multiple school reintegration interventions aimed at working with the child, the parent and the teacher, while simultaneously using the broader school community as a protective factor for reintegration; however, they also concluded that none of these interventions were assessed for efficacy.

Van Niekerk et al. (2012) refers to a variety of community interventions conducted in HIC (USA and UK) in their review study. Typically, these interventions focus on psycho-education programs for younger children. These programs use tools such as story books and animated videos at hospitals, and they also use individualised video methods during school visits to assist child burn survivors in their return to school. Both these intervention strategies have been found to be successful.

It appears that community interventions may be more prominent than interventions for parents and families. However, there still appears to be paucity of community interventions. Identified community interventions appear to focus more on the needs of the burns child and appear to not be as focused on the needs of the family system. Similarly, a limited amount of community interventions have been assessed for efficacy. Lastly, similarly to the contexts of child and parent/family interventions, community interventions were all aimed at contexts of HIC.

### **2.5 Conclusion**

From the above literature review it is evident that child burn mortality and injury is a crisis that is predominantly affecting LMICs and LICs. It is evident that child burn injuries have a serious impact on the well-being of the child burn survivor. Furthermore, parents of child burn survivors also experience great distress. PTSD, depression, anxiety, adjustment problems and health issues are some of the major concerns identified for parents of child burn survivors.

Although parents of child burn survivors are evidently an at-risk group, few studies regarding interventions for parents were found. Of these, the majority of identified interventions had been applied within HICs. Only one intervention was identified for families of burn survivors in a LIC. No systematically evaluated interventions for families were found. Similarly, only a few community intervention programmes were identified. Some, but not all of these interventions had been evaluated. It is evident from the current literature review that research has mostly focused on child interventions for HICs and that intervention strategies for LMICs and LICs have not yet been identified. Of these intervention strategies only CBT and social skills training interventions have been evaluated and found to be effective.

It is clear that there is a gap in burns research, especially regarding burns interventions for families and the promise held by these burn interventions. Furthermore, there is a major gap in information regarding intervention strategies for LMICs and LICs. Further research is needed to address this gap, in order to effectively aid the holistic recovery process of the child burn survivor and their family – especially within LMICs and LICs.

The impact of burns points to a need for Systemic Family Interventions especially within LMICs and LICs. However, studies on interventions in LMICs and LICs, are limited. In addition to this, the efficacy of many current interventions have not been evaluated.



## CHAPTER 3. METHODOLOGY

### 3.1 Introduction

Methodology can be understood as a motivation for and execution of the best appraisal to understanding a research question (Hedge, 2015). This chapter will focus on the procedure followed by the researcher in answering the research question. This includes a description and discussion of research design, study protocol, eligibility, exclusion criteria, search strategies, data extraction methods and data analysis.

### 3.2 Research Design

The research design used for this research project took the form of a systematic review. A systematic review is applied to find, evaluate and summarise findings with regards to an identified research question. These findings are used to inform researchers and provide them with evidence-based answers relating to an enquired topic (Boland et al., 2017). Furthermore, the aim of a systematic review is to assist researchers in finding gaps in research and identify ways to improve on current studies (Gough et al., 2012). Due to its methodological rigour, systematic reviews are viewed as the standard for compiling evidence in health care. For this reason, it is helpful to use systematic reviews to inform clinical decision-making (Moher et al., 2015).

Keeping in mind the clinical nature of the research question, the use of a systematic review was found to be the most effective research method to address the aims and research question for this study, as it assisted the researcher in systematically evaluating and summarising current psychosocial interventions available for families of child burn survivors. In addition, a systematic review allows for quality assessment of current interventions being used. It thereby assisted the researcher in identifying gaps within current interventions for families of burn survivors. It is clear from the research question and literature review that evaluating the evidence for current interventions is crucial to inform future research and interventions.

Systematic reviews are typically used for intervention studies or used to comment on the effectiveness of interventions (Gopalakrishnan & Ganeshkuman, 2013). Some include only quantitative studies (Hornsby, et al., 2019), others only qualitative (Rhodes et al., 2007) and some combine quantitative and qualitative (Shaw et al., 2015). For the purpose of this study, both quantitative and qualitative studies will be included for assessment, due to the lack of

quantitative studies objectively assessing interventions for families of child burn survivors in the literature review. It is recommended by Noyes et al. (2019) that both qualitative and quantitative studies of interventions be included in systematic reviews to understand the complex nature of interventions. Additionally, including both qualitative and quantitative studies may assist in understanding the complex systems interventions are often entrenched in. It is hoped that this method could assist in identifying diverse evidence. (Noyes, et al., 2019)

Therefore, by including both quantitative and qualitative studies, the researcher hopes to identify diverse evidence of available psychosocial interventions for families of burns survivors as well as reiterate indications from previous research emphasizing the need for more quantitative intervention studies.

### **3.3 Study Protocol**

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) process was developed in response to the absence of standardised protocols for systematic reviews in published studies (Moher, et al., 2015). Therefore, this systematic review was conducted following the PRISMA Statement checklist as a guide for reporting. The PRISMA Statement checklist (Appendix E) is a standardised protocol, consisting of 27 reporting items, specifically developed to ensure clear protocol and scientific rigour for Systematic Reviews and Meta-analysis (Panic et al., 2013). The main categories of evaluation for this checklist, used to guide the researcher, included: Title, abstract, introduction, methods, results and discussion. In addition to this protocol, the PRISMA flow diagram (see figure 3.2) in conjunction with the relevant inclusion and exclusion criteria, provided a guideline for all steps in the review process including the identification, screening and inclusion of full text studies for review.

### **3.4 Eligibility Criteria**

#### **3.4.1 Inclusion criteria**

All the available English-medium peer-reviewed journals between 1990 and 2019 were reviewed for this study. Additionally, the PICO framework guided the development of the study's inclusion criteria to inform the research question. This framework is supported by the Cochrane Collaboration and guides researchers in identifying components of systematic reviews, specifically exploring evidence-based medicine. It does this by guiding the researcher in identifying the Population (P), Intervention (I), Comparison (C) and Outcomes (O) of a study (Higgins & Green, 2011).



The inclusion criteria used to identify relevant titles, abstracts and articles were as follows:

*Population (P):*

The specific population for this study included the families of child burn survivors. For the purpose of this study the term families (family) include caregivers, parents or grandparents. The term child burn survivors include children under the age of 18 with various forms of burn injuries.

*Intervention types (I):*

The intervention types included in this study were all acute and post-discharge psychosocial interventions: counselling, psychologist or psychiatrist support, psychodynamic therapy, cognitive behavioural therapy, art therapy, social work contact, support groups, psycho-education, home adjustment programs, family therapy, nursing support, management support, and management education.

*Comparison/Control (C):*

This was not applicable for this study as the review included both quantitative and qualitative studies.

*Outcomes (O):*

Intervention studies which specifically explored and measured psychological well-being and psycho-social well-being of families of child burn survivors were included. Therefore, the outcomes for this study included psychological well-being of parents of child burn survivors. Specific examples of these include depression, PTSD, acute stress disorder, adjustment problems, anxiety, physical health, isolation, feelings of guilt and self-blame.

Psychosocial well-being of parents of child burn survivors was an additional outcome. Specific examples of these include parent-child relationship, coping, management and home-based care outcomes.

### **3.4.2 Exclusion criteria**

Any preventative interventions, purely medical interventions or burns interventions not aimed at families of child burn survivors were excluded from the search criteria. Furthermore, unpublished articles, books, book chapters, conference proceedings, letters, editorials, and dissertation papers were excluded from the systematic review. Grey literature was excluded from this systematic review to increase inclusion of high level of evidence studies to inform best practice. (Green, 2005)

All studies prior to 2000 were initially excluded from the search as the researcher wanted to identify the most recent interventions. However, the exclusion cut-off date was later adjusted to exclude all studies prior to 1990 as a limited amount of studies were identified between 2000 and 2019.

### **3.4.3 Study selection**

In order to ensure access to a wide variety of interventions, studies such as case studies, comparative studies, review studies, randomised control studies and non-randomized control studies were all considered during the screening process. Both quantitative and qualitative designs were included.

### **3.5 Search strategies and Information sources**

The researcher's search strategy was adjusted throughout the systematic review process. Initially, the researcher conducted a search in June 2019, specifically looking for English-medium peer-reviewed journals published between 2000 and 2019 which met PICO criteria.

In order to access relevant articles, the researcher specifically searched for abstracts in the various databases comprising the relevant key terms. To ensure the extraction of relevant abstracts and full text articles, search terms that included all variations of 'Psychosocial Interventions' pertaining to 'Families of Child Burn Survivors' were used. These search terms were identified through consultation with co-researchers and initially comprised an extensive list of search terms comprising of variants of the following: Psychosocial Interventions, Parents, Burns, Child, Psychological and Psychosocial Well-being. However, due to the limited number of articles accessed through these search terms, a second meeting with a co-researcher was conducted to discuss alternatives for the key word search process. Upon further investigation a decision was made to exclude variations of 'child' and 'outcomes' as key search

terms as these two categories of search terms limited the amount of article hits. The following search terms allowed for more hits and a wider pool of articles and were used for the final search:

(family OR parents OR caregiver) AND (intervention OR program\* OR management OR therapy OR support OR help OR counsel\*) AND (burn victim\* OR burn survivor\* OR burn OR scalding)

It should be noted that during this initial screening process in June 2019, a limited number of relevant articles (four articles) were identified within the stipulated inclusion time line 2000 – 2019. Concern with regards to the limited research in the field of family burns interventions was discussed during consultation with co-researchers. In order to clarify this, a specialist in the field (L. Frenkel) was consulted to identify whether research with regards to family interventions was indeed limited. It was found during this discussion that this was indeed the case. After consulting with co-researchers, a collaborative decision was made to extend the search time line from 1990 to 2019 to ensure methodological rigour. A second search was conducted in January 2020 which ensured for a slight increase in relevant articles. The data extraction process below reports on the revised time line.

### **3.6 Data extraction process**

#### ***3.6.1 Selection of databases and searching key terms***

A literature search was performed via the University of the Western Cape (UWC)'s library using the metadata online research platform EBSCOhost. Within EBSCOhost the following databases were selected to assist the identification of articles: Academic Search Complete, PsycARTICLES, CINAHL Plus, Health Source: Nursing/Academic Edition, SocINDEX and ERIC. Scopus was also used as an additional and separate database. Within these databases the above specified key terms and limits were used to search for relevant articles.

The data extraction process was as follows: The researcher conducted two separate, but identical data extraction processes for EBSCOhost as well as SCOPUS. The researcher identified 1130 article hits within EBSCOhost. From these 1130 articles EBSCOhost electronically removed 365 duplicate articles, which left 765 articles. From these 765 an additional seven duplicate articles were manually removed, leaving a total of 758 articles available for title screening within EBSCOhost. Similarly, within SCOPUS, the researcher

identified 833 article hits. However, of these 833 articles, 51 duplicate articles were found which had already been identified within EBSCOhost. Subsequently, these duplicates were manually removed by the researcher, which left a total of 782 articles available for title screening. Consequently, a total of 1540 articles were eligible for title screening from both EBSCOhost and SCOPUS.

Table 3.1 summarises the outcome of these processes, providing a breakdown of total hits for each of these databases, as well as duplicate removal.

**Table 3.1 Summary of total article hits**

<b>Total article hits</b>	<b>1963</b>
<b>EBSCOhost hits:</b>	<b>1130</b>
Academic Search Complete	400
PsycARTICLES	11
CINAHL Plus with full text	410
Health Source:Nursing/Academic Edition	127
SocINDEX	31
Medline	134
ERIC	17
<b>Duplicates electronically removed by EBSCOhost</b>	<b>365</b>
<b>Total EBSCOhost articles after electronic duplicate removal</b>	<b>765</b>
<b>Duplicates manually removed</b>	<b>7</b>
<b>Total EBSCOhost articles after manual duplicate removal</b>	<b>758 *</b>
<b>SCOPUS:</b>	<b>833</b>
<b>Duplicates electronically removed by Scopus:</b>	<b>0</b>
<b>Total SCOPUS articles after electronic duplicate removal</b>	<b>833</b>
<b>Duplicates manually removed</b>	<b>51</b>

<b>Total SCOPUS articles after manual duplicate removal</b>	<b>782*</b>
<b>Total articles included for Title screening:</b>	<b>1540</b>

### **3.6.2 Title screening, abstract screening, full article reading process and reference mining**

#### *3.6.2.1 Title screening*

The researcher conducted the title screening process separately for EBSCOhost as well as SCOPUS. First, 758 EBSCOhost articles were identified through an EBSCOhost search after duplicate removal. Once articles were identified, the researcher continued with the title screening process. In order to identify appropriate studies, key words and variations of key words, in conjunction with PICO guidelines, were used to identify relevant titles. Key words used to guide the researcher during this process included: family, parents, caregivers, intervention, program, management, therapy, support, help, counsel, burn victim, burn survivor, burn, and scalding.

Examples of appropriate, identified key words included in titles included: ‘*Psychosocial interventions. Pharmacologic and psychological modalities*’; ‘*The inextricable link in caring for families of critically burned children*’; ‘*Considerations for psychosocial support following burn injury - a family perspective*’.

Those article titles which included key terms were identified as relevant and were subsequently listed within an excel document used for both title and abstract screening. (See APPENDIX A). Through this process a total of 117 titles were identified as including specified key terms and meeting inclusion criteria. This process was subsequently repeated for SCOPUS as well. Of the 782 SCOPUS articles, 23 articles which included the specified key terms were identified. A total of 1400 titles were subsequently excluded from EBSCOhost and SCOPUS, leaving a total of 140 titles which included key words. See the PRISMA flow chart (figure 3.2) for summary of this process.

#### *3.6.2.2 Abstract Screening*

Following this process, the researcher continued with the abstract screening process using the abstract screening tool (APPENDIX A) to assist the researcher in identifying studies which included key terms, PICO’s as well as inclusion criteria. Each of these processes were

documented in an excel spread sheet and relevant abstracts were included. Specific reasons for exclusion of irrelevant articles were also specified.

Typically, abstract articles identified as appropriate for further screening met PICO and inclusion criteria, and included key words such as “parent, program, burn, support”; “ burn, families, support”; “burn, caregivers, families, intervention”; “family support, family, burn survivors, interventions, burn”. See full list of included abstracts highlighted in green and tabled summary of abstract keywords, PICO’s and Inclusion Criteria in (APPENDIX A).

Reasons for exclusion included incorrect intervention types such as medical interventions or preventative interventions or interventions targeting an incorrect population type such as families of adult burn patients, child burns patients or burns staff. See (APPENDIX A) for a full list of abstract exclusion criteria.

From the total of 140 titles, 124 abstracts did not meet PICO’s or inclusion criteria. These were excluded from further review, which left a total of 16 abstracts eligible full article reading. It should be noted that the researcher had difficulty in accessing one article which appeared to meet inclusion criteria (Barnes & Bud, 1999) during the abstract screening phase. Various institutions and colleagues were contacted in the hope of accessing this article, yet it remained inaccessible. Therefore, it could not be included for further screening.

#### *3.6.6.3 Full text reading*

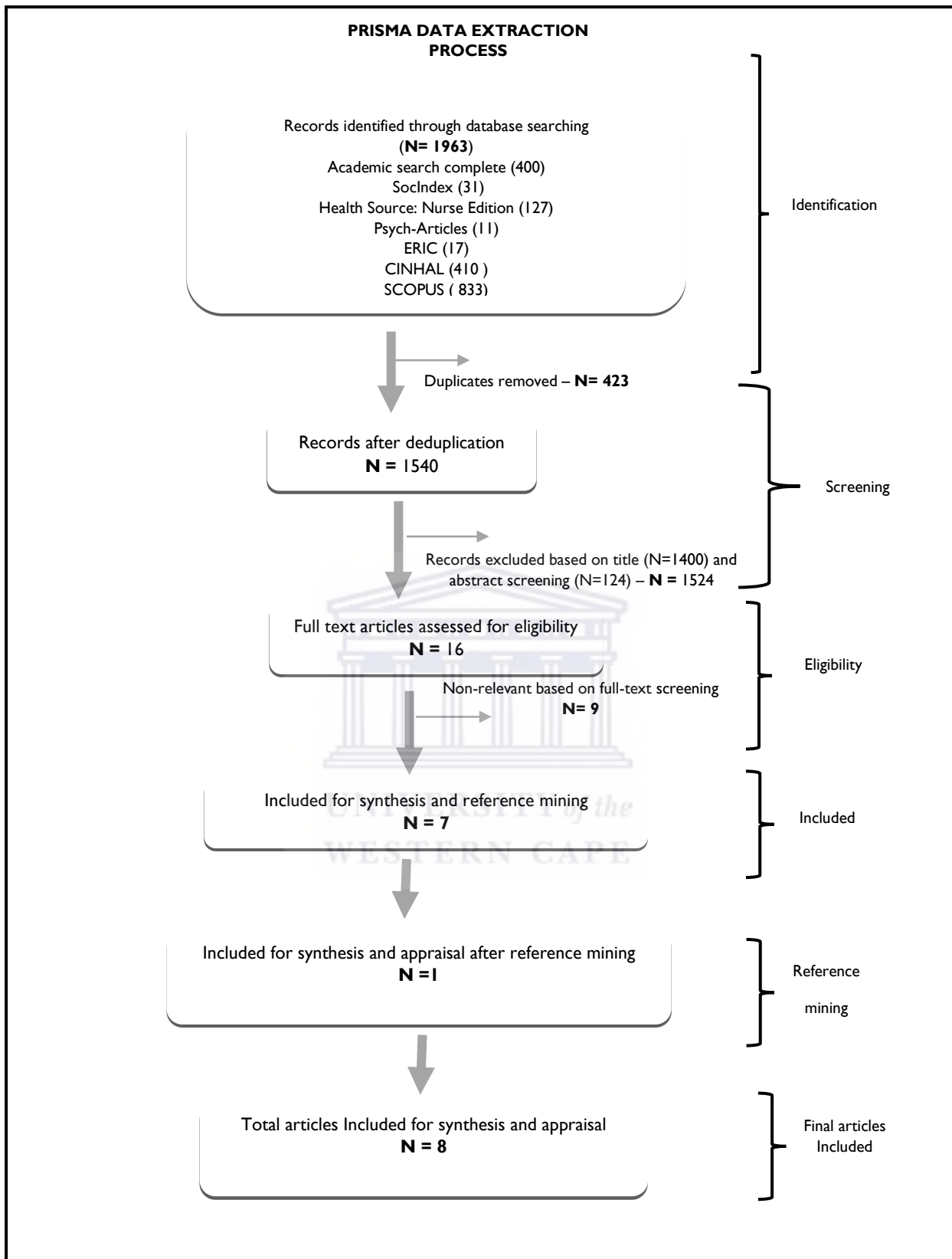
Each of the 16 eligible articles underwent in-depth reading by the researcher. Of these 16 articles, seven were identified as appropriate for appraisal. Nine articles were subsequently excluded for further critical appraisal. See APPENDIX B for reasons for excluding full articles after full text reading. It should be noted that one of the articles excluded was noted as providing rich information regarding psychosocial interventions for the families of adult and child patients (Bauman & James, 1990). This article was highlighted as relevant for later discussion.

#### *3.6.6.4 Reference mining*

A total of seven articles were identified as appropriate for appraisal. After discussion with co-researchers, the researcher decided to apply an additional step of reference mining to ensure methodological rigour and access articles that may potentially not have been identified through databases. Reference mining was applied to all seven articles in the hope of accessing

additional relevant articles that met inclusion criteria. Through this process, most articles meeting inclusion criteria were written prior to 1990. Therefore, these studies were not selected for further analysis. However, one study which was conducted between 1990 and 2019 and met inclusion criteria was identified through reference mining. This article was identified in the reference list of Barnett et al. (2017) who referenced the study by Frenkel (2007). Therefore, a total of eight articles were identified as appropriate for appraisal. The following PRISMA Data Extraction Process diagram gives an outline of this data extraction process.





**Figure 3.2**



### 3.7 Application of Critical Appraisal process

For the purpose of appraisal two separate evaluation tools for qualitative and quantitative studies, developed and recommended by Long et al. (2002), were used to guide the researcher through the critical appraisal process. These evaluative tools were specifically designed for systematic reviews focusing on social care practice (Long et al., 2002). Due to this study's focus on psycho-social interventions and including of qualitative and quantitative studies, this evaluative tool was found to be appropriate for assisting the researcher with the evaluation process. However, to assist the researcher in a simultaneous appraisal of quantitative and qualitative studies, an adjusted version of this tool (APPENDIX C and D) incorporated the quantitative and qualitative appraisal tools of Long et al. (2002). These tools, which had previously been used by researchers (Petersen, 2015; Adams & Savahl, 2017), was used to critically appraise the identified studies aimed at psychosocial burns interventions for families of child burn survivors. The evaluative tool has seven sub-sections which was used to appraise both qualitative and quantitative studies. These sub-sections include: Study overview; literature review; study setting, sample and ethics; ethics; data collection; and data analysis; as well as policy and practice implications.

During the data extraction process, two reviewers assessed the studies using the above appraisal tools (APPENDIX C and D) to minimize bias.

As part of this process both reviewers separately read the identified eight articles. After reading the full articles, reviewers worked through all 25 items on the appraisal tool in conjunction with the relevant study. If the reviewer was able to answer 'yes' for an item for a specific study, one point was allocated on the appraisal tool for that study item. Consequently, if the reviewer found that that particular item was not relevant to a particular study the reviewer would answer 'no' for that item and allocate a zero for that item. This process was repeated for all eight studies. Depending on the specific total score (see Appendix C for criteria), a 'strength category' was allocated to a specific study. Studies with a scored percentage of <40 were categorised as weak, those with a scored percentage of 41 – 60% were categorized as moderate, those with a scored percentage of 61-80% were categorised as strong and those studies with a scored percentage of >80 were categorised as excellent. Given the paucity of intervention studies, and to be more inclusive, the range 'moderate' to 'excellent' was utilised. Studies which scored within the 'weak' range were excluded to ensure high-quality evidence reporting. The scores of the two reviewers were averaged and a consensus was reached between the two

reviewers in order to identify which articles were strong enough to be included in the data analysis. Where there were disagreements, a third reviewer was called in.



### 3.8 Outcome of critical appraisal tool

Summary of averaged scores obtained for the identified studies.

Summary of averaged appraisal scores of reviewer 1 and reviewer 2 for inclusion/exclusion for synthesis								
<b>Study</b>	George and Hancock (1993) Reducing paediatric burn pain with parent participation.	Jenkins et al. (1996) A randomized Single blind evaluation of a discharge teaching book for Paediatric patients with burns.	Hart and Mantorin (1997) Collaboration between hospital social work and pastoral care to help families cope with serious illness and grief.	Frenkel (2007). A support group for parents of burned children: A South African Children's hospital Burns Unit.	Sveen et al. (2017): Internet-based information and support program for parents of children with burns: A randomized controlled trial.	Barnett et al. (2017). Qualitative analysis of a psychological supportive counselling group for burn survivors and families in Malawi.	Armstrong-James et al. (2019). Using photo elicitation to explore family's experience of burn camps.	Heath et al. (2019). Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children.
<b>Average Score between two researchers</b>	14	21.5	8.5	12	20.5	18.5	20.5	19
<b>Percentage</b>	56%	86%	34%	48%	82%	74%	82%	76%
<b>Category</b>	Moderate	Excellent	Weak	Moderate	Excellent	Strong	Excellent	Strong
<b>Include/Exclude</b>	Yes	Yes	No	Yes	Yes	Exclude:  After consultation with third researcher – not appropriate population	yes	Exclude:  After consultation with third researcher – intervention not clear
<b>Total studies included for synthesis</b>	5							

### **3.9 Studies examined but not eligible for review**

Articles initially screened and appraised but later deemed inappropriate for inclusion, after consultation with fellow researchers, included Heath et al. (2019), Baumann and James (1990) and Barnett et al. (2017). These studies included adult burns patients and lacked clarity on some participant characteristics. For this reason, these studies were later removed from the final list of intervention studies. However, due to valuable findings within these studies, an in-depth separate discussion of these studies will follow in the discussion section.



## **CHAPTER 4. RESULTS AND DISCUSSION**

This section explored results and findings of this systematic review. Specifically, the researcher reported on search findings and study characteristics, identified intervention categories as well as commented on limitations, implications for practice and research recommendations as reported in identified studies. Lastly, the researcher commented on studies identified, which weren't eligible for further review. These results were unpacked using narrative synthesis.

### **4.1 Results**

#### **4.1.1 Search findings and study characteristics**

A limited number of studies were identified through the screening process. Out of the total of 1963 identified articles, 1540 studies underwent full text review resulting in five studies meeting full criteria. The studies were published between 1990 and 2019.

These studies include child burn survivors, families of child burn survivors (parents, caregivers, siblings) as well as burns care staff as participants. The majority of studies were conducted in High Income Countries. The sample size was small across studies and the total number of participants ranged between 21 to 123. The majority of studies were conducted during the rehabilitation phase in a hospital setting. See Table 4.1.2 for summary of interventions.

The five identified studies were grouped into three intervention categories. These five studies were categorised according to focus of intervention as identified in studies. These intervention categories included: 1) Interventions aimed at providing support, 2) Medical Interventions with psycho-educational/psycho-social components and 3) Family Burns Camps. The phase of intervention, type of intervention, setting of intervention, time line of intervention, participants in intervention, type of study, study aim, outcomes, evaluation methods and efficacy of intervention will be discussed in each of these intervention categories.

#### 4.1.2 Summary of Interventions table

Author and country	Participants	Setting	Intervention type and duration	Facilitator	Phase of intervention	Study design	Aim of study	Evaluation type/ timing	Psycho-social outcomes	Results/ Efficacy
1. Armstrong-James et al., 2019  (England)	N=21 (Family members)  Paediatric burn survivors < 14: n=6  Mothers: n=6  Fathers=n=3  Siblings=5  Aunt=1	Activity Hotel, South West England	3 day Family Burns Camp	Clinical Psychologist and Volunteers	Rehabilitation phase	Qualitative: Phenomenological/Exploratory study	Identify family's experience of burns camp	Photo-elicitation interviews  Post intervention only (exact time post intervention not indicated)	Not specified	Self-reported by parents:  <b>1) Improved functioning for family as a whole</b>  Motivated for increased family time, trauma memory replaced with happier memories, challenging activities and new skills beneficial  <b>2) Benefits for parents:</b>  Benefited from sharing experiences with those who could relate; developed bond with other families; assisted in normalising emotions and accept feelings; letting go of shame and guilt; sense of hope; motivated to continue friendships outside group.
2. Sveen et al., 2017  (Sweden)	N=62  Parents of paediatric burn survivors < 18  N=42 mothers N= fathers	Uppsala Burn Centre	6 weeks  Psychoeducational support program	Self-managed via secure website, additional input from Therapist (Psychologist/Psychologist/analyst)	Rehabilitation phase	Randomised control trial, cross sectional study  Intervention group: n=31  Control group :n=31	Evaluate feasibility of online information and self-help program for parents  Hypothesis:	<b>Primary outcomes:</b> <b>1. Stress</b> (Assessed Pre-intervention/baseline and post intervention at 6 weeks post assessment, 3 months and 12 months.)	<b>Primary:</b> <b>Stress:</b> 1) PTS 2) Parental Stress 3) Perceived Stress	<b>Quantitative data:</b>  Intervention significant effect on PTS scores short term.  Intervention group scored significantly lower scores on

Author and country	Participants	Setting	Intervention type and duration	Facilitator	Phase of intervention	Study design	Aim of study	Evaluation type/ timing	Psycho-social outcomes	Results/ Efficacy
							Intervention group would report decline in stress, specifically PTSD.	<p>a) Impact of event scale (Swedish Revised version) - measuring Post Traumatic Stress (IES-R)</p> <p>b) The Short Form Parenting Stress Index measuring child and parent stress (PSI-SF)</p> <p>c) The Perceived Stress Scale (PSS) measuring perceived stress among parents</p> <p><b>Secondary outcomes:</b></p> <p><b>1.Parents health:</b> [Pre intervention/baseline only]</p> <p>a) Montgomery-Asberg Depression Rating Scale (MADS) measuring depression symptoms</p> <p>b) Part of Guilt Scale and clinical interviewing</p> <p>c) Short form family environment Scale (FES-SF)</p> <p><b>2.Child's health:</b> [Pre intervention/baseline only]</p> <p>a) Strength and difficulties questionnaire (SDQ) measuring child's health as perceived by parents.</p>	<p>Impact of Event Scale at 3 months ( <math>\beta</math>= -11.5, SE=3.88, <math>p</math>=0.003) and 12 months ( <math>\beta</math>= -7.89, SE=3.38, <math>p</math>=0.020)</p> <p>No significant difference at baseline or 12 months.</p> <p>No significant effect on Parenting Stress Index or Perceived Stress Scale.</p> <p><b>Reported feedback:</b></p> <p>1) Talking about accident assisted in processing</p> <p>2) new skills to talk about accident with family was helpful</p> <p>3) validation, mindfulness, relaxation technique helpful</p> <p>4) Tips to manage daily obstacles helpful e.g.. management of burns wound</p> <p>5) Time consuming/insufficient time</p> <p>6) Access to program through the use of internet positive</p>	

Author and country	Participants	Setting	Intervention type and duration	Facilitator	Phase of intervention	Study design	Aim of study	Evaluation type/ timing	Psycho-social outcomes	Results/ Efficacy
								b) Short form Child Stress Reaction Checklist (CSRC-SF)  <b>3. Feasibility of program :</b> [During and post intervention] a) Participant evaluation form b) Participant adherence  <b>4. Research participation</b> [Post intervention only] a) Reaction to research participation Questionnaire parent version (RRPQ-P)		
3. Frenkel, 2007  (South Africa)	Sample size unclear  N=8-12 caregivers per group with paediatric patients <5	Red Cross Children's hospital Burn Unit, Cape Town	5 week out-patient family psychological support group	Two clinical Psychology Masters' students with their Supervisor	Rehabilitation phase	Qualitative Case report	Developing insight into the experience of parents of paediatric burn survivors	Used semi-structured interviews post intervention	Not clearly specified : group focused on providing a space for parents to express difficult emotions/ feel heard	<b>Self-reported feedback from parents:</b> 1) Sense of hope 2) Realized they are not alone/sense of community established amongst members 3) Benefited from talking about their feelings 4) Established good relationship with hospital staff. 4) Continuation of support amongst group members outside group



Author and country	Participants	Setting	Intervention type and duration	Facilitator	Phase of intervention	Study design	Aim of study	Evaluation type/ timing	Psycho-social outcomes	Results/ Efficacy
4. George and Hancock, 1993  (Canada)	N=not stated  Two groups of participants:  Parents of paediatric burn patients (age not specified)  Nursing staff	Hospital for sick children, Toronto	Parent Participation program – wounds management  Time line not specified  Two-fold approach:  1) Training and preparing nursing staff 2) Implementing of parent participation program	Nursing staff in conjunction with support from Social Worker/ other health care staff as required	Acute phase	Qualitative/Descriptive case study	To describe and evaluate the development and implementation of a parent participation program in a burn unit aimed at addressing needs of children and families	[Pre-intervention:]  Questionnaires to assess nursing staff anxiety about program  [Post intervention:]  Informal feedback from parents:  Verbal and written comments  Observations from surgeons  Post intervention Questionnaire for nursing staff	Addressing needs of caregivers and paediatric patients – not clearly specified.	<b>Nursing staff:</b> 1) Staff post intervention questionnaire responses positive regarding program  2) Training assisted nursing staff with confidence and resulted in commitment in implementation of program  <b>Parents:</b> 1) Decreased parent and child's anxiety  2) Appreciated being able to maintain parental relationship within hospital  3) Gained better understanding of healing process and rehabilitative needs of child
5. Jenkins et al., 1996  (Canada)	N=123  Families (NAI and Non-NAI) of child burn survivors <17	Winnipeg Children's Hospital	Inpatient Discharge Teaching Book	Multi-disciplinary burns care team	Discharge/preparation for Rehabilitative phase	Quantitative:  A randomized single-blind  Intervention group (Received discharge book intervention) N = 62  Comparison group (received routine discharge teaching) N = 61	Assess knowledge of burn care and satisfaction with discharge teaching book	[Post intervention – conducted during first follow-up visit]  1) Open ended questionnaire to assess knowledge gained	Burns care knowledge	Recipients of discharge book had higher knowledge scores. Improvement was modest  Greatest influence of book on knowledge scores in non-NAI population  Similar effect seen in average knowledge

Author and country	Participants	Setting	Intervention type and duration	Facilitator	Phase of intervention	Study design	Aim of study	Evaluation type/ timing	Psycho-social outcomes	Results/ Efficacy
								<p>2) 5- point Likert scale used to ascertain interviewer's satisfaction with answers of parents</p> <p>3) Questionnaire and interview to assess patient's satisfaction with instructions and material to assist in care</p> <p>4) Subjective rating of the interview by interviewer.</p>		<p>scores between intervention and comparison group of NAI, but not significant.</p> <p>Bivariate analysis: Greater knowledge found in intervention group with average of <math>0.79 \pm 0.15</math> versus <math>0.73 \pm 0.15</math> in comparison group (<math>p &lt; 0.05</math>)</p> <p>Stepwise multiple regression: Influence of book limited to families with scald burns (<math>p &lt; 0.05</math>).</p> <p>Factors negatively correlated with knowledge: Being NAI with no safety devices at home</p> <p>Factors positively correlated with knowledge: English first language, extensive burns, younger child, fewer children at home.</p>

### **4.1.3 Intervention categories**

#### *4.1.3.1. Medical Interventions with psycho-educational/psycho-social components.*

##### *Phase and type of intervention:*

Two interventions were medical interventions with psycho-social components; these targeted burns wound management during either acute phase or rehabilitation phase. Both these interventions were educative yet differed in focus.

George and Hancock's (1993) parent participation program included a prominent psycho-social component which is rooted in family-centred care and was conducted during the acute phase of paediatric patients' burns care. It focused on equipping parents to become part of their child's acute burns care regime in hospital, as part of the multi-disciplinary team. This was in contrast to Jenkins et al. (1996) intervention which was rooted in a purely educational framework, conducted at the onset of the rehabilitative phase and focused on educating parents in terms of burns care knowledge and management at home.

George and Hancock's (1993) intervention included two components. Firstly, it involved educating multi-disciplinary staff (specifically focusing on nursing staff). This training component aimed to improve staff understanding and commitment. The training itself included educational sessions where literature was reviewed; progress made by the pain management committee was assessed and procedural changes that assist in reducing anxiety-related pain was identified. During these educational sessions staff practiced problem solving during treatment with, for example, an agitated parent or resistant parent through role play. Lastly, support was also provided to the medical team during these sessions.

The second component of this intervention included screening to see if parents were appropriate to participate in the program. If deemed appropriate and parents gave consent to participate, nursing staff would outline treatment standards, emphasise the emotionally supportive role parents play during treatment, assist parents in identifying pain management strategies, and provide parents with debriefing sessions post procedure. Debriefing sessions focused on identifying parents' emotional state, unpacking questions of parents, emphasising information about the burn and commenting on parents' supportive efforts. These sessions often included the presence of a social worker.

The interventions of Jenkins et al. (1996) included equipping parents with a burns care discharge book prior to discharge in preparation for wound care at home. Intervention was conducted by various burn team disciplines (e.g. Occupational Therapists, Physical Therapists, Nursing Staff) in the days prior to discharge. The team prepared parents for discharge by discussing discharge instructions and simultaneously taught parents the content of the discharge book. This purely educative stance suggests that parents received minimal emotional support as part of this intervention.

*Setting of intervention:*

Both studies were conducted in hospital settings in Canada (High-Income Country).

*Intervention Time line:*

Neither of these studies clearly indicated time line of intervention.

*Participants:*

Both interventions included families of paediatric burn patients. However, the study conducted by George and Hancock (1993) specifically included parents whereas that of Jenkin et al. (1996) included families. The meaning of the concept 'families' was not specified in the study by Jenkin's et al. (1996) and it is not clear how many parents or other caregivers (e.g. grandparents, aunts, uncles) were included in this study.

Additionally, the study by George and Hancock (1993) included nursing staff as additional participants of their intervention. This study (1993) did not specify the age of parent's children. Jenkins et. al (1996) stated that parent with children under 17 were included in their study.

George and Hancock (1993) did not report on the sample size of either parents or nursing staff. Jenkins et al.'s (1996) sample size included 123 parents.

George and Hancock (1993) did not comment on the ethnicity or socio-demographic status of participants. The majority of families included in Jenkin's (1996) study were North American Indian Families.

*Type of study:*

A quantitative and qualitative design was used for each of these studies. George and Hancock (1993) used a descriptive case study to explore the development and impact of their intervention in comparison to the study by Jenkins et al. (1996), who used a randomised single-blind approach to evaluate their research.

*Aim or focus of study:*

The aim of these two medical interventions differed. George and Hancock's (1993) intervention had a psycho-educational as well as psycho-social aim. This intervention aimed to address the needs of paediatric patients, their families and caregivers with a secondary aim of increasing staff members' 'buy in' for the program. It was hoped that the discharge book produced by Jenkins et al. (1996) would assist in improving families' burn care knowledge and satisfaction.

*Outcomes:*

The outcomes of these interventions differed. George and Hancock's study (1993) did not report the measurement of specific psychological outcomes, in comparison to that of Jenkins et al. (1996) who had a clear burns knowledge outcome. Despite any report of clear psychological outcome, it is hypothesized that an increase in burns care knowledge may have resulted in increased confidence and reduced anxiety, as was evident in the study by George and Hancock (1993). However, this remains to be explored.

*Type of Evaluation:*

Type of evaluation varied between formal assessment and informal assessment measures. George and Hancock (1993) evaluated parents' as well as nursing staff's experience of the parent participation program through informal written and verbal feedback. No objective evaluation was used to evaluate their experience. In contrast, Jenkins et al. (1996) used various formal assessment measures, such as open-ended questionnaires, to ascertain knowledge gained. This was in conjunction with a five-point Likert scale used by interviewers to ascertain the quality of the answers. Additionally, subjective interviewer ratings were used to assess parent attitude during interviewing.

#### *Efficacy of intervention:*

Both these interventions indicated a degree of efficacy. The Jenkins et al. (1996) intervention indicated that families who received the discharge book showed significantly higher scores in in burns knowledge when compared to the control group. This was evidenced by the average score of  $0.79 \pm 0.15$  for the intervention group versus  $0.73 \pm 0.15$  for the control group ( $p < 0.05$ ). However, a significant difference in knowledge scores between intervention and control groups was only found for non-NAI families. Although the increase in knowledge scores was also found for NAI families, the difference in increased knowledge scores between control and intervention groups was not as significant. Additionally, reported caregiver satisfaction was found to be high for NAI families. However, non-NAI families were less satisfied. Jenkins et al. (1996) intervention indicated a degree of efficacy for non-NAI families. Yet, the efficacy of this intervention for NAI families appears to not be as effective. Therefore, this intervention appears to not be as effective for diverse groups.

Self-reported feedback from George and Hancock's (1993) intervention indicated that parents and nurses both experienced the intervention as positive. Efficacy is evident in this study as parents self-reported decreased anxiety for parent and child, appreciation for maintenance of the parent-child relationship and improved in-depth understanding of their child's needs. It suggests that this intervention assisted in addressing emotional needs of both parent and child and that the intervention aim was successfully accomplished.

#### *4.1.3.2. Interventions aimed at providing support*

##### *Phase and type of intervention:*

Two interventions focused on providing support to parents. Both these interventions were conducted during the rehabilitative phase. However, these interventions differed in terms of level of therapeutic contact, format and content. Frenkel's (2007) supportive intervention format was conducted in a traditional therapeutic group format and was rooted in psychodynamic principles. In contrast, the intervention of Sveen et al. (2017) was more structured in format and rooted within CBT, Acceptance and Commitment Therapy and Mindfulness theory. Furthermore Frenkel's (2007) intervention allowed for weekly physical contact with group members and therapists where patients were provided with a space to discuss whatever felt pressing to them, whereas the Sveen et al. (2017) supportive intervention was accessed via a secure website. Through this website patients gained access to weekly online modules which ranged from burns rehabilitation information to psycho-education about

trauma, as well as techniques rooted in CBT, ACT and mindfulness to assist with coping and processing. Participants received written feedback on weekly homework assignments from their therapist.

*Setting of intervention:*

Both interventions were conducted in a hospital setting. However, interventions differed in terms of the country it was conducted in. Sveen et al.'s (2017) intervention was conducted in Sweden (a High-Income Country), whereas Frenkel's (2007) intervention was conducted in South Africa (a Low-Middle Income Country).

*Intervention time line:*

Interventions were similar in timeline. Sveen et al.'s (2017) intervention was conducted over a 6-week period. Similarly, Frenkel's (2007) study was conducted over a five-week period.

*Participants:*

Both studies included caregivers of paediatric burns patients. The study by Sveen et al. (2017) specifically included only parents, whereas Frenkel's (2007) study included mothers, fathers, grandmothers, aunts and older siblings.

The study by Sveen et al. (2017) included parents of children under 18. Frenkel's (2007) study did not specify the age of the caregiver's children. However, it is hypothesized that they were under five years old as the majority of patients in the unit were of this age.

Both studies commented on socio-demographic variables of groups. The Sveen et al. (2017) study included parents with stable socio-economic circumstances and good family functioning. Frenkel's (2007) study included Afrikaans-speaking caregivers from predominantly mixed racial origin ('coloured'), as well as Xhosa-speaking black African caregivers and Afrikaans-speaking white caregivers. The socio-economic status of these families was not stated.

The Sveen et al. (2017) study sample size of 62 parents was relatively small. Frenkel's (2007) sample size was not clearly indicated but ranged between 8-12 caregivers per group.



*Type of study:*

The study design for these two studies differed in terms of qualitative and quantitative nature. Frenkel's (2007) study used a case report structure to provide insight into the parent's experience of the support group, whereas Sveen et al. (2017) used a randomized control study to assess the efficacy of their intervention.

*Aim and focus of study:*

Frenkel's (2007) study focused on developing a group space which gave parents an opportunity to express their feelings while creating a listening culture in group where parents found mutual support from one another. In comparison the Sveen et al. (2017) study focused on exploring "the feasibility and effects of online information and self-help program with minimal therapeutic contact for parents of children and adolescent who have been hospitalised for burns" (p. 584).

*Outcomes:*

The Sveen et al. (2017) study specifically measured the stress experienced by parents and measured various sub-categories of stress. These included Post Traumatic Stress, Perceived Stress and Parenting Stress. Additionally, secondary outcomes included socio-demographic and burn related variables, parent health (depression, fear-avoidance, guilt and embitterment, and family functioning), child health perceived by parent, research participation and feasibility of program. No specific outcomes were identified for Frenkel (2007).

*Type of evaluation:*

Evaluation for these interventions differed. Sveen et al. (2017) conducted a formal evaluation using standardised measures with strong psychometric properties. The Impact of Event Scale, the Short Form Parenting Stress Index and the Perceived Stress Scale were used to assess primary outcomes. Assessment was conducted at baseline, post intervention (six weeks after baseline), as well as three-month and 12-month follow-up. Additionally, feasibility of the program was assessed using a participant evaluation form after intervention as well as three-month and 12-month follow-up.

Secondary measures were assessed prior to intervention. Researchers used structured clinical interviewing: the *Montgomery-Asberg Depression Rating Scale* to measure depressive symptoms and injury related to fear-avoidance; items from the *Guilt Scale* to measure parent



guilt; the *Short Form Family Environment Scale* to measure family functioning as well as the *Strengths and Difficulties questionnaire* to measure child's health as perceived by parents.

The *Reaction to Research Participation questionnaire: parent version* and participant evaluation form, in conjunction with participants' adherence to logging, was used to measure the feasibility of the program post intervention.

In contrast to Sveen et al. (2017), Frenkel (2007) did not formally evaluate psychological outcomes. However, the self-report from parents and reflections from the researcher provide insight to shifts of psychological outcome.

#### *Efficacy of intervention:*

Both support groups indicated a degree of efficacy. The Sveen et al. (2017) study showed significant decrease in Post-Traumatic Stress scores at 3 months ( $\beta = -11.5$ ,  $SE = 3.88$ ,  $p = 0.003$ ). No significant difference between the intervention and control group was found at baseline or 12 months. Furthermore, no significant effect was found for parenting stress and perceived stress, indicating that intervention was only partly effective as only one of three outcomes measured showed decline after intervention. There was no effect found on any secondary outcomes: MADRS, fear avoidance, guilt, SDQ or FES. With regards to feasibility of program 11/11 parents found the program informative and comprehensible. 9/11 reported the program as meaningful and 8/11 reported the program as supportive. 2/11 reported the program as upsetting and 3/11 as boring.

Reported feedback indicated that talking about the event via this platform assisted in processing. Validation, mindfulness and relaxation techniques were identified as helpful. Parents also reported that they gained practical knowledge in terms of every day obstacles regarding managing their child, e.g. managing burn wounds, and found that their ability to effectively communicate with family and their child about the event had improved. Access to the website was reported as easy, although some parents found the program time-consuming.

Similarly, parents in Frenkel's (2007) study self-reported that talking about their feelings was beneficial. Additionally, parents reported that they gained a sense of hope, established a sense of belonging and community in group and developed relationships with hospital staff. Some group members reported continuation of support outside the group.

#### *4.1.3.3. Burns Camps*

##### *Phase and type of intervention:*

One intervention included a Family Burns Camp conducted during the rehabilitative phase (Armstrong-James, et al., 2019). This intervention treated the family systemically. A combination of a structured and an unstructured framework was used in this intervention. Camp format included families eating together with volunteers, whilst allowing families the opportunity to choose how they would like to spend their time together at camp. Families were encouraged to attend a group ice breaker activity (bowling) on the first day and parents attended a separate parent group session on the second day which was facilitated by a Clinical Psychologist. During this time children took part in activities arranged by camp volunteers. The type of activities conducted by volunteers were not discussed.

##### *Setting of intervention:*

The intervention by Armstrong-James et al. (2019) was conducted in at an activity hotel in the United Kingdom; this country has been classified as an HIC.

##### *Intervention time line:*

The Armstrong-James et al. (2019) intervention was conducted over a three-day period (a weekend).

##### *Participants:*

Armstrong-James et al. (2019) participants included six families of child burn survivors from South West England. Sample size was small and included 21 group participants which included paediatric burn patients 14 years and younger, mothers, fathers, siblings and an aunt. Further socio-demographic variables were not specified.

##### *Type of study:*

This study design was a qualitative study design which focused on exploring family members experience of a Family Burns Camp.

##### *Type of evaluation:*

Evaluation was conducted using photo-elicitation and thematic analysis. Photos taken by families during their time at camp were used during interviews. A structured interview method

was used post-intervention and families were interviewed as a collective. No standardised assessment measures were used, yet photo-elicitation interviews with participants provided rich feedback regarding psychological outcomes.

*Aim and focus of intervention:*

The aim of this study was to evaluate family members' experience at a Family Burns Camp. Additional aims were not stated, but it is hypothesized that by choosing burns families with various rehabilitative periods (three months to 11 years), this intervention additionally focused on facilitating a sense of hope as well as affirmed growth and resilience in families. Furthermore, it is hypothesized that, similar to Frenkel's (2007) support group, the parent group aimed to facilitate a space for families to express difficult emotions and feel affirmed. Lastly, it is suggested that the challenging group activities may have been aimed at increasing the child burn survivor's confidence and affirm their ability, while simultaneously addressing parents' fears. By systemically including the family it is hypothesized that an aim of the Family Burns Camp was to assist family members to re-connect through fun activities and allow them a space to feel 'normal' as a family.

*Outcomes:*

No clear outcomes were reported for the study by Armstrong-James et al. (2019).

*Efficacy of intervention:*

As an intervention, Family Burns Camps show promise. Self-report from parents indicated that intervention increased family members motivation to continue quality family time. Parents reported that it assisted in replacing their trauma memories with happier memories and benefited from observing their child gain more skills and witnessing their ability. Parents bonded with other families and benefited from their shared experience. This was found to normalize their own experiences and, at the same time, assisted them in accepting difficult emotions and letting go of guilt and shame. Additionally, parents were motivated to continue new friendships outside of the intervention context.

#### **4.1.4 Reported limitations of studies**

*Small sample size:*

Most studies referred to the small sample size (Armstrong-James, et al., 2019; Sveen et al., 2017; Jenkins et al., 1996; Barnett et al., 2017). Even though it was not specifically reported

by Frenkel's (2007) study, sample size was found to be objectively small. George and Hancock (1993) did not comment on sample size.

*Limited random sampling of participants:*

Only two studies (Sveen et al., 2017; Jenkins et al., 1996) applied random sampling to access participants. Other studies (Barnett et al 2017; George and Hancock, 1993; Armstrong-James et al., 2019; Frenkel, 2007) did not include random sampling and invited all eligible participants to be part of their studies. This possibly increased the risk of bias.

*Pre-morbid functioning of parents unclear:*

Furthermore, Sveen et al. (2017) and Armstrong-James et al. (2019) both commented on their lack of knowledge of pre-morbid functioning of their sample group. Sveen et al. (2017) reported that they did not have clarity with regards to psychological functioning of parents prior to intervention. Armstrong-James et al. (2019) similarly reported a lack of knowledge regarding parents' coping ability prior to intervention. It was hypothesized in both studies that the impact of intervention may have been more significant if pre-morbid functioning had suggested more severe dysfunction.

*Attrition rate:*

A high attrition rate was reported by Sveen et al. (2017). Although this was not necessarily reported in other articles, it is hypothesized that attrition may have played a contributing factor in other studies. This specifically applies to support group interventions, such as Frenkel (2007), as the consistency of group attendance throughout this group intervention was unclear.

*Bias:*

Methodological rigour is questioned in Jenkins's (1996) study and it is hypothesized that rater bias may have influenced scores allocated to participants during interviews, as interviewers allocated subjective knowledge scores and parent attitude during interview scores. Despite the attempt by researchers to reduce bias by consulting with culturally sensitive authorities, it is possible that cultural and language differences amongst discharge book trainees and interviewers may have contributed to lower knowledge scores for parents of NAI families.

*Severity of injury and hospital stay time:*

With regard to severity of injury and time spent in hospital, Sveen et al. (2017) accounts for the role this may have played in their study. Sveen et al. (2017) found that the outcome may potentially have been more effective amongst patients who had endured more severe burns and endured a longer hospital stay, which suggests that group members within this study may have been psychologically better adjusted than those in need of the intervention.

*Intervention time line:*

Armstrong-James et al. (2019) identified limited intervention time as a possible limitation and questioned the impact the intervention may have had over an extended time period. Sveen et al. (2017) commented that participants reported on the time-consuming nature of the intervention. It is hypothesized that participants may in future struggle to successfully complete the program due to it being time-consuming. This may in future impact on poor completion. George and Hancock (1993) did not comment on any limitations in their study.

#### **4.1.5 Reported Implications for practice**

The following suggestions were made by the identified studies in terms of practical suggestions.

*Practical changes burn care units:*

All studies identified emphasized the need for practical changes in burns care units to effectively assist families of child burn survivors.

*Important role of the burns care team for continuation of family support:*

Armstrong-James et al. (2019) emphasized the importance of ongoing involvement of families during rehabilitation and the need for this to be promoted. Specifically, it was noted that nursing staff could be beneficial in guiding families with ongoing rehabilitative involvement and consequently refer families to appropriate intervention care. Similarly, George and Hancock (1993) found that a well- and specifically trained and prepared multi-disciplinary team holds the key to effectively managing families in burns care units which in turn facilitates effective recovery for their children. Specific burns unit standards with high standards of specific training is encouraged. Frenkel (2007) suggested that a family burns support group should be part of permanent hospital service and that this service should be provided by a permanent psychologist and in-house translator.

*Funding for specialized care:*

Frenkel (2007) emphasized the lack of resources for medical care. This suggests advocacy for funding for more specialized care.

*Train staff to be culturally sensitive:*

Jenkins et al. (1996) emphasized the importance of medical staff needing to be culturally and language sensitive when working with burns patients from culturally diverse groups.

*Need for accessible and cost-effective rehabilitation interventions*

Sveen et al. (2017) commented on the cost-effective and accessible nature of their intervention. This suggests that this intervention could be easily recommended to patients whom may have difficulty accessing hospitals as part of outpatient rehabilitative treatment management program.

#### **4.1.6 Reported Research Recommendations of studies**

Recommendations for future research possibilities were noted by all studies involved.

*Objective evaluation of interventions needed:*

All qualitative studies (Frenkel, 2007; Armstrong-James et al, 2019; George & Hancock, 1993) expressed a need for future research to objectively measure interventions. Armstrong-James, et al. (2019) specifically emphasized the importance of quantitative pre- and post-testing.

*Investigation of additional psycho-social outcomes:*

Measurement of specific psycho-social outcomes was identified as crucial for future research by Armstrong-James et al. (2019) and Sveen et al. (2017).

Armstrong-James et al. (2019) suggested research with regards to the efficacy of interventions for families of adolescent burns patients, and highlighted the need to explore appearance issues, social confidence and perceived support typically associated with this developmental group. Sveen et al. (2017) suggested further evaluation regarding prevention of PTS symptoms in patients with more severe and recent burns, or parents with more significant psychological difficulties.

#### **4.1.7 Studies examined, but not eligible for study:**

Three studies (Barnett et al., 2017; Baumann & James, 1990; Heath et al., 2019), as previously mentioned, were excluded from the final list of intervention studies. However, due to the valuable findings evident within these interventions, these interventions will still be discussed as compared to the final list of included intervention studies.

##### *Type of intervention:*

Various methods of intervention were considered, but studies that included supportive interventions for families of burn survivors were later excluded.

Two interventions included support groups. However, these support groups differed in terms of aims and format. The Barnett et al. (2017) support group was facilitated by a counsellor. This group was less structured and, similar to Frenkel (2007) and Armstrong-James et al. (2019), parent groups allowed a space for participants to freely discuss their thoughts and feelings. However, the Barnett et al. (2017) study differed in format with the introduction of a weekly discussion topic. In comparison, the Baumann and James (1990) support group was co-facilitated by social workers and various health care specialists. It included a stronger, more structured psycho-educational component of weekly topics presented by various specialist speakers, and this allowed less space for free discussion and sharing.

Similar to the Sveen et al. (2017) study, Heath et al. (2019) focused on exploring parents' and health care professionals' opinions on a parent-focused peer-informed supportive website. This study did not include an actual intervention but commented on the potential of a peer-informed supportive website as an intervention method by simultaneously using a psycho-educative, supportive approach. This website included information about parents' experiences, psycho-education and advice on stress management rooted in CBT; information on supporting their child as well as their sibling; and information on helpful resources. As the study did not measure the impact of the intervention but assessed the website itself, this study was excluded from the final list of articles. However, it is hypothesized that a follow-up study evaluating the actual intervention may soon be released.



*Setting of intervention:*

Two studies (Barnett, et al., 2017; Baumann & James, 1990) were conducted in a hospital setting. The setting of Heath et al. (2019) study was not specified as this was not an actual intervention.

*Intervention timeline:*

Time of intervention was not clearly stated in all three studies. Barnett's (2017) intervention was conducted over a 12-week period. However, the timeline of Baumann and James's (1990) intervention was not clear. Actual intervention was not conducted for the Heath et al. (2019) study.

*Participants:*

The Barnett et al. (2017) study comprised 48 caregivers ranging from age 19 to 63, as well as burn patients ranging from age 12 to 45. The exact number of adult patients wasn't specified. Baumann and James's (1990) study included burn victims and their families. Baumann and James (1990) make reference to the inclusion of adult patients and child patients; however, the exact amount of differently aged participants wasn't specified. As these studies included adult patients and parents of adult patients without clear indication of the ratio of child patients and parents of child patients, these studies were excluded from the final list of studies. The Heath et al. (2019) study included 31 participants. The group consisted of nine parents and 22 professionals.

*Type of study:*

Two studies (Baumann & James, 1990; Barnett et al., 2017) were of a qualitative nature. The Heath et al. (2019) study used mixed methods within a PAR approach.

*Aim and focus of study:*

The Barnett et al. (2017) intervention aimed to provide a space for patients to discuss difficult emotions and created an opportunity for families to find support within the group. A similar aim was indicated by Frenkel (2007). The aim of Baumann and James's (1990) intervention was to address educational and emotional needs. Heath et al. (2019) focused on testing accessibility of a prototype website. It was hoped that this intervention will in future assist with normalizing family members' experiences while simultaneously encouraging them to seek support, as well as provide a platform for professionals to seek support for families.



### *Outcome of study:*

Clear outcomes were not specified by Barnett et al. (2017) and Baumann and James (1990). Outcomes for Heath et al. (2019) included determining acceptability of their website.

### *Evaluation types:*

Formal assessment varied amongst these studies. Health et al. (2019) used a think aloud approach and thematic analysis to interpret qualitative data of parents' feedback regarding the website. Quantitative assessment measures such as the eHealth Impact Questionnaire were used, which aimed to measure parents' attitudes toward health websites prior to exposing them to the website. The eHealth Questionnaire was used post website exposure to measure parents' attitudes toward the website. Professionals were asked to fill in this form keeping in mind the assumed parental response. Formal evaluation was not conducted by either Barnett et al. (2017) or Baumann and James (1990). Barnett et al. (2017) used thematic analysis of support group session notes to assess families' experience of the group. A case study was used by Baumann and James (1990) to provide insight with regards to the impact of the program on group members.

### *Efficacy of intervention:*

The degree of reported efficacy varied between studies. Efficacy in Bauman and James's (1990) study was not clearly indicated as only two cases were discussed in this study. Participants in Barnett et al. (2017) study reported a benefit from speaking to individuals with whom they could relate and they found relief in talking about burns. Additionally, parents reported that they had learnt coping skills to assist with their stress and general psychological well-being. Lastly, the group assisted in decreasing hospital anxiety and provided insight with regards to the benefits of social support. Although the Heath et al. (2019) intervention was not formally assessed, both professionals and parents were positive about the potential of a website-based intervention.

## **4.2 Discussion**

### **4.2.1 Main Findings**

#### *Limited evaluation methodologies:*

Sample size was limited in all studies. It is hypothesized that the small sample size can potentially be ascribed to a low burden of burn injuries in High Income Countries, in contrast

to Low Income Countries who experience a high burden of burn injuries as previously identified by Mock et al. (2008) and WHO (2018).

Additionally, the use of small sample sizes in low-income countries which have high burden of burn injuries (Frenkel, 2007; Barnett et al., 2017) could be ascribed to the lack of resources and limited funding that consequently make it difficult to access a wider pool of participants.

Small sample sizes in studies (Frenkel, 2007; Armstrong-James et al., 2019; Sveen, et al., 2017; Jenkins et al., 1996) limit reliable reporting with regards to intervention efficacy. However, in comparison to qualitative interventions (Frenkel, 2007; George and Hancock, 1993; Armstrong-James, 2019), quantitative interventions (Jenkins et al., 1996; Sveen et al., 2017) included slightly larger sample sizes. Yet, these were still relatively small for quantitative studies. Hackshaw (2008) emphasised the importance of studies needing to be large enough to provide reliable evidence, specifically regarding trial interventions. Therefore, consideration for future studies should include larger sample sizes to assist in specifying efficacy of interventions.

Participant categories varied across studies. Of the identified five interventions, three included parents and children (Armstrong-James, et al., 2019; Jenkins et al., 1996; Frenkel, 2007), one included parents and nursing staff (George & Hancock, 1993), and a one included only parents (Sveen et al., 2017).

The type of participant seen within the identified interventions and the lack of 'purely parent interventions' speaks to the complex and systemic nature of burns intervention and bi-directional effect of burns on family and staff. This suggests a need for systemically focused interventions.

Furthermore, diverse populations were identified across studies. Differences in terms of types of caregivers, socio-economic status, language, cultural differences, ethnicity, geographic location and pre-morbid psychological functioning were only briefly discussed. These factors may potentially cause difficulty if interventions were to be applied in diverse populations and the applicability of these interventions within diverse contexts would need to be explored.

Only two random control studies (Sveen et al., 2017; Jenkins, et al., 1996) were identified within this systematic review. Random control studies have been found to show the highest standard with regards to scientific rigour (Young et al., 2019). Therefore, the limited number of random control studies is concerning and may also indicate limited advocacy for psychosocial burns interventions and consequently, inadequate funding for random control studies.

Many studies did not clearly report outcomes. Only four outcomes were clearly stated: PTS, Perceived Stress, Parenting stress (Sveen, et al., 2017) and burns care knowledge (Jenkins, 1996). These outcomes were identified by quantitative studies. The majority of studies identified in this literature review were of a qualitative nature (Armstrong-James, et al., 2019; Frenkel, 2007; George & Hancock, 1993) and explored interventions instead of describing a clearly defined outcome prior to intervention.

Evaluation of interventions ranged from formal objective evaluations using standardised assessment tools with strong psychometric properties (Sveen, 2017), to questionnaires (Jenkins et al., 1996), to self-reported methods of evaluation which lacked objective evaluation (Frenkel, 2007; Armstrong-James et al., 2019; George & Hancock, 1993). Therefore, it is evident that the identified intervention studies lacked objective measures. This finding corroborates with that of Druery et al. (2017) who specifically emphasises the lack of knowledge in terms of psychosocial outcomes in burns research. It is hypothesized that due to the bio-medical model that dominates burns care, psychosocial interventions receive less funding for adequate evaluation of interventions.

Efficacy of interventions varied and was difficult to establish as there were only two Random Control studies (Sveen, et al., 2017; Jenkins et al., 1996) allowing for insufficient evaluation of efficacy. Improvement was indicated across all studies to some degree. It was found that internet-based support groups appear to show efficacy with regards to decreasing PTS but do not indicate any change with regards to parental stress and perceived stress (Sveen et al., 2017). Therefore, internet-based interventions for parental stress and perceived stress appear to be ineffective.

Furthermore, less structured support groups appear to be particularly effective in addressing feelings of guilt and shame, normalizing parents experience, establishing a sense of community

and support, and creating a sense of hope for parents (Frenkel, 2007; Armstrong-James et.al, 2019).

Medical interventions with a combined educative and psychosocial component show efficacy with regards to decreasing parent anxiety, maintaining a healthy parent-child relationship and improved understanding of their child's needs (George & Hancock, 1993). Consequently, they indirectly ensure the long-term commitment of parents during the rehabilitative phase of their child's treatment. The psychosocial effect of purely educationally-based medical interventions remains unclear (Jenkins et al., 1996).

Family burn groups systemically improve family functioning (Armstrong-James et al., 2019).

*Supportive and Rehabilitative Interventions:*

The paucity of interventions was evident as this systematic review identified only five studies between 1990 and 2019 which targeted psychosocial interventions for families of child burn survivors. These research findings corroborate with other researchers' findings regarding a lack of acute and rehabilitative psychosocial interventions for families of burn survivors (Van Niekerk, et al., 2004).

This finding, in conjunction with observations of epidemiological, preventative and medical interventions dominating the burn literature (as evidenced through this study's systematic review screening process), suggests that psychosocial interventions and the potential of these interventions should be highlighted as a priority within the burns research field.

Medical and preventative models still appear to dominate in hospital settings. It appears that hospital settings are typically burns patients' first place of contact and the primary place of accessing interventions. This is evident as this setting dominated as the intervention setting for the identified studies (Frenkel, 2007; George & Hancock, 1993; Sveen et al., 2017; Jenkins et al., 1996). Within hospital settings practitioners typically do not make use of systemic interventions or have enough awareness with regards to psycho-social variables and their impact on family functioning and burn recovery. A lack of psycho-social awareness of the role of the family in a bio-medically dominated context may be a contributing factor to the limited psychosocial interventions for burns families.

Additionally, paediatric burns patients are identified as the index patient within hospital settings. Therefore, interventions do tend to focus on the needs of the index patient. This factor, in conjunction with limited systemic and psycho-social knowledge, may further contribute to lack of family interventions.

Lastly, it is known that funding for specialist burn care, especially in LIC, is limited (Frenkel, 2007). This may have contributed to limited research focusing on family interventions.

Interventions with a supportive component proved to be prominent in this systematic review. This finding aligns with the reported need for parent support in literature. Specifically, this need is highlighted by Heath, et al. (2018) who found that parents of paediatric burns patients are at risk when they experience lack of support and this may consequently lead to feelings of isolation, which in turn may lead to various adjustment difficulties.

It was noted by Heath et al. (2018) that barriers to parental support was rooted in 1) lack of support from someone who could relate to what parents were going through, 2) lack of access to support due to daily life obligations and 3) lack of information and resources (Heath et al., 2018). Therefore, identifying interventions which mostly include a supportive component (Frenkel, 2007; Armstrong-James et al., 2019; Sveen et al., 2017) is promising.

The promising nature of supportive interventions is evident as all identified supportive interventions or interventions with supportive components, whether traditional support groups (Frenkel, 2007; Armstrong-James et al., 2019; Barnett, 2017) or psycho-educative supportive websites (Sveen, 2017; Heath, 2019), attempt to tap into underlying psychological variables of isolation as well as the barriers which inhibit parent support in various ways. It appears that a less structured support group (Frenkel, 2007; Barnett, 2017; Armstrong-James et al., 2019) provided a rich experience to parents. Talking freely about their feelings assisted parents in normalizing their experiences. It also created a platform where parents could relate to one another and experience a sense of community while simultaneously instilling a sense of hope. Lastly, it cultivated supportive relationships which transpired beyond group time. (Frenkel, 2007; Armstrong-James et al., 2019) Therefore, unstructured support groups appear to have addressed the barrier of lack of peer support as stated by Heath et al. (2019).

In comparison, psycho-educative Supportive websites (Sveen, et al., 2017; Heath et al., 2019) which include CBT interventions, therapeutic input in conjunction with peer input show great promise for future support group formats. The Sveen et al (2017) study indicated that their intervention assisted in processing, improved coping skills, management of burns and decreased PTS. Therefore, it is evident that this intervention assisted in addressing additional barriers to support and isolation such as poor access to support and a lack of resources and information regarding burns and trauma (Heath et al, 2018).

In terms of medical interventions, it appears that interventions with stronger family-centred and supportive underpinnings (George & Hancock, 1993) may be more beneficial for families than purely psycho-educative medical interventions (Jenkins et al., 1996) which tend to be one-dimensional. These family-centred and supportive underpinnings speak to the systemic treatment of families of child-burn survivors. The bi-directional nature of such systems becomes evident in the George and Hancock (1993) intervention which simultaneously provided support to nurses and parents and indirectly provided support to the child patient in this regard. Therefore, family-centred medical interventions show promise for future acute inpatient interventions.

Similar to George and Hancock's (1993) family-centred underpinning, the Family Burns Camp of Armstrong-James et al. (2019) also attempted to systemically address the needs of the family. Through doing this, not only were parents' needs addressed, but also the needs of the family as a whole.

Interestingly, the study by Armstrong-James et al. (2019) reported that parents experienced a decline in feelings of shame and guilt. It is hypothesized that systemic treatment of the family may have assisted in this regard, as parents reported that witnessing their children partake in new and challenging activities was helpful. It may be that witnessing their child outside of the 'victim' role and seeing them as a capable child may have assisted parents in shaking off their feelings of guilt and shame. This emphasises the powerful function of systemic treatment of families.

Additionally, it may be that the Armstrong-James et al. (2019) population group, which included families of much older burn injuries (up to 11 years), played a significant role in this regard. It is hypothesised that families with older burn injuries may have already processed



feelings of guilt and shame and developed a healthier perspective with regards to these feelings. The inclusion of such families in a group that contains more recent burn injuries may facilitate healthy discussion and allow these families to process and release guilt and shame. Shame and guilt contribute to severe adjustment difficulties in parents (Hawkins et al., 2018). Therefore, addressing family interventions systemically may hold the key to addressing shame and guilt.

From the identified group of interventions, it appears that a combination of interventions with various modalities show promise with regards to family interventions. Family-centred parent participation programs show great promise with regards to managing anxiety and equipping parents for rehabilitation phase. With regards to the rehabilitation phase, structured peer-informed, psycho-educative website interventions that are rooted in CBT, in conjunction with unstructured support groups, appear to address families' psychological needs and equip them with the necessary coping skills. Additionally, systemically orientated interventions such as Burns Camps show promise with regards to recovery for the family as a whole.

Of these, the majority of interventions targeted the rehabilitative phase (Armstrong-James et al. 2019; Jenkins et al., 1996; Frenkel, 2007; Sveen et al., 2017) and only one intervention was aimed at the acute phase (George & Hancock, 1993). However, treatment at acute phase has been identified as a critical phase of intervention due to parents being at risk of developing PTS or adjustment difficulty, and experiencing anxiety as well as guilt and shame during this phase (Bakker et al., 2013; McGarry, 2013; Philips & Rumsey, 2008; Heath et al., 2019). Therefore, a gap with regards to acute phase interventions for parents is indicated. It is hypothesised that parents' need for psychosocial support during the acute phase may be overshadowed by the medical needs of their child – the identified index patient – and provides insight as to why acute phase interventions may be limited.

Despite the importance of acute phase intervention, the rehabilitative phase has been identified as equally important due to continuing stressors such as ongoing treatment and adjustment difficulties at home (Le Brocque, Hendrikz & Kenardy, 2010). Thus, the identification of existing rehabilitative interventions, though limited, is promising.

### *High Income Context Bias:*

In the studies the majority of identified interventions were restricted to HIC. This is concerning, as Stokes and Johnson (2017) report that the ‘burden of burns [still] disproportionately falls to the world’s poor residing in low- and middle-income countries (LMIC’s)’ (p. 243). It is hypothesised that, due to the LIC being overburdened and under resourced in burns units, the limited funding has primarily been directed to medical interventions to assist in crisis management and that the significant burden of this has possibly not allowed for a shift towards rehabilitative systemic family focus.

Furthermore, the majority of the identified interventions were conducted within hospital settings. Hospital settings as the only source of intervention for families may hold implications for families of LICs. Potential contextual issues for LICs is highlighted in the study by Guest et al. (2018) which explores the difficulty burns staff encounter while treating burns patients in hospital settings. Staff noted that patients often experienced problems with accessing psychosocial services. This was typically due to difficulties such as geographic distance and transport difficulty.

Within the South African context, many patients who access tertiary hospital settings rely on public transport. Additionally, the majority of burns patients accessing burns care within tertiary hospitals are from LICs. For such patients, public transport is often a luxury. Therefore, alternative, accessible and affordable burns interventions, e.g. community-based interventions or website-based interventions for families within LICs, need to be considered with regards to intervention development.



## CHAPTER 5. RECOMMENDATIONS AND CONCLUSION

### 5.1 Summary of key findings:

The main findings from this systematic review of psychosocial interventions for families of child burn survivors suggests that evaluation methodologies are limited within this field. This is evident by the identified small sample sizes, limited randomized control studies, unclear reporting of outcomes and lack of objective measuring with consequent difficulty in establishing efficacy of interventions.

Furthermore, this systematic review identified supportive and rehabilitative interventions for families of child burn survivors. However, the paucity of interventions was evident. Majority of interventions were targeted at rehabilitative phase, with limited interventions targeting acute phase. It was found that family centred parent participation programs show promise as an acute phase intervention, whereas structured peer informed psycho-educative website interventions (rooted in CBT) as well as unstructured support group interventions show promise as rehabilitative interventions. Similarly, family burns camps also show promise as a rehabilitative intervention.

Lastly, findings from this systematic review suggest a high-income context bias. This was evident as majority interventions identified were conducted within High Income Countries. Therefore, applicability of interventions conducted in HICs within LICs is queried. Furthermore, the majority of interventions were conducted in hospital settings. Therefore, access to psychosocial interventions to the most vulnerable and high-risk groups of society appear to be restricted.

### 5.2 Recommendations for future research

From the above findings it is hoped that practitioners and researchers will continue to explore, investigate and develop new psycho-social interventions for families of paediatric burns patients.

Due to the lack of evidence-based knowledge regarding the efficacy of psychosocial interventions for families of paediatric burns patients, it is recommended that future research focus on evaluating the efficacy of current or developing interventions through use of objective quantitative measures and randomized controlled studies. Additionally, clearly defined

psychological outcomes need to be identified prior to intervention. Larger sample sizes in future studies are specifically recommended to ensure reliability and validity.

Furthermore, the effectiveness and feasibility of interventions in diverse communities should be explored, especially when considering implementing interventions (previously carried out in HIC's) into LIC conditions. Furthermore, the appropriateness of the settings for such interventions (especially within LICs) need to be explored.

### **5.3 Implications for practice**

It is recommended that professionals in burns care focus on developing and implementing both acute and rehabilitative phase interventions as the needs of parents, e.g. continuous trauma exposure, feelings of isolation, shame, guilt, experience of the unknown, stress etc. are prominent in both these phases.

Specifically, it is recommended that medical interventions with a strong psycho-social and supportive component eg. parent-participation programs are considered for acute phase treatment. Non-structured support groups, structured supportive interventions eg. peer informed psycho-educative websites and family burns camps can be considered for rehabilitation phase treatment.

Furthermore, the needs of parents appear to be fluid and interchangeable throughout these two phases. It is hoped that practitioners in future move from seeing acute and rehabilitative interventions for parents as two separate processes, and instead view them as fluid processes and treat them as such.

Additionally, systemically focused interventions are needed to address the bi-directional impact of burns. Therefore, it is hoped that more interventions for families in future will be grounded in family-centred and systems theory.

It is hoped that this evidence can assist in identifying effective interventions which can assist in informing policy for burns care, especially in LICs where there is a great need for burns interventions as well as a lack of specialist care funding. It is additionally hoped that this data will assist in motivating increased funding for psycho-social burns care.

#### **5.4 Study Limitations**

The findings of this systematic review are limited to a small amount of identified psycho-social intervention studies. It is possible, due to the exclusion of grey literature and non-peer reviewed articles, that interventions may have been missed during this systematic review process. Additionally, it is possible that the choice of key words may have contributed to the identification of limited studies. Due to inclusion of quantitative and qualitative studies, it was not possible for the researcher to effectively evaluate bias and validity. Additionally, reports with regards to efficacy were limited due to the inclusion of limited quantitative assessment measures in the identified studies. Therefore, the researcher was not able to effectively comment on the efficacy of interventions.

#### **5.5 Concluding comments**

In conclusion, the psychosocial interventions for families of child burn survivors are limited. There is currently a large knowledge gap in evidence-based psychosocial interventions for families of child burn survivors. No evidence-based intervention for LICs have been identified to date and most interventions identified took place within HICs, despite literature advocating for more LIC interventions.

There is a need for more evidence-based quantitative studies to assist in the development of psycho-social interventions for the families of child burn survivors.

Reflections from the identified LIC studies shine light on the current lack of funding available to ensure effective and evidence-based interventions. This indicates the need for global policy makers to assist in motioning change with regards to funding for burns intervention research in LIC's.

Of the identified interventions, those that are internet-based and incorporate supportive and psycho-social components that are cost effective, easily accessible and assist in decreasing PTS symptoms, are promising. Furthermore, Family Support Groups, Parent Participation Programs during acute wound management and Family Burns Camps have been identified as interventions with potential. Yet, the impact of these interventions on psychological well-being needs to be objectively measured.

However, family support groups as well as internet-based psycho-educative and supportive interventions show potential as intervention methods for LICs. In order to effectively assist families of paediatric burn survivors in LICs, additional evidence-based research should be conducted within LICs, with a specific focus on the impact of intervention on psychological well-being of families of child burn survivors.



## REFERENCE LIST:

- Adams, S., & Savahl, A. (2017). Nature as children's space: A systematic review. *The Journal of Environmental Education*, 0 (0), 1-31. <http://doi.org/10.1080/00958964.2017.1366160>
- Albertyn, R., Bickler, S.W., & Rode, H. (2006). Paediatric burn injuries in sub Saharan Africa – an overview. *Burns*, 32, 605-612. <https://doi.org/10.1016/j.burns.2005.12.004>
- Al-Mousawi, A.M, Mecott-Rivera, G.A., Jeschke, M.G., & Herndon, D.N. (2009). Burn teams and burn centers: the importance of a comprehensive team approach to burn care. *Clinics in Plastic Surgery*, 36(4), 547-554. <https://doi.org/10.1016/j.cps.2009.05.015>.
- Armstrong-James, L., Cadogan, J., Williamson, H., Rumsey, N., & Harcourt, D. (2019). Using photo- elicitation to explore families' experience of burn camp. *Journal of Family Nursing*, 25(1), 81-108. <https://doi.org/10.1177/1074840718817630>
- Bakker, A., Maertens, K.J.P., Van Son, M.J.M., & Van Loey, N.E.E. (2013). Psychological consequences of pediatric burns from a child and family perspective: A review of the empirical literature. *Clinical Psychology Review*, 33, 361-371. <https://doi.org/10.1016/j.cpr.2012.12.006>.
- Barnett, B.S., Mulenga, M., Kiser, M.M., & Charles, A.G. (2017). Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi. *Burns*, 43, 602-607. <https://doi.org/10.1016/j.burns.2016.09.027>.
- Baumann, J.A., & James, G.L. (1990). A Support Group for Burn Victims and Their Families. *Social Work with Groups*, 12(4), 159-169. [https://doi.org/10.1300/J009v12n04\\_10](https://doi.org/10.1300/J009v12n04_10)
- Blakeney, P., & Creson, D. (2002). Psychological and physical trauma: Treating the whole person. *Journal of Conventional and Weapons and Destruction*, 6(3).
- Boland, A., Cherry, M.G., & Dickson, R. (2017). *Doing a systematic review: A student's guide*. 2<sup>nd</sup> Edition. Sage Publishers.

- Bradshaw, D., Bourne, D., & Nannan, N. (2003). *What are the leading causes of death among South African children?* MRC Policy Brief. Cape Town: Medical Research Council. [https://www.unicef.org/southafrica/SAF\\_publications\\_mrc.pdf](https://www.unicef.org/southafrica/SAF_publications_mrc.pdf)
- Bronfenbrenner, U. (1994). *Ecological models of human development*. International encyclopaedia of education, volume 3, 2<sup>nd</sup> edition. Oxford: Elsevier. Reprinted in : Gauvain, M. and Cole, M. (Eds). (1993). *Readings on the development of children*, 2<sup>nd</sup> edition, 37-43. Freeman.
- Burrows, S., Van Niekerk, A., & Laflamme, L. (2010). *Fatal injuries among urban children in South Africa: Risk distribution and potential for reduction*. Bulletin of the World Health Organ, 88, 267-272. <https://doi.org/10.2471/BLT.09.068486>
- Dallos, R., & Draper, R. (2015). *An Introduction to Family Therapy. A Systemic Theory and Practice. 4<sup>th</sup> Edition*. Mc Graw Hill Education and Open University Press
- Delgado, J., Raminéz-Cardich, M.E., Gilman, R.H., Lavarello, R., Dahodwala, N., Bazán, A., Rodríguez, V., Cama, R.I., Tovar, M., & Lescano, A. (2002). Risk factors for burns in children: crowding, poverty, and poor maternal education. *Injury Prevention*, 8, 38-41.
- Dorn, T., Yzermans, J.C., Spreeuwenberg, P.M., & Van der Zee, J. (2007). Physical and mental health problems in parents of adolescents with burns – a controlled, longitudinal study. *Journal of Psychosomatic Research*, 63, 381-389. <https://doi.org/10.1016/j.jpsychores.2007.02.005>
- Egberts, M.R., Van de Schoot, R., Geenen, R., & Van Loey, N.E.E. (2017). Parents' Posttraumatic Stress After Burns in Their School-Aged Child: A Prospective Study. *Health Psychology*, 36(5), 419-428. <https://doi.org/10.1037/hea0000448>..
- Frenkel, L. (2007). A support group for parents of burned children: A South African Children's Hospital Burns Unit. *Burns*, 34, 565 – 569. <http://doi.org/10.1016/j.burns.2016.08.039>
- George, A., & Hancock, J. (1993). Reducing paediatric burn pain with parent participation. *Journal Burn Care Rehabilitation*, 14, 104-107. <https://doi.org/10.1097/00004630-199301000-00022>

- Gopalakrishnan, S., & Ganeshkumar, P. (2013). Systematic Reviews and Meta-analysis: Understanding the Best Evidence in Primary Healthcare. *Journal of Family Medicine and Primary Care*, 2(1), 9-14. <https://doi.org/10.4103/2249-4863.109934>
- Gough, D., Oliver, S., & Thomas, J. (2012). *An introduction to systematic reviews*. Sage Publications
- Green, S. (2005). Systematic reviews and meta-analysis. *Singapore Med J*,46(6), 270-274
- Hackshaw, A. (2008). Small studies strengths and limitations. Editorial. *Eur Resp Journal*, 32,1141-1143. <https://doi.org/10.1183/09031936.00136408>
- Hawkins, L. Centifanti, L., Holman, N., & Taylor, P. (2018). Parental adjustment following pediatric burn injury: the role of guilt, shame, and self-compassion. *Journal of paediatric psychology*,1-9.<https://doi.org/10.1093/jpepsy/jsy079>
- Hall, E. Saxe, G., Stoddard, F., Kaplow, J., Koenen, K., Chawla, N., Lopez, C., King, L., & King, D. (2006). Posttraumatic stress symptoms in parents of children with acute burns. *Journal of Pediatric Psychology*, 31(4), 403-412. <https://doi.org/10.1093/jpepsy/jsj016>
- Heath, J., Williams, H. and Williams, L., & Harcourt, D. (2018). Parent-perceived isolation and barriers to psychosocial support: a qualitative study to investigate how peer support might help parents of burn-injured children. *Scars, Burns and Healing*, 4. <https://doi.org/10.1177/2059513118763801>.
- Heath, J. (2016). Depression: An antecedent and consequence of burn-injuries to children. *Austin Journal of Emergency and critical care medicine*, 3(1).
- Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2019). Supporting children with burns: developing a UK parent-focused peer-informed website to support families of burn-injured children. *Patient Education and Counselling*, 1-6. <http://doi.org/10.1016/j.pec.2019.04.003>
- Hedge, S. (2015). *Essays on research methodology*. India: Springer publications.
- Higgins, J.P.T., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions*. Version 5.1.0 [updated March 2011]. The Cochrane Collaboration. <http://handbook.cochrane.org>.



- Hornsby, N., Blom, L., & Sengoelge, M. (2019). Psychosocial Interventions Targeting Recovery in Child and Adolescent Burns: A Systematic Review. *Journal of Pediatric Psychology*, 1-19. <https://doi.org/10.1093/jpepsy/jsz087>
- Horridge, G., Cohen, K., & Gaskell, S. (2010). BurnEd: Parental, psychological, and social factors influencing a burn-injured child's return to education. *Burns*, 36, 630 – 638. <https://doi.org/10.1016/j.burns.2009.08.013> |
- Jenkins, H., Blank, V., Miller, K., Turner, J., & Stanwick, R.S. (1996). A Randomized Single-Blind Evaluation of a Discharge Teaching Book for Pediatric Patients With Burns. *Journal of Burn Care and Rehabilitation*, 17(1), 48-61.
- Kaneshiro, N.K., Zieve, D., & Conaway, B. (2019, June 3). *Developmental milestones record*. MedlinePlus. <https://medlineplus.gov/ency/article/002002.htm>
- Le Brocque, R.M., Hendrikz, J., Justin A., & Kenardy, J.A. (2010). Parental Response to Child Injury: Examination of Parental Posttraumatic Stress Symptom Trajectories Following Child Accidental Injury. *Journal of Pediatric Psychology* 35(6), 646–655. <https://doi.org/10.1093/jpepsy/jsq035>
- Lehna, C. (2015). Childhood Burn Survivors' and Their Siblings' Perceptions of Their Body Image. *Journal of Pediatric Nursing*, 30, 117-125. <https://doi.org/10.1016/j.pedn.2014.09.009>
- Long, A.F., Godfrey, M., Randall, T., Brettell, A., & Grant, M.J. (2002). *Developing evidence based social care policy and practice. Part 3: feasibility of undertaking systematic reviews in social care*. University of Leeds: Nuffield Institute for Health.
- Philips, C., & Rumsey, C. (2008). Considerations for the provision of psychosocial services for families following paediatric injury – a quantitative study. *Burns*, 34(1), 52-62. <https://doi.org/10.1016/j.burns.2006.12.003>
- Stokes, M.A.R. & Johnson, W.D. (2017). Burns in the third world: An unmet need. *Annals of Burns and Fire Disasters*, XXX (4), 243-246.
- Mc Garry, S., Girdler, S., Mc Donald, A., Valentine, J., Wood, F., & Elliot, C. (2013). Pediatric medical trauma: The impact on parents of burn survivors. *Burns*, 39, 1114-1121. <https://doi.org/10.1016/j.burns.2013.01.009>. Epub 2013 Mar 5.



- Mock, C., Peck, M., Peden, M., & Krug, E. (2008). *A WHO plan for burn prevention and care*. World Health Organization. [http:// www.who.int/iris/handle/10665/97852](http://www.who.int/iris/handle/10665/97852)
- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Pettigrew, M., Shekelle, P., Stewart, L.A., & PRISMA-P Group (2015). *Preferred reporting items for systematic reviews and meta-analysis protocols (PRISMA-P) 2015 statement*. *Systematic reviews*, 4(1), 1-9.
- NIH. (2018, January). *Burns: What is a burn*. National Institute of General Medical Sciences. [https://www.nigms.nih.gov/education/pages/factsheet\\_burns.aspx](https://www.nigms.nih.gov/education/pages/factsheet_burns.aspx)
- Oster, C., Hensing, I., Löjdström, T., Sjöberg, F., & Willebrand, M. (2014). Parent's Perception of Adaption and Family Life After Burn Injuries in Children. *Journal of Pediatric Nursing*, 29, 606-613. [https://doi.org/ 10.1016/j.pedn.2014.06.010](https://doi.org/10.1016/j.pedn.2014.06.010)
- Pan, R., Dos Santos, B.D, Nascimento, L.C., Rossi, L.A., Geenen, R., & Van Loey, N.E. (2017). School reintegration of pediatric burn survivors: an integrative literature review. *Burns*, XXX, 1-18. <https://doi.org/10.1016/j.burns.2017.05.005>
- Panic, N., Leoncini, E., De Belvis, G., Ricciardi, W., & Boccia, S. (2013). Evaluation of the Endorsement of the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) Statement on the Quality of Published Systematic Review and Meta-Analyses. *Plos One*, 8 (12), 1-7. [https://doi.org/ 10.1371/journal.pone.0083138](https://doi.org/10.1371/journal.pone.0083138). eCollection 2013.
- Peden, M., Oyebite, K., Ozanne-Smith, Hyder, A.A., Branche, C., Rahman, A.K.M.F., Rivara, F., & Bartolomeos, K. (2008). *World Report on child injury prevention*. World Health Organisation. Switzerland.
- Petersen, C. (2015). *Youth Violence Perpetration: A systematic review of Community-Level Protective Factors and Community Resilience*. (Unpublished master's thesis). University of the Western Cape. Cape Town. South Africa
- Petridou, E., Trichopolous, D., Mera, E., Papadatos, Y., Papazoglou, K., Marantos, & A., Skondras, C. (1998). Risk factors for child burn injuries: a case-control study from Greece. *Burns*, 24,123-128. [https://doi.org/10.1016/S0305-4179\(97\)00095-8](https://doi.org/10.1016/S0305-4179(97)00095-8)
- Popay, J., Roberts, H., Snowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the Conduct of a Narrative Synthesis in*

*Systems Reviews*. A product from the ESRC Method programme. Lancaster University. The University of York. South Hampton Solent University. University of Exeter. University of Plymouth.

Rhodes, S.D., Foley, K.L., Zometa, C.S., & Bloom, F.R. (2007). Lay Health Advisor Interventions Among Hispanics/Latinos: A Qualitative Systematic Review. *American Journal of Preventative Medicine*, 33(5), 418-427. <https://doi.org/10.1016/j.amepre.2007.07.023>

Seedat, M., Van Niekerk, A., Jewkes, R., Suffla, S., & Ratele, K. (2009). Health in South Africa 5 Violence and injuries in South Africa: prioritising an agenda for prevention. *Lancet*, 374, 1011 – 1022. [https://doi.org/10.1016/S0140-6736\(09\)60948-X](https://doi.org/10.1016/S0140-6736(09)60948-X). Epub 2009 Aug 24

Shaw, J., Downe, S., & Kingdon, C. (2015). Systematic mixed-methods review of interventions, outcomes and experiences for imprisoned pregnant women. *Journal of Advanced Nursing*, 71(7), 1451-1463. <https://doi.org/10.1111/jan.12605>

Sveen, J., Andersson, G., Buhrman, B., Sjöber, F., & Willeberand, M. (2017). Internet based information and support program for parents of children with burns: A randomized controlled trial. *Burns*, 43, 583 -591. <https://doi.org/10.1016/j.burns.2016.08.039>

Turton, W. (2014). *An introduction Psychosocial Interventions* in Walker, S. (Ed.), *Psychosocial Interventions for Mental Health Nursing*, 1<sup>st</sup> edition. SAGE publishers.

Van Niekerk, A., Titi, N., Lau, U., & Arendse, N. (2012). *Childhood Burns in South Africa: Towards Evidence for Prevention Action and Policy*. In Van Niekerk, A., Suffla, S., and Seedat, M. (Eds.), *Crime, Violence and Injury in South Africa: 21st Century Solutions for Child Safety* (pp.8-22). PsySSA Press.

Van Niekerk, A., Du Toit, N., Nowell, M.J., Moore, S., & Van As, A.B. (2004). *Child burn injury: Epidemiological, management and emerging injury prevention studies*. In Suffla, S., Van Niekerk, A. and Duncan, N. (Eds.), *Crime, violence and injury prevention in South Africa: Developments and challenges* (pp. 145-157). Medical Research Council. University of South Africa.

Van Niekerk, A., Titi, N., Lau, U., & Arendse, N. (2011). Flame and scalding burns in children. In: Van Niekerk, A., Suffla, S., Seedat, M., & Ratele, K. eds. *Crime, Violence and*

*Injury in South Africa: Enabling Child Safety*, 01/2011: chapter; Cape Town: South African Medical Research Council, 2011

Wesson, H.K.H., Bachani, A.M., Mtambeka, P., Schulman, D., Mavengere, C., Stevens, K.A., Millar, A.J.W., & Hyder, A.A. (2013). Pediatric burn injuries in South Africa: A 15-year analysis of hospital data. *Injury Int.J.Care Injured*, 44, 1477-1482. <https://doi.org/10.1016/j.injury.2012.12.017>

WHO. (2018, March 6). *Burns*. World Health Organization Fact. [https:// www.who.int/en/news-room/fact-sheets/detail/burns](https://www.who.int/en/news-room/fact-sheets/detail/burns)

Willebrand, M., & Sveen, J. (2016). Perceived support in parents of children with burns. *General Hospital Psychiatry*, 38, 105-108. <https://doi.org/10.1016/j.genhosppsy.2015.10.004>



## APPENDIX A

EBSCOHOST TITLE AND ABSTRACT SCREENING PROCESS:													
Nr	Screening for abstract	Database	Author	Yr	Title	Aim: Type of intervention appropriate (acute/ post discharge psychosocial intervention) :	Outcome of study (psychosocial wellbeing)	Target population (Families child burn survivors)	Type study	Key words (abstract)	Incl	Excl	Reason exclude
5	1	CINAHL	Summers	1991	Psychosocial support of the burn patient	yes, Psychosocial support groups by psychiatric nurses	support	families of adult burn patients	case study	burn, families, support, intervention		1	inappropriate population - Adult patients
12	1	CINAHL	George & Hancock	1993	Reducing pediatric burn pain with parent participation	yes, Psychoed intervention for parents of burn survivors	copng strategies for parents and pain reduction	parents of children 6-12	Descriptive study	parent, program, burn, support		1	
18	1	CINAHL	Molter	1993	When is the burn injury healed? Psycho-social implications for care	yes, Psycho-social intervention for recovery	reducing stress and trauma	families of burn patients	Descriptive study	burn, families, support		1	
24	1	CINAHL	Tinsley et al.	1994	Surgeon's, nurses' and bereaved families' attitudes toward dying in the burn centre.	No intervention	assess attitudes to death evaluation	Surgeons and families of adult burn survivors	quantitative	burn, support, families		1	no intervention, inappropriate population
25	1	academic search complete	No name	1994	Guidance for parents on child safety	No, Psycho-education, but preventative	educate burn prevention	parents	Descriptive study	parents, help, scalding		1	inappropriate intervention
26	1	CINAHL	Rizzone et al	1994	PTSD in mothers of children and adolescents with burns	No intervention	assess factors affecting ptsd	parents of child burn survivors	quantitative	parents, burn, support, therapy		1	no intervention
28	1	CINAHL	Doctor	1994	parent participation during painful wound care procedures	Yes, Acute intervention, parent assistance with dressing changes	anxiety relief	burned children	quantitative	burn, parent, support		1	inappropriate population
30	1	Medline	Hollyoak	1994	Electric iron contact burns in an Australian paediatric population	No intervention	none - epidemiology study	electric contact burns amongst children	prospective analysis	burns, caregivers, help		1	no intervention

40	1	CINAHL	Jenkins et al	1996	A randomized single-blind evaluation of a discharge teaching book for pediatric patients with burns	Yes, Burn care intervention post discharge	burns rehabilitation assistance	caregivers of child burn survivors aged 6-12	randomized controlled study	burn, caregivers, families, intervention	1	
41	1	CINAHL	Watkins et al	1996	Postburn psychological adaptation of family members of patients with burns	yes, supportive interventions	Assistance with coping and adjustment	Families of child and adult burn survivors	Descriptive study	family support, family, burn survivors, interventions burn	1	
43	1	medline	Bryant & Touyz	1996	the role of the clinical psychologist on a burn unit in general teaching hospital	Yes, clinical psychological intervention acute and long term	adjustment and rehabilitation assistance	Families of burn patients	Descriptive study	burn, management, families, intervention	1	
44	1	CINAHL	Johnson & Lindschau	1996	Staff attitude toward parent participation in the care of children who are hospitalised	No intervention	none, measures staff attitudes	Staff working with families of burn victims	quantitative	parents, burns, support	1	no intervention, inappropriate population
46	1	CINAHL	Cronin et al	1996	a 1 year prospective study of burns in an irish paediatric burns unit	No intervention	none	child burn survivors	prospective study	burns, parents, help	1	no intervention, inappropriate population
48	1	CINAHL	Foertsch et al	1996	psycho-social forum parent participation during burn debridement in relation to behaviour distress	Yes, parent participation during debride-ment	Behavioural distress management	child burn survivors	quantitative	parent, programs	1	inappropriate population
49	1	CINAHL	Wilson	1996	care of the burn patient	No intervention	none, description of burn injuries and wound care	burn survivors	review article	burn, family support, burn victims, intervention	1	no intervention



50	1	CINAHL	Wong et al	1996	outcome studies for burn patients in hong kong: patients satisfaction	No, medical intervention	no, medical	child and adult burn survivors	quantitative	burns, therapy, families, support	1	inappropriate intervention - medical
51	1	Medline	Hargrave & Sells	1997	the development of a forgiveness scale	No intervention	none	Families	quantitative	family, burns, family therapy	1	no intervention, inappropriate population
53	1	CINAHL	Fletchall & Hickerson	1997	Burn rehabilitation forum. Managed health care: therapist responsibilities.	No, intervention for reimbursement	no	burn survivors and families	Descriptive study	burn, therapy, families, therapy program	1	inappropriate intervention and population
55	1	CINAHL	Davis & Sheeley Adolphson	1997	Psycho-social interventions. Pharmacologic and psychological modalities	yes, medical and psychological support	recovery	burn survivors	??	caregiver, burns, interventions	1	inappropriate population
56	1	CINAHL	Mertens et al	1997	Outpatient burn management	??					1	inappropriate intervention
59	1	CINAHL	Heinberg et al	1997	Psychologic factors involved in the decision to undergo reconstructive surgery after burn injury	no intervention	no	adult burn survivors	quantitative	burn, burn survivors, family, interventions	1	no intervention, inappropriate population
61	1	CINAHL	Hart & Matorin	1997	Collaboration between hospital social work and pastoral care to help families cope with serious illness and grief	yes, social work/pastoral care intervention	Maximising family capacity	families of child burn survivor	case study	program, families, intervention	1	
75	1	CINAHL	Docking	1999	Trauma, electrical burn injuries	partially, supportive	supportive	families of burn survivors	Descriptive study	burn, management, support, family, help	1	Unsure?? Full reading needed
76	1	Medline	Barnes & Bud	1999	Family centred burn care	Yes, family support inpatient admission	Supportive, improvement in recovery	families of child burn survivors	Descriptive study	burn, family support	1	UNABLE TO ACCESS

78	1	CINAHL	Thompson et al.	1999	A qualitative analysis of family member needs and concerns in the population of patients with burns.	No intervention, needs explored of parents	none	families of child burn survivors	qualitative	family support, family, burns, burn, support, family	1	No intervention
80	1	CINAHL	Corraro et al.	2000	The cool kids coalition: a community effort to reduce scald burn risk in children	no, preventative community intervention	injury reduction	parents of vulnerable preschool children	?	burns, parent, intervention, program	1	inappropriate intervention
87	1	CINAHL	Blakeney et al.	2000	Anxiety: current practices in assessment and treatment of anxiety of burn patients	yes, acute intervention	anxiety reduction	burn victims - child and adult	quantitative	management, burn, family	1	inappropriate population
89	1	medline	Morgan et al.	2000	Ambulatory management of burns	No, medical acute intervention	no	burn survivors	Descriptive study	family, burns, burns management, burn, help	1	inappropriate intervention an population
91	1	CINAHL	Welker et al.	2000	Day care injuries in children	no, epidemiology and injury patterns	no	child burn victims	quantitative	burns, helps, parents	1	no intervention, inappropriate population
93	1	medline	Königová	2001	Quality of life in burn victims a holistic approach	no intervention	quality of life	child and adult burn survivors	Descriptive study	burns, families, therapy	1	no intervention, inappropriate population
99	1	CINAHL	Gilboa & Gilboa	2001	Long term psychosocial adjustment after burn injury	no intervention, exploratory	quality of life	adult burn survivors	exploratory study	burns, burn victims, support, family	1	no intervention, inappropriate population
105	1	PsychArticles	Trief et al	2001	Collaboration on an inpatient burn unit	Yes, collaborative support	yes	No, adult burn survivors	discussion	families, burn, program, victims,	1	inappropriate population - adult survivors
106	1	Medline	Leslie et al	2001	management of multiple burn casualties in high volume without a verified burn unit.	no, medical intervenin	no	No, adult burn survivors	reporting statistics	interventions, burns, family	1	inappropriate intervention, inappropriate population



109	1	CINAHL	Young	2002	rehabilitation of burn injuries	medical and psychological intervention	Physical and psychological rehabilitation	Adult burn survivors	Descriptive study	burns, family, management, support	1	inappropriate population , also medical
111	1	CINAHL	Stoddard et al	2002	Psychosocial forum. Treatment of pain in acutely burned children	medical and psychological intervention	yes	child burn survivors	Descriptive study	burns, management, help, family	1	inappropriate population
112	1	CINAHL	Helvig	2002	Managing thermal injuries within WOCN practice.	Yes, nursing intervention	yes, in addition to medical	Unsure, possible adult burn patients and families	article discussion	burn, burns, management family	1	Unsure?? Full reading needed
113	1	academic search complete	Dauber et al	2002	chronic persistent pain after severe burns: a survey of 3 burn survivors.	no, survey	no	adult burn survivors	survey	burn survivors, burn survivors interventions, burns, family, burn victims	1	no intervention and inappropriate population
114	1	academic search complete	Rochet & Hareb	2002	burns rehabilitation	no, medical intervention	no	adult burn survivors	Descriptive study	burns, therapy, family	1	inappropriate intervention and population , french lang
116	1	CINAHL	Bradford	2002	Life in recovery: rebuilding from trauma	no , support group for trauma patients	yes	No, trauma patients and families	Descriptive study	families, program, support, burn (out)	1	inappropriate intervention and population
132	1	academic search complete	Tyack and Ziviani	2003	what influences the functional outcome of children at 6 months post-burn?	no intervention	yes	no, child burn survivors	quantitative	parent, burns, caregivers, support	1	no intervention and inappropriate population
139	1	academic search complete	Lancet	2003	Treatment of children with severe burns.	no intervention, medical treatment	no	no, child burn survivors	essay	burns, burns management, family	1	inappropriate intervention and population
140	1	medline	Kripner et al.	2004	Care for children after burn injury	yes, medical and psychological family intervention	yes	no, child burn survivors	Descriptive study	burn, therapy, family	1	inappropriate population

141	1	medline	Johansen et al.	2004	A feasibility study of email communication between the patient's family and the specialist burns team.	Yes, management wound care assistance for parents	??	Yes	case study	parents, burns, families, support	1	Incorrect intervention - only medical outcome focus
150	1	academic search complete	Dewar	2004	Hot beverage scalds in Australian children	no, epidemiology and injury patterns	no	no, child burn survivors	quantitative	burn, management, scalding, programs, caregivers	1	no intervention and inappropriate population
151	1	academic search complete	Taylor	2004	Evaluation of a pediatric scald burn clinical pathway	no, acute medical intervention	no	no, child burn survivors	quantitative	burn, management,	1	medical intervention and inappropriate population
157	1	CINAHL	Morad et al.	2004	Burn injuries and adolescents in Israel	no, incident rate reporting	no	no, child burn survivors	quantitative	burn, family, program	1	no intervention and inappropriate population
161	1	academic search complete	Zengerle-Levy	2004	Practices that facilitate critically burned childrens holistic healing	yes	yes, assistance with holistic healing	no, child burn survivors and nurses	interpretive study	families, burns, help	1	inappropriate population
168	1	academic search complete	Drago	2005	Kitchen scalds and thermal burns in children five years and younger	no, description of burn patterns	no	no, child burn survivors	Descriptive study	burns, intervention, parents	1	no intervention and inappropriate population
173	1	academic search complete	Saxe et al	2005	Pathways to PTSD, part 1 children with burns	no, etiology of PTSD	no	no, child burn survivors	quantitative	burn, families, support	1	no intervention and inappropriate population
179	1	academic search complete	Dyregrov	2005	experiences of social networks supporting traumatically bereaved	no, interventions for families of trauma - support groups	yes	no, families of trauma survivors	qualitative	support, family, parents, burn (out)	1	inappropriate intervention and population
181	1	academic search complete	Zengerle-Levy et al	2006	The inextricable link in caring for families of critically burned children	Yes	yes	Yes, parents and paediatric patients	qual	burn, survivors, therapies, families,	1	

184	1	academic search complete	Carlsson et al.	2006	Burns injuries in small children, a population based study in Sweden	no, characteristics of burn injuries	no	no	retrospective design	burn, burns, parents, family, programme	1	no intervention and inappropriate population
188	1	ERIC	Hamilton	2006	Evidence based practice for outpatient clinical teams	possible	possible	families of burn survivors	column	burns, therapy, families, support	1	column article
190	1	medline	Hamoui et al.	2006	Depression in mothers of burned children	no intervention, predicting prevalence and predicting factors	yes	yes	quant	parents, burns, support	1	no intervention, prevalence of depression only
191	1	Medline	Hall et al	2006	PTS symptoms in parents of children with acute burns	No, model for ptsd development	yes	yes	quant	parent, burns, family, interventions	1	no intervention
196	1	academic search complete	Cohn	2006	A psychotherapy service exposed	No	no	families of trauma	Descriptive study	burns, help, families, interventions	1	inappropriate intervention and population
208	1	medline	Langer et al	2006	Analysis of burn treatment for children at Bochum University Hospital	no, epidemiology of burns	no	child burn survivors	retrospective epidemiological study	burns, families	1	no intervention
211	1	medline	Bond	2006	Mothers beliefs about knowledge, child development and parenting strategies: expanding the goals of parenting programs	no intervention	no	no	qualitative	parent, program	1	no intervention, inappropriate population
223	1	academic search complete	Van Niekerk et al.	2007	Caregiver experiences, contextualisations, and understanding of the burn injury to their child. Accounts from low income South Africa.	No, understanding of caregiver regarding burns accident	no	yes	qual	burn, caregivers, parents, interventions	1	no intervention

2 3 1	1	academic search complete	Phillips et al	2007	considerations for psychosocial support following burn injury - a family perspective	no, only identify what support programmes may need to address	yes	yes	quant	parents, family, support programmes, burn	1	No intervention
2 3 6	1	CINAHL	Ewings et al.	2008	Pediatric upper extremity burns: outcomes of emergency department triage and outpatient management	no, epidemiology of pediatric burns	no	no	quant	burns, management, interventions, parents	1	No intervention and wrong population
2 4 3	1	academic search complete	Phillips & Rumsey	2008	Considerations for the of psychosocial services for families following paediatric burn injury - a quantitative study	no, report on distress experienced by parents	yes	yes	mixed methodology	parents, support programmes, family, burn,	1	No intervention
2 4 9	1	academic search complete	Peck et al.	2008	Burns and injuries from non-electric appliance fires in low- and middle-income countries: part II. A strategy intervention using the Haddon Matrix	no, epidemiology and proposed interventions	no	no	??	burns, interventions, caregivers	1	No intervention
2 5 0	1	academic search complete	Rea et al.	2008	Use of the internet by burn patients, their families and friends.	no, internet usage measured as coping tool	no	yes, but additional as well	quant	burns, parents, management, burn, family	1	No intervention
2 5 1	1	academic search complete	Bittle	2008	Care of burn patients	no, exploring needs of burns patients	yes	No, adult burn survivors	exploratory study	burn, parents, program	1	no intervention, inappropriate population
2 6 5	1	academic search complete	Mashreky et al.	2008	Burn injury: economic and social impact on a family	no, exploring social and economic impact of burns	no	yes	exploratory study	burn, management, families, program	1	no intervention

267	1	medline	Okoro et al.	2009	Childhood burns in south eastern nigeria	no, burn trends explored	no	no, child burn survivors	quantitative	burns, intervention	1	no intervention, inappropriate population
278	1	CINAHL	Guzel et al	2009	Scalds in pediatric emergency department: a 5 year experience	no, characteristics of scalds	no	no, child burn survivors	retrospective study	burns, scalding, programs, families	1	no intervention, inappropriate population
279	1	academic search complete	Sacco et al.	2009	Support groups facilitated by families of former patients. Creating family inclusive critical care units	Yes, support group	yes	Possible - families of burn survivors - kids?	qual	support, burn, family, families	1	Unsure - Full reading needed
280	1	medline	Balseven-Odabaşı et al	2009	Burn injuries in children up to seven years	no, investigative study characteristics of burns	no	no, child burn survivors	quant	burn, program, parents	1	no intervention, inappropriate population
286	1	academic search complete	Rahzani et al.	2009	Disfiguring burns and the experienced reactions in Iran: consequences and strategies - a qualitative study.	no, exploring experience of adult burn survivor	no	No, adult burn survivors	qual	burns, support program, family	1	no intervention, inappropriate population
307	1	academic search complete	Greenfield	2010	The pivotal role of nursing personnel in burn care.	yes, nursing care	yes	adult burn survivors	exploratory study	management, burn, family	1	inappropriate population
314	1	CINAHL	Simons et al	2010	Predicting functional outcome for children on admission after burn injury: do parents hold the key?	No intervention, assessment of family and child adaptive functioning	yes	Yes	quant	caregiver, family, parents, burn, support	1	No intervention
370	1	academic search complete	Graham et al.	2012	Are parents in the UK equipped to provide adequate burns first aid?	no, preventative first aid intervention	no	no	quant	burns, parents, help	1	inappropriate intervention and population



374	1	CINAHL	Syed-Abdul et al.	2012	Telemedicine utilization to support the management of burns treatment involving patient pathways to in both developed and developing countries: a case study.	More medical intervention	kind of	no, doctors, medical personal and families	case study	support, management, burns, burn victim, help, families	1	Medical intervention and wrong pop
384	1	CINAHL	Tompkins et al.	2012	The American Burn Association/Sriners hospital for children burn outcomes program: a progress report at 15 years.	Yes, possible psycho-social	possible	possible	Unusure	burn, program, parent, management	1	No, progress report
389	1	Medline	Bakker et al.	2012	Acute Stress reactions in couples after a burn event to their young child.	No intervention, stress reaction in parents	yes	yes	quant	burn, parents', support, family	1	No intervention
403	1	academic search complete	Backstrom et al.	2013	Prediction of psychological symptoms in family members of patients with burns 1 year after injury	No intervention, predictors identified	yes	no, families adult burn survivors	quant	family, burns, support, interventions	1	No intervention and wrong population
415	1	academic search complete	Ravindran et al.	2013	Embracing survival: a grounded theory study of parenting children who have sustained burns.	no, exploring parenting	no	yes, parents of child burn survivors	qualitative	family, burn, parents, support	1	no intervention
426	1	academic search complete	McGarry et al.	2013	Paediatric medical trauma: The impact on parents of burn survivors.	no intervention, impact of trauma on parents assessed	yes	yes	quant	parents, burn, burn survivors, interventions	1	No intervention

4 3 1	1	PsychArticles	Bakker et al.	2 0 1 3	Course of traumatic stress reactions in couples after burn event to their young child.	no intervention, course of ptsd tracked	yes	yes	quant	burn, parents, support, family, programs	1	No intervention
4 3 5	1	academic search complete	Kramer & Landolt	2 0 1 4	Early psychological intervention in accidentally injured children aged 2-16 : a randomized control trial.	Yes, CBT intervention for child burn survivors	yes	No, child burn survivors	quant	burns, interventions, parents, counseling, support	1	Child intervention not for parents
4 3 7	1	CINAHL	Van Beelen et al.	2 0 1 4	Effectiveness of web based tailored advice on parents' child safety behaviors: randomized controlled trial.	no, prevention program	no	yes	quant	parents, counseling, intervention, supports	1	prevention intervention
4 5 1	1	CINAHL	Backstrom et al.	2 0 1 4	Health related quality of life in family members of patients with burns	No intervention, measures Health related quality of life of parents	yes	yes	quant	burn, family, support	1	No intervention only measures HRQOL
4 6 0	1	medline	Rode et al.	2 0 1 4	Burn care in South Africa: a micro cosmos of Africa	Unclear	unclear	No	??	burn, burns, families, management	1	Not intervention for families
4 6 2	1	academic search complete	Tepeneu et al.	2 0 1 4	Pediatric burns and scalds - modern therapeutic concepts	No, medical intervention	no	no, child burn survivors	??	burns, management, therapy	1	inappropriate intervention
4 7 0	1	medline	Vlastelica	2 0 1 4	Psychological support to burn patients	No, need for interventions stated	yes	No, adult burn survivors	??	burn, burns, support, family	1	no intervention
4 7 2	1	academic search complete	Spiwak et al.	2 0 1 4	Creation of a standardized burn course for low income countries: meeting local needs.	no, intervention for students	no	no, students	quant	burn management, burn, caregivers	1	inappropriate intervention and population



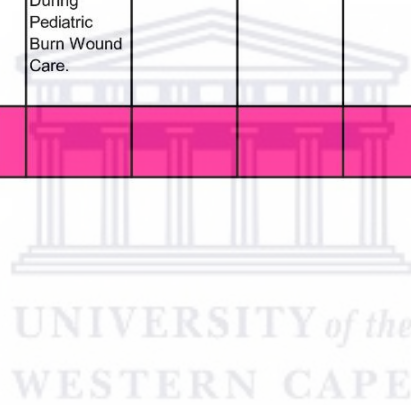
476	1	CINAHL	Gullick et al.	2014	The trauma bubble: patient and family experience in serious burn injury	No intervention, family experience	yes	yes , but als adult parents possibly	qual	burn, families, support, management	1	No intervention, family experience
477	1	CINAHL	Oster et al.	2014	Parent's perception of adaptation and family life after burn injuries in children.	No intervention, experience of parent explored	yes	yes	qual	parent's, burn, family, support	1	No intervention, experience of parents
489	1	academic search complete	Othman et al.	2015	Childhood burns in Sulaimaniyah province, Iraqi Kurdistan: A prospective study of admissions and outpatients.	no intervention, focused on epidemiology of child burns	no	No, paediatric burn patients	prospective study	burns, burn, families, interventions	1	No intervention and wrong population
490	1	medline	Liodaki et al.	2015	Management of pediatric hand burns	no, medical management	no	No, paediatric burn patients	review study	burns, management,	1	inappropriate intervention
508	1	academic search complete	Cubitt et al.	2015	Evaluating an outreach service for paediatric burns follow up	No, medical intervention	no	no, paediatric burn patients	retrospective analysis	burns, parents, management	1	Medical intervention and incorrect population
530	1	academic search complete	Willebrand & Sveen	2015	Perceived support in parents of children with burns	No intervention, exploring experience of families	Yes	Yes	quant	burn, burns, parent, parent's, support,	1	No intervention, only experience
540	1	academic search complete	Crouch	2016	A breath of fresh air: a family ceremony	Yes	yes	no, general paediatric patients parents	case study	family, help	1	no, inappropriate population and intervention type
561	1	academic search complete	Johnson et al.	2016	Emerging from the trauma bubble: redefining normal after burn injury	no intervention, exploring experience of families and coping strategies	yes	yes - unsure only child parents	qual	families, burn, supports, burn survivor	1	No intervention, only experience
578	1	CINAHL	Tropez-Arceneaux et al.	2016	The psychological impact of first burn camp in Nicaragua	No, intervention targeted at child burn survivor	yes	no	Quant	burn, burns, therapy, program, parent	1	Intervention for child survivor

597	1	academic search complete	Sveen et al.	2017	Internet based information and support program for parents of children with burns: a randomized controlled trial.	Yes	Yes	Yes	randomized controlled trial	help, program, parents, intervention,	1	
598	1	academic search complete	Bond et al.	2017	Anxiety, depression and ptsd related symptoms in spouse and close relatives of burn survivors: when the supporter needs to be supported.	No intervention, symptoms measured	Yes	No, caregivers of adult burn survivors	Quant	burn survivors, burn, burns, family	1	No intervention and wrong population
599	1	academic search complete	Barnett et al.	2017	qualitative analysis of a psychological supportive counselling group for burn survivors and families in malawi	Yes, support group	Yes	Yes, caregivers of child burn survivors	Qualitative	therapy, burn, support, burn survivors, caregivers, counselor, family, help	1	
603	1	PsychArticles	Egberts et al	2017	Parents post traumatic stress after burns in their school aged child: a prospective study	No intervention, symptoms and impact of trauma measured	Yes	Yes	Quant	parent's, burn, parents, support	1	No intervention
624	1	academic search complete	Chernoff & Cueva	2017	The role of alaska's tribal health workers in supporting families	No	yes	no	qual	support, families, parent, program	1	No appropriate intervention or population
648	1	academic search complete	Stiles	2018	Emergency management of burns : part 1	No, highlighting criteria and process of referral for burns patients	Possible	Burns patients	Article	burn, burns, families, management, support	1	No intervention or measurement - only article

6 4 9	1	CINAHL	Ozdemir & Saritas	2018 Is the quality of life of turkish burn patients family affected during acute care?	no, measuring factors affecting qol	yes	families of burn survivors		burn, family	1	no intervention
6 5 0	1	CINAHL	Zens et al.	2018 A pediatric burn outpatient short stay program decreases patient length stay with equivalent burn outcomes	No, medical intervention - short stay medical treatment	Possible	No, paediatric burn patients	Quant	burn, burns, program, management, family	1	Medical intervention for inorrect population
6 5 1	1	academic search complete	Paul et al	2018 Initial assessment, treatment and follow-up of minor pediatric burn wounds in four patients remotely: a preliminary communication	No, telemedicine intervention (medical)	No	No, paediatric burn patients	Pilot study	burn, management, burns, helps, families	1	Medical intervention for inorrect population
6 5 9	1	academic search complete	Chuang et al	2018 The burn rehabilitation center post-Formosa Fun Coast Dust Explosion Disaster - A pilot report from Chang-Gung memorial hospital - Taoyuan in Taiwan.	yes, multidisciplinary intervention	possibly	no, burn patients and families	??	victims, burn, burn survivors, family	1	No specific intervention
6 7 5	1	Health Source: Nursing	Dinesh et al.	2018 Our Inner-city Children Inflicted With Burns: A Retrospective Analysis of Pediatric Burn Admissions at Harlem Hospital, NY.	No intervention, merely reported on identifying data	No	Yes	Retrospective study	burns, management, caregiver, parents, family	1	Not an intervention study

6 8 2	1	medline	Yenikomshian et al	2019	Evaluation of Burn Rounds Using Telemedicine: Perspectives from Patients, Families, and Burn Center Staff.	No, telemedicine intervention (medical)	no	families of burn patients	quantitative	burn, families, support, burns therapy	1	inappropriate medical intervention
6 8 6	1	CINAHL	Parrish et al.	2019	Parent Distress Following Pediatric Burn Injuries	no, prevalence of parent distress	yes	yes, parents of child burn survivors	quantitative	burn, caregivers, parents	1	no intervention
6 9 5	1	academic search complete	Armstrong-James et al.	2019	Using Photo-Elicitation to Explore Families' Experiences of Burn Camp.	Yes, photo elicitation intervention through burn camp	Yes	Yes, Families of child burn survivors	Qualitative - thematic analysis	Family, burn, families, parent, support, burns	1	
6 9 9	1	academic search complete	Kornhaber et al.	2019	Burn care and rehabilitation in Australia: health professionals' perspectives.	Yes burn care and rehabilitation	Unsure	Broad population		Burn, burns, families, support	1	not intervention study - perspective of health care workers
7 0 7	1	Health Source: Nursing	No name	2019	The Role of Social Work in U.S. Burn Centers	No, identified role of social workers	no	no, social workers working with burned patients	quant	burn, families, counselling, therapy, program	1	no intervention assessed
7 1 1	1	Health Source: Nursing	No name	2019	Brief Motivational Interviewing Increases Participation in the Take Charge of Burn Pain Self-Management Program	Yes, motivational interviewing	yes	No, adult burn survivors	quant	burn, management, program, intervention	1	inappropriate population
7 3 8	1	Health Source: Nursing	Backstrom et al.	2019	Identifying the Needs of Family Members in Burn Care-Nurses' Different Approaches	Yes, nursing approaches to support families in hospital to assess family needs	Yes	Yes, Families of child burn survivors	Explorative with qualitative design	Burn, family, support, burn survivors,	1	

7 5 1	1	academic search complete	Heath et al.	2019	Supporting children with burns: Developing a UK parent-informed website to support families of burn-injured children	Yes, Burn specific peer informed supportive website to psycho-ed	yes, to empower, self-care, support	Parents of child burn survivors	PAR	Burn, help, parents, support, interventions, help	1	
7 6 1	1	medline	Brown et al	2019	Impact of Parental Acute Psychological Distress on Young Child Pain-Related Behavior Through Differences in Parenting Behavior During Pediatric Burn Wound Care.	No intervention, only measures parent behaviour as mediator for burns child recovery	Yes	Yes	Mediation analysis	burn, parents, support	1	Not intervention study
	117										15	102



SCOPUS title and abstract screening													
NR	Title include abstract screening	Database	Author	Yr	Title	Aim: Type of intervention appropriate (acute/ post discharge psychosocial intervention) :	Outcome of study (psychosocial wellbeing)	Target population (Families child burn survivors)	Type study	Key words (abstract)	I n c l	E x c l	Reason exclude from full reading
2	1	scopus	Manktelow	1990	Burn injury and management in Liberia	no intervention	no	no, adult burn patients	review	burn, management, caregivers		1	wrong pop , no intervention, review study
9	1	scopus	Bauman & James	1990	A support group for burn victims and their families	yes, support group	yes	families of child and adult burn survivors	case study	support, burn victims, families, burn	1		
19		scopus	Summers	1991	psychosocial support of the burned patient	copy							
32		scopus	Gorden , Hancock	1993	reducing pediatric burn pain with parent participation	copy							
44		scopus	Molter	1993	When is the burn injury healed? Psychosocial implications for care	copy							
51		scopus	Rizzone et al	1994	PTSD in mothers of children and adolescents with burns	copy							
52		scopus	Gordon & Doctor	1994	parent participation during painful would care procedures	copy							
59		scopus	Doctor	1994	parent participation during painful would care procedures	copy							
85		scopus	Jenkins et al	1996	A randomized single-blind evaluation of a discharge teaching book for pediatric patients with burns	copy							



86		scopus	watkins et al	1996 Postburn psychologic adaptation of family members of patients with burns	copy								
87		scopus	Bryant & Touyz	1996 the role of the clinical psychologist on a burn unit in general teaching hospital	copy								
88		scopus	Cronin et al.	1996 a 1 year prospective study of burns in an irish paediatric burns unit	copy								
91		scopus	Foertsch et al	1996 psychosocial forum parent participation during burn debridement in relation to behaviour distress	copy								
112	1	scopus	Kendall-Grove et al	1998 Rates of dysfunction in parents of pediatric patients with urns	no intervention, looks at dysfunction of family	yes	yes	quant	family, parents, burn, interventions	1	no intervention		
115	1	scopus	Chan et al.	1998 Parental perception of the adequacy of pain control in their child after discharge from emergency department	no intervention, assessed parents management ability without intervention	no	yes	quant	burn, parent, management	1	no intervention		
160	1	scopus	Thornton & Battistel	2001 Working with burns survivors: a social work approach	Yes, social work intervention and support group suggestions	yes	Unsure, possible adult burn patients and families	article discussion	burn, families, management, support	1	Not intervention - only suggestions		
168		scopus	Gilboa	2001 Long term psychosocial adjustment after burn injury	copy								
170		scopus	Konigova	2001 Quality of life in burn victims a holistic approach	copy								
176	1	scopus	Purdue et al	2002 Pediatric Burn care	no, management pitfalls in burns care	no	no	quant	burns, families, management, caregivers	1	no intervention, wrong pop		



177		scopus	Helvig	2002	Managing thermal injuries within WOCN practice.	copy								
179		scopus	Bradford	2002	Life in recovery; rebuilding from trauma	copy								
181		scopus	Rochet	2002	Burns rehabilitation	copy								
196		scopus	Tyack and Ziviani	2003	what influences the functional outcome of children at 6 months post-burn?	copy								
212	1	scopus	Dogra	2004	Initial management of burns	no intervention, discussion about management considerations	no	yes	discussion	burns, management, victim, family		1	no intervention	
226		scopus	zengerle-levy	2004	Practices that facilitate critically burned childrens holistic healing	copy								
236		scopus	Saxe et al	2005	Pathways to ptsd, part 1 children with burns	copy								
239		scopus	Dyregrov	2005	experiences of social networks supporting traumatically bereaved	copy								
242		scopus	zengerle-levy	2006	The inextricable link in caring for families of critically burned children	copy								
249		scopus	Hall et al	2006	PTS symptoms in parents of children with acute burns	copy								
252		scopus	El Hamaoui	2006	Depression in mothers of burned children	copy								
255	1	scopus	Tanaka et al	2006	Management of burn scars and scare contracture in pediatric patients with long term follow-up	no, medical management of burn	no	no	survey	management, burns, victims, families		1	no intervention	

264		scopus	Bond, Burns	2006 Mothers beliefs about knowledge, child development and parenting strategies: expanding the goals of parenting programs	copy								
276		scopus	Van Niekerk et al	2007 Caregiver experiences, contextualisations, and understanding of the burn injury to their child. Accounts from low income South Africa.	copy								
279		scopus	Phillips et al.	2007 Considerations for psychosocial support following burn injury - a family perspective	copy								
282	1	scopus	Satapathy & Walia	2007 A home-based disaster psychosocial intervention programme: case study of a school fire disaster victim in India	Yes, psycho- ed to parents (but also play therapy to child)	Yes	No child burn survivor	case study	burn, therapy, intervention program, parents, program,	1	wrong population group		
284		scopus	Ewings, Pollack	2008 Pediatric upper extremity burns: outcomes of emergency department triage and outpatient management.	copy								
295		scopus	Philips, Rumsey	2008 Considerations for the of psychosocial services for families following paediatric burn injury - a quantitative study	copy								
304		scopus	Rea et al.	2008 Use of the internet by burn patients, their families and friends.	copy								

308	1	scopus	Kassira & Namias	2008	Outpatient management of psychiatric burns	No, medical intervention	no	No, paediatric burn patients	??	burns, management, family, help	1	Medical intervention and wrong pop
435	1	scopus	Lloyed et al	2012	Outpatient burns : prevention and care	no, medical intervention burns	no	no	discussion	burns, help, family	1	Medical intervention wrong pop
437		scopus	Tompkins et al.	2012	The American Burn Association/Schriener hospital for children burn outcomes program: a progress report at 15 years.	copy						
452		scopus	Graham et al.	2012	Are parents in the UK equipped to provide adequate burns first aid?	copy						
463		scopus	Bakker et al	2012	Acute Stress reactions in couples after a burn event to their young child.	copy						
480		scopus	Ravindran et al	2013	Embracing survival: a grounded theory study of parenting children who have sustained burns.	copy						
481		scopus	Backstrom et al	2013	Prediction of psychological symptoms in family members of patients with burns 1 year after injury	copy						
505		scopus	McGarry et al	2013	Paediatric medical trauma: The impact on parents of burn survivors.	copy						
511		scopus	Bakker et al	2013	Course of traumatic stress reactions in couples after burn event to their young child.	copy						

515		scopus	Oster et al	2014	Parent's perception of adaptation and family life after burn injuries in children.	copy							
521	1	scopus	Moi , Gjengedal	2014	The lived experience of relationships after major burn injury	no intervention, exploring impact relationships	no	no	phenomological study	burns, family, support, programme		1	no intervention, wrong pop
522		scopus	Gullick et al	2014	The trauma bubble: patient and family experience in serious burn injury	copy							
528		scopus	Kramer, Landolt	2014	Early psychological intervention in accidentally injured children aged 2-16 : a randomized control trial.	copy							
598		scopus	Cubitt	2015	Evaluating an outreach service for paediatric burns follow up	copy							
601	1	scopus	Jennings, Cullen, Mark, Jaeger	2015	Developing a pediatric burn treatment program in a community hospital	Yes	yes	No, paediatric burn patients	Article	burn, families, program		1	wrong population group
614		scopus	Willebrand & Sveen	2016	Perceived support in parents of children with burns	copy							
647		scopus	Johnson et al.	2016	Emerging from the trauma bubble: redefining normal after burn injury	copy							
668		scopus	Tropez et al	2017	The psychological impact of first burn camp in Nicaragua	copy							
684	1	scopus	Koohi, Bagheri-Nesami, Esmaeili, Mousavinasa b	2017	Effect of family participation in primary care provision to reduce pain anxiety among burn ICU patients	Yes	yes	No, intervention targeted at child burn survivor	Quant	support, family, burn, intervention		1	Intervention for child survivor - using parents

687		scopus	Barnett et al	2017 qualitative analysis of a psychological supportive counselling group for burn survivors and families in malawi	copy							
688		scopus	Sveen et al	2017 Internet based information and support program for parents of children with burns: a randomized controlled trial.	copy							
689		scopus	Egberts et al	2017 Parents post traumatic stress after burns in their school aged child: a prospective study								
692	1	scopus	Bond et al	2017 Anxiety, depression and PTSD related symptoms in spouses and close relatives of burn survivors: When the supporter needs to be supported	No intervention, symptoms measured	Yes	No, caregivers of adult burn survivors	Quant	burn survivors, burn, burns, family		1	No intervention and wrong population
698	1	scopus	Chirongoma, Chengetanai, Tadyanemhandu	2017 First aid practices, beliefs, and sources of information among caregiver regarding paediatric burn injuries in Harare, Zimbabwe: A cross sectional study	No intervention, only assessed first aid measures	no	yes	cross sectional study	caregivers, burns, burn management		1	No intervention
731	1	scopus	Capek et al.	2018 Fifteen years of burn care at shriners hospital for children, Galveston	no, discussion of hospital work	no	no	discussion	burn, families, intervention		1	no intervention for family
732	1	scopus	Griese, Burns, Farro	2018 Pathfinders: promoting healthy adjustment in bereaved children and families	No, trauma and grief intervention - not specifically burns survivors	yes	no		program, family		1	Incorrect intervention and population

734	1	scopus	Andrews, Jones, Moeieman, Calvert, Kinghorn, Litchfield, Bishop, Deeks, Mathers	2018 Below the surface: Parent's views on the factors that influence treatment adherence in paediatric burn scare management: a qualitative study	No, views patients views on burn scare management	No	yes	qualitative	parents, burn, management	1	No intervention
740	1	scopus	Egberts, de Jong, Hofland, Geenen, Van Loey	2018 Parental presence or absence during paediatric burn would care procedures	No intervention, parent's experience explored	Yes	Yes	qual	burn, parents', parents, support	1	No intervention
767		scopus	Parrish et al	2019 Parent Distress Following Pediatric Burn Injuries	copy						
768	1	scopus	Suurmond et al	2019 Psychological distress in ethnic minority parents of preschool children with burns	no intervention, explored impact on parents	yes	yes	quant	burns, parents, support, help, family's	1	no intervention
769		scopus	Backstrom et al	2019 Identifying the Needs of Family Members in Burn Care-Nurses' Different Approaches	copy						
776		scopus	Yenikomshian et al	2019 Evaluation of Burn Rounds Using Telemedicine: Perspectives from Patients, Families, and Burn Center Staff.	copy						
793		scopus	Armstrong	2019 Using Photo-Elicitation to Explore Families' Experiences of Burn Camp.	copy						
797	1	scopus	Dos Santos et al	2019 Anxiety, coping, and significant social network of the caregiver of a child with burns	No, measures coping strategies	yes	Yes, Caregiver of child burn victim	Qualitative	caregiver, burns, victim, support, family	1	Not intervention study

819		scopus	Heath et al	Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children	copy									
823	1	scopus	Kim & Ban	2019 Rebuilding life after burn injuries in Korea: Using photovoice	Yes	yes	no, adult burn patients	?	burn, survivors, support, family		1	inappropriate population group		
										23			1	22





## APPENDIX B:

Full article screening – inclusion and exclusion						
Title	Author	Year	Include	Exclude	Reason excluding	Appraise article
1. When is the burn injury healed? Psychosocial implications of burn care	Molter	1993	No	Yes	Conceptual paper– actual intervention not explored or evaluated	No
2. Postburn psychologic adaptation of family members of patient with burns	Watkins et al.	1996	No	Yes	Conceptual study unpacking stages of burns intervention	No
3. The role of the Clinical Psychologist on a burn unit in a general hospital	Bryant and Toyz	1996	No	Yes	No intervention – impact of burns during various phases unpacked	No
4. Electrical Burn injuries	Docking	1999	No	Yes	No intervention – exploration of management needs	No
5. Managing thermal injuries within WOCN practice	Helvig	2002	No	Yes	Medical management of burns	No
6. The inextricable link in caring for families of critically burned children	Zengerly-Levy	2006	No	Yes	Conceptual paper	No
7. Support groups facilitated by families of former patients – creating family inclusive critical care units	Sacco et al.	2009	No	Yes	Intervention aimed at trauma in general. Too broad and not specific to population criteria.	No
8. Identifying the needs of family members in burn care – nurses' different approaches.	Backstrom et al.	2019	No	Yes	Intervention aimed at parents, but nurses are primary population in this study	No

9. Reducing paediatric burn pain with parent participation	George and Hancock	1993	yes	No	N/A	Yes
10. A randomized single blind evaluation of a discharge teaching book for paediatric patients with burns.	Jenkins et al.	1996	Yes	No	N/A	Yes
11. Collaboration between Hospital social work and pastoral care to help families cope with serious illness and grief.	Hart and Mantorin	1997	Yes	No	N/A	Yes
12. Internet based information and support program for parents of children with burns: a randomized controlled trial	Sveen et al.	2017	Yes	No	N/A	Yes
13. Qualitative analysis of a psychological support group for burn survivors and families in Malawi	Barnett et al.	2017	Yes	No	N/A	Yes
14. Using photo elicitation to explore families' experiences of a burn camp	Armstrong-James et al.	2019	Yes	No	N/A	Yes
15. Supporting children with burns: developing a UK parent focused peer informed website to support families of burn-injured children	Heath et al.	2019	Yes	No	N/A	Yes
16. A support group for burn victims and their families	Bauman and James	1990	No	Yes	Includes adult burns patients. Percentage of adult patients unclear in comparison to child patients and family members.	No

					NOTE: include in discussion – relevant points regarding intervention	
<b>Reference mining article via Barnett et al., 2017</b>						
17. A Support group for parents of burned children : A South African Children’s Hospital Burns Unit.	Frenkel	2007	Yes	No	N/A	Yes
Total articles included for appraisal	8					
Total articles excluded for appraisal:	9					



## APPENDIX C:

### Reviewer 1 critical appraisal

Review Area	Key Question	Article 1	Article 2	Article 3	Article 4	Article 5	Article 6	Article 7	Article 8
<b>1. Study overview</b>									
Details	Author, title, source, year	George and Hancock (1993) Reducing paediatric burn pain with parent participation. Journal of burn care and rehabilitation. Source: CINAHL	Jenkins, Blank, Miller, Turner and Stanwick (1996) A randomized Single blind evaluation of a discharge teaching book for Pediatric patients with burns. Journal of burn care and rehabilitation. Source: CINAHL	Hart and Mantorin (1997) Collaboration between hospital social work and pastoral care to help families cope with serious illness and grief. Journal: Psychiatric Services Source: CINAHL	Frenkel (2007). A support group for parents of burned children: A South African Children's hospital Burns Unit. Journal: Burns. Source: Barnett et al. (2017) - Article found through Reference mining	Sveen et al (2017): Internet-based information and support program for parents of children with burns: A randomized controlled trial.	Barnett, Mulenga, Kiser, Charles (2016). Qualitative analysis of a psychological supportive counselling group for burn survivors and families in Malawi. Journal: Burns Source: Academic Search Complete	Armstrong-James (2019). Using photo elicitation to explore families' experience of burn camps. Unpublished Source: Academic Search Complete	Heath, Williams on, Williams and Harcourt (2019). Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children Source: Academic Search Complete
Purpose	Aim/s of study mentioned?	Yes, describing and evaluating the development and implementation of parent participation program in burns unit in Hospital for sick children in Toronto, Canada.	Yes	Yes, a case vignette illustrating the effectiveness of a hospital program training hospital chaplains based on pastoral care and social work intervention strategies for families	Yes, description of support groups for families of paediatric burns	Yes, aimed evaluating feasibility and effect of internet-based self-help group for parents of burned children (focus PTSD symptoms)	Yes, to provide an account of support group for burn survivors and caregivers in Sub-Saharan Africa	Yes, Explore family member's experiences of a specialized 3 day family burn camp	Yes, a Participatory Action Approach with parents and professionals to determine the acceptability of a website for parents/caregivers of burn-injured children

				who experience grief (family of a child burn survivor)					
Key findings	Are key findings mentioned?	Yes	Yes	Yes	Yes, evaluation of group services given	Yes, decrease in PTSD symptoms and informative and meaningful and learnt skills valued	Yes, themes of psychological growth, development of relationships useful, benefit of returning to a "community" where could share thoughts openly	Yes, Parents identified peer support as beneficial—normalized experience and emotions, helped to let go of guilt feelings. Additionally, assisted in developing start of parent/carer group to assist in coping with healthcare needs.	Yes, website considered to be highly acceptable and accessible psychosocial intervention
Evaluative summary	Are strengths/weaknesses of study mentioned?	Yes	No	N/E	Yes Disadvantage: Service was interrupted due to calendar, not funded by hospital and is not secured.	Yes: <i>Strength:</i> Nationwide inclusion of children with burns <i>Limitations:</i> Wide inclusion criteria, no initial screening to assess elevated symptoms, low amount of family conflict with stable social and economic circumsta	Yes, Limitation only: Short time frame, small sample size, non-audio recorded, financial restraints	Yes, Only included families of children up to 14 years of age. Participants were first time campers. No knowledge of how families previously functioned prior to camp.	Yes, Strength: PAA empowered participants and assisted in development of an acceptable resource.  Limitations: Participants were self-selected, little ethnic diversity and not representative of

						nces, relatively small sample and high attrition rate			UK paediatric burn patients. Suggesting possible social desirability
	Are the limitations of the study discussed?	No	Yes	No	No	Yes	Yes, Small sample size and short time frame of intervention.	Yes, Only included families of children up to 14 years of age. Participants were first time campers. No knowledge of how families previously functioned prior to camp.	Yes
<b>2. Literature Review</b>								Yes	
	Literature review provided?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
	Uses seminal and most recent studies?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
<b>3. Study, setting, sample and ethics</b>									
Type of study	Type of study mentioned?	Yes	Yes	Yes, a case vignette	Yes, case report	Yes, randomized control trial with a 6 w intervention group, a waiting list control group and pre and post assessment	Yes, Exploratory Qualitative Study	Yes, qualitative study using photo elicitation	Yes
Study setting	Setting mentioned?	Yes	Yes	No	Yes, Child Guidance	Yes	Yes, KCH hospital	Yes	No

					e Clinic at UCT				
Sample	Sample and population specified?	Yes	Yes	Yes	Yes, mothers, aunts, sisters, older siblings, sometimes father (age not specified)	Yes, sample: parents of all consecutively admitted children (under 18 years) at Uppsala and Linköping Burn Centre, Sweden	Yes, Population: 102 burn patients Sample: Children (12+) and parents of child burn survivors (total of 18)	Yes, Population: Families of South West Children's Burn's Service Centre in England. Sample: Families (parents and child burn survivors aged 2-14)	Yes, sample: parents of all consecutively admitted children (under 18 years) at Uppsala and Linköping Burn Centre, Sweden
	Is the sample appropriate for the study aim/s?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
<b>4. Ethics</b>	Was ethics committee approval obtained?	No	No	No	No	Yes, approved by Regional Ethics Review Board in Uppsala, Sweden	N/E	Yes, by the first author's research ethic committee.	Yes, approved by Regional Ethics Review Board in Uppsala, Sweden
	Was informed consent obtained?	Yes	Yes	No	No	Yes	Yes	Yes	Yes
	Have ethics issues been appropriately addressed?	Yes	Yes	No	No	NE	N/E	Yes	N/E
<b>5. Data Collection</b>									
Appropriateness of data collection method	Was data collection method appropriate for study aim/s?	Yes	Yes	N/E	No	Yes	Yes	Yes	Yes
Data Collection process	Is data collection process adequately described (range of questions, length of interview or administration of questionnaire)?	No	Yes	N/E	No	Yes	No	Yes	Yes
Reflexivity/validity	Is reflexivity/validity discussed/addressed?	No	Yes	N/E	No	NE	N/E	Yes	No



<b>6. Data Analysis</b>									
	Data analysis mentioned and adequately described?	No	Yes	N/E	NO	Yes	Yes	Yes	Yes
	Is adequate evidence provided to support results/findings ? (raw data, iterative analysis.	No	Yes	N/E	No	Yes	No	Yes	Yes
	Findings interpreted within context of other studies and theory?	Yes	Yes	Yes	No	Yes, iCBT interventions in treating PTSD	Yes	Yes	Yes, iCBT interventions in treating PTSD
	Are sources of bias in methodology discussed?	No	Yes	N/E	No	NE	No	No	N/E
	Is the potential impact of diverse contexts on the relevance of the findings discussed?	No	Yes	No	No	No	No	No	No
<b>7. Policy and practice implications</b>									
	Are conclusions justified given context of study?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Are the implications for interventions discussed?	No	Yes	Yes, that pastoral care can assist in decreasing stress experienced by families and improves communication between family and staff members.	Yes	Yes, program had a beneficial effect on pts symptoms. Perceived by parents as informative, meaningful and valued skills learnt. Program has potential role in reducing stress in parents of children with burns.	N/E	Yes	N/E

	Are implications for policy and practice discussed?	No	No	Yes, suggested that this intervention can assist in decreasing length of hospital stay and improve communication between family and staff	Yes	Yes, easily accessible, cost-effective and could be implemented in burn care rehabilitation	No	Yes	Yes, easily accessible, cost-effective and could be implemented in burn care rehabilitation
	Are recommendations given for future research/interventions?	Yes	Yes	No	No	Yes, further evaluation needed for prevention of symptoms in parents of children with more recent burns, or parents with clinically significant psychological symptoms.	Yes	Yes	Yes, evident in limitation discussion
<b>Included (Y/N)</b>									
<b>Total score:</b>		15/25	22/25	8/25	12/25	20/25	16/25	23/25	19/25
<b>Average %</b>		60%	88%	32%	48%	80%	64%	92%	76%
<b>Weak (&lt;40%) Moderate (41%-60%) Strong (61%-80%) Excellent (&gt;80%)</b>		Moderate	strong	Weak	Moderate	Excellent	Strong	Excellent	Strong

## APPENDIX D:

### Reviewer 2 Critical Appraisal

Review Area	Key Question	Article 1	Article 2	Article 3	Article 4	Article 5	Article 6	Article 7	Article 8
<b>1. Study overview</b>									
Details	Author, title, source, year	Jenkins, Blank, Miller, Turner and Stanwick; A randomized single-blind evaluation of a discharge teaching book for paediatric patients with burns; Journal of Burn Care and Rehabilitation; 1996	Hart and Matrimon; Collaboration Between Hospital Social Work and Pastoral Care to Help Families Cope With Serious Illness and Grief; PSYCHIATRIC SERVICES ; 1997	George and Hancock; Reducing Pediatric Burn Pain with Parent Participation; Journal of Burn Care and Rehabilitation; 1993	Armstrong-James, Cadogan, Williamson, Ramsey, Harcourt; Using photo-elicitation to explore families' experiences of burn camp; SOURCE ; 2018	Sveen, Internet-based information and support program for parents of children with burns: A randomized controlled trial, 2017	Frenkel, A support group for parents of burned children : A South African Children's Hospital Burns Unit, 2008	Heath, j. et al., Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children, 2019	Barnett, BS et al., Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi, 2017
Purpose	Aim/s of study mentioned?	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Key findings	Are key findings mentioned?	Yes	No	Yes	Yes	Yes	No	Yes	Yes
Evaluative summary	Are strengths/weaknesses of study mentioned?	No	No	No	No	Yes	No	Yes	No
	Are the limitations of the study discussed?	No	No	Yes	No	No	No	No	No
<b>2. Literature Review</b>									
	Literature review provided?	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
	Uses seminal and most recent studies?	Yes	NE	Yes	Yes	Yes	Yes	Yes	Yes
<b>3. Study, setting, sample and ethics</b>									
Type of study	Type of study mentioned?	Yes, A Randomized Single-Blind Evaluation	Yes, case study	Yes, Evaluation	Yes, A qualitative study using photo-elicitation	Yes	Yes	Yes	Yes
Study setting	Setting mentioned?	Yes	Yes	Yes	Yes	Yes	Yes	No (academic and charity sectors/internet)	Yes

								mediated – too vague)	
Sample	Sample and population specified?	Yes	Yes	No, authors do not specify the number of participants, nor do they explicitly state who evaluated the programme. They mention parents and surgeons when discussing results, but this is inadequate.	Yes	Yes	Yes	No (9 parents, 22 professionals)	Yes
	Is the sample appropriate for the study aim/s?	Yes	No, one case is insufficient	NE	Yes	Yes	Yes	NE	Yes
<b>4. Ethics</b>	Was ethics committee approval obtained?	NE	NE	NE	Yes	Yes	NE	Yes	Yes
	Was informed consent obtained?	Yes	NE	NE	Yes	Yes	No (For the intervention but not study)	Yes	Yes
	Have ethics issues been appropriately addressed?	No	No	No	No	Yes	No (For the intervention but not study)	Yes	Yes
<b>5. Data Collection</b>									
Appropriateness of data collection method	Was data collection method appropriate for study aim/s?	Yes	NE	Yes	Yes	Yes	NE	Yes	Yes
Data Collection process	Is data collection process adequately described (range of questions, length of interview or administration of questionnaire)?	Yes	No, questions were not provided, nor length of interviews etc.	No	Yes	Yes	No	Yes	Yes
Reflexivity/validity	Is reflexivity/validity	Yes	Yes	No	Yes	No	No (For the	No	No

	ty discussed/addressed?						intervention but not study)		
<b>6. Data Analysis</b>									
	Data analysis mentioned and adequately described?	Yes	No	No	Yes, thematic analysis	Yes	No	Yes	Yes
	Is adequate evidence provided to support results/findings? (raw data, iterative analysis.	Yes	No	No	Yes	Yes	Yes	Yes	Yes
	Findings interpreted within context of other studies and theory?	Yes	No	Yes	No	Yes	Yes	Yes	Yes
	Are sources of bias in methodology discussed?	Yes	No	No	No	NE	NE	Yes	No
	Is the potential impact of diverse contexts on the relevance of the findings discussed?	Yes	Yes		No	Yes	Yes	Yes	Yes
<b>7. Policy and practice implications</b>									
	Are conclusions justified given context of study?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Are the implications for interventions discussed?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Are implications for policy and practice discussed?	Yes – practice, not policy	Yes	Yes	No	No	No	No	Yes
	Are recommendations given for future research/interventions?	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
<b>Included (Y/N)</b>									
<b>Total score:</b>		21/25	9/25	13/25	18/25	21/25	12/25	19/25	21/25
<b>Average %</b>		84%	36%	52%	72%	84%	48%	76%	84%
<b>Weak (&lt;40%) Moderate (41%-60%) Strong (61%-80%) Excellent (&gt;80%)</b>		Excellent	Weak	Moderate	Strong	Excellent	Moderate	Strong	Excellent

## APPENDIX E

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	
----------------------	----	---	--

