A Qualitative Meta-synthesis of the Caregiving Experiences of Family Caregivers for Children with Terminal Illness

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Content

Part 01

Introduction

Background

The incidence of childhood cancer has been increasing year by year since the 1960s (Ye et al.,2019). However, with the progress of medical technology, many sick children can prolong their life time with the help of medical technology (Yu et al., 2016). In cases where the child's death is expected, the sick child is usually treated with palliative care for a period of time until the end of life (Kars, 2009). However, in children's palliative care, children at the end of life cannot be cared for at home or receive professional care in hospital without the participation of the children's parents (Pousset, 2010; Alisha, 2013).

Aim

By systematically integrating and analyzing the chosen qualitative studies ,we aim to understand the caregiving experiences of parents for children with terminal illness. and thereby provide essential information for health social workers to better their services.

Part 02

Research Methods

Methods

Qualitative Meta-synthesis

Qualitative Meta-synthesis can explore the care experience in the field of health (Martin, 2016), so as to have a more comprehensive understanding of the care experience of parents of sick children at different stages of their children's diseases.

Search Strategy

The Database

- Web of Science
- PubMed
- Embase
- CNKI
- WANFANG DATA

Keywords

- Pediatric care
- Hospice care for children
- Children Are at End of Life
- family
- qualitative

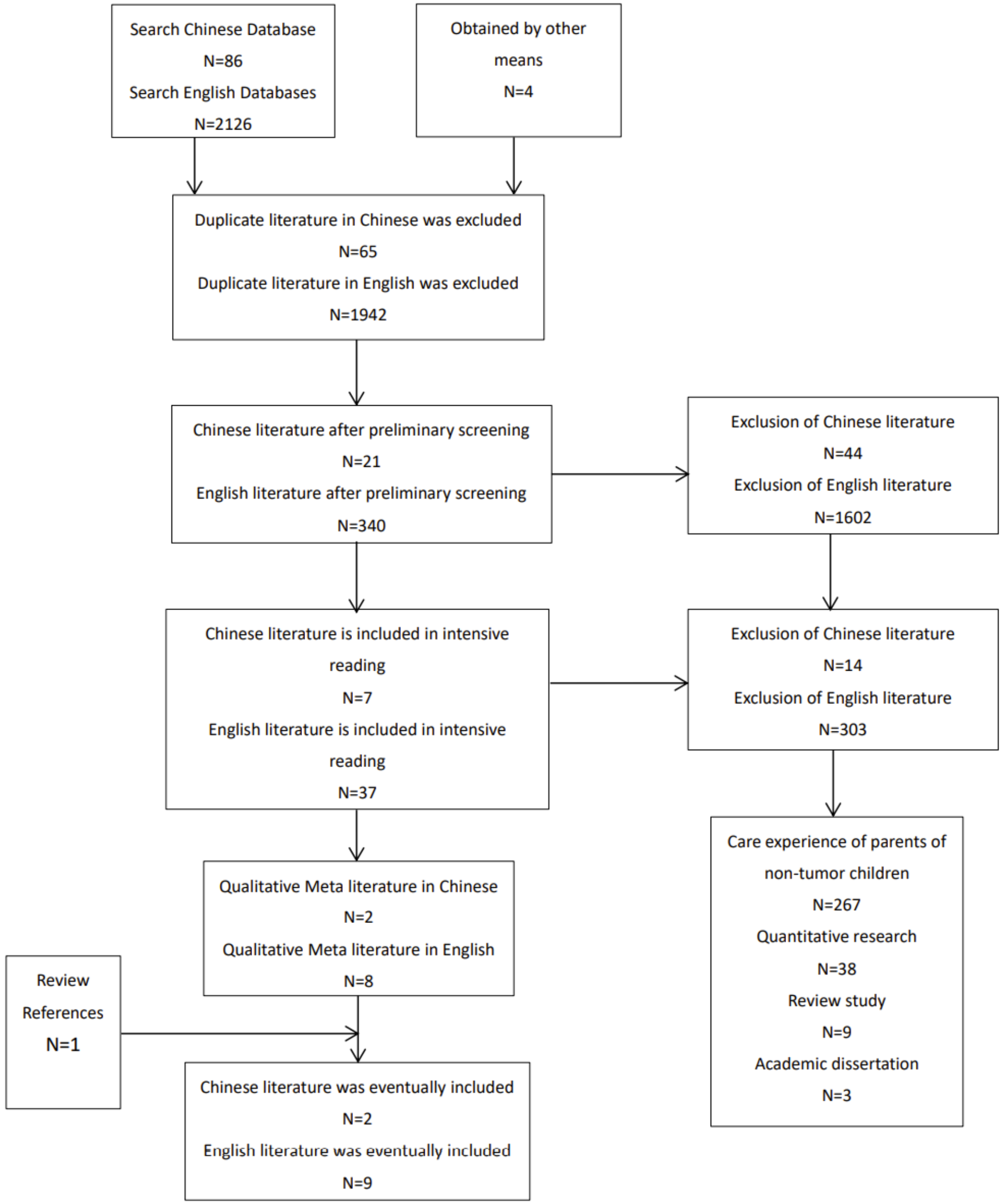
Inclusion and exclusion criteria

1.Literature in English or Chinese;
2.Qualitative or hybrid methods involving qualitative research;
3.A child diagnosed with a terminal illness;
4.The study subjects were children's parents;

1.Literature not in Chinese or English;
2.Full text or incomplete data cannot be obtained;
3.Not using qualitative research methods or using inappropriate literature;
4.Master's thesis。

Selection process

- Literature published between the establishment of the database and January 1, 2021 was searched;
- A researcher initially screened the literature by reading titles, abstracts, and conclusions;
- A researcher peruses the screened literature to select the literature to be included in the study;
- The researchers in this study disagreed about the literature, and third-party professionals coordinated it.


Search Chinese Database
N=86
Search English Databases
N=2126

Obtained by other means
N=4

Duplicate literature in Chinese was excluded
N=65
Duplicate literature in English was excluded
N=1942

Chinese literature after preliminary screening
N=21
English literature after preliminary screening
N=340

Exclusion of Chinese literature
N=44
Exclusion of English literature
N=1602

Chinese literature is included in intensive reading
N=7
English literature is included in intensive reading
N=37

Exclusion of Chinese literature
N=14
Exclusion of English literature
N=303

Care experience of parents of non-tumor children
N=267
Quantitative research
N=38
Review study
N=9
Academic dissertation
N=3

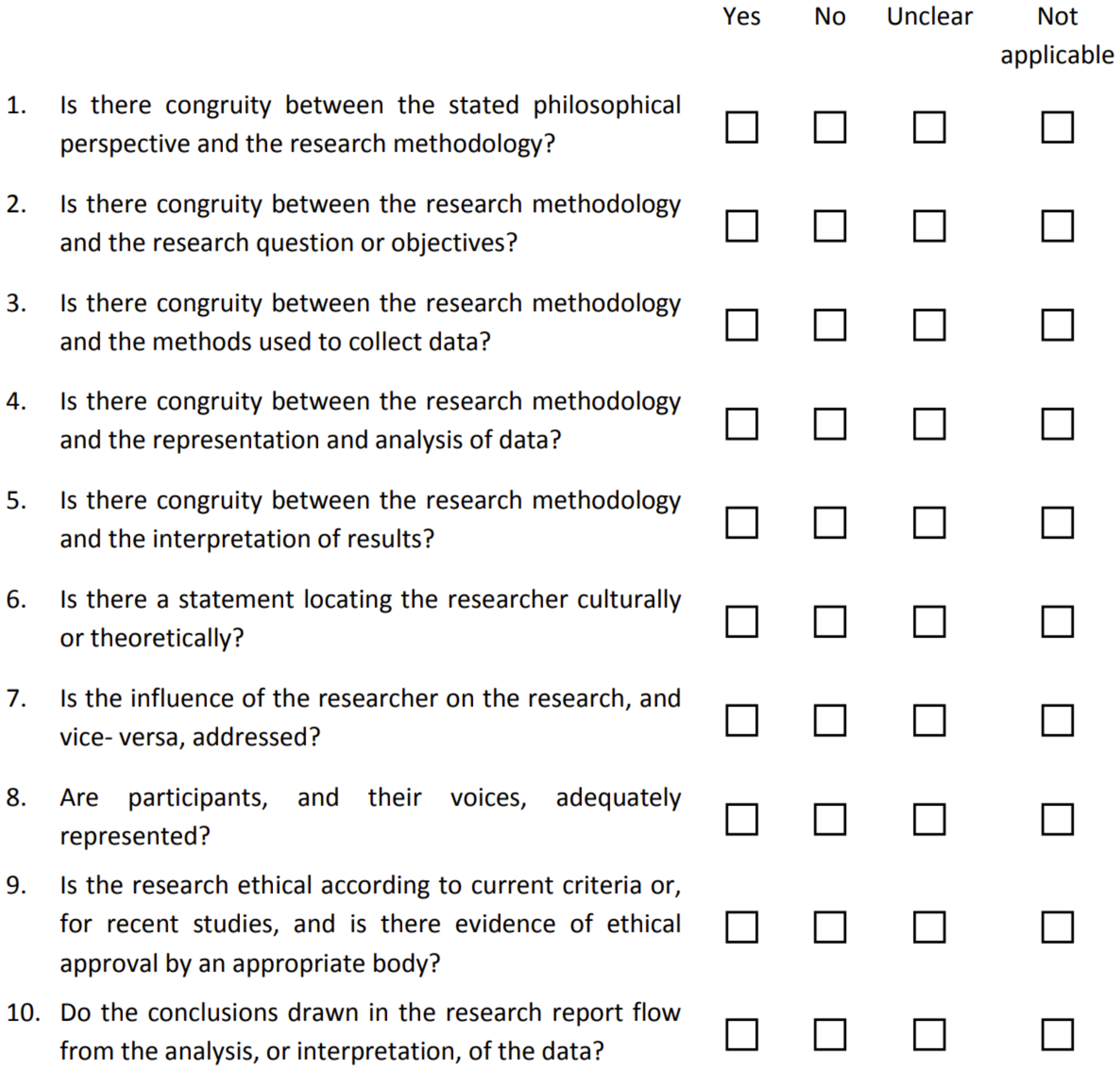
Qualitative Meta literature in Chinese
N=2
Qualitative Meta literature in English
N=8

Review References
N=1

Chinese literature was eventually included
N=2
English literature was eventually included
N=9

Selection process

Systematic Reviews Checklist for Qualitative Research is an evaluation tool. Each literature answers 10 questions with "Yes, No, Unclear, Not applicable". The affirmative answer is 1 point, and 8-10 is rated as grade A; 5-7 is graded as B; 0-4 is grade C. Grade A is directly included with low risk, Grade C is directly excluded with high risk, and Grade B is also directly excluded with high risk. The inclusion or not is decided by the two authors after consultation.



	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Part 03

Results

Characteristics of the included studies

Author	Aims	Data collection method	Characteristics
Jiao et al., 2019	To explore the humanistic care experience and needs of parents of children with acute leukemia for PICC maintenance, and to provide reference for the formulation of targeted nursing measures.	Semi-structured interview	15 parents
Zengjie et al., 2017	The purpose of this study is to explore the psychological resilience in the care process of parents after the onset of children's disease (malignant tumor), as well as the connotation and characteristics of psychological resilience.	Semi-structured interview	78 parents
Maha et al., 2017	To explore mothers' decision-making experiences in palliative care for children from the perspective of mothers in Jordan.	Participatory observation, Semi-structured interview	24 parents
Lisa et al., 2016	Explore parents' life experiences and learn about their experiences of caring for a child with a life-affecting illness.	Open interview	47 parents
De Vos et al., 2015	Exploring how doctors and parents communicate these decisions when withdrawing life-sustaining treatment after a child becomes ill.	Participatory observation, interview	37 parents

Characteristics of the included studies

Author	Aims	Data collection method	Characteristics
Jane et al., 2015	Explore whether parents want to make decisions for their children at the end of life.	Semi-structured interview	25parents
Gaab et al., 2013	Explore how primary caregivers communicate their illness and impending death to children with a life-affecting illness.	Semi-structured interview	21parents
Kari et al., 2011	Explore the religious, spiritual, or philosophical experiences of parents with children at risk.	Interview	73 parents
Marijke et al., 2011	This study explores the process that parents go through when their child cannot be cured from a parent's perspective.	Open interview	44 parents
Shayna et al., 2010	To explore the end-of-life experience of children with brain tumor and their families.	Semi-structured interview Focus groups	25 parents
Leanne et al., 2008	The purpose of this study was to explore parents' knowledge of palliative care of children who had died of cancer and their experience of receiving palliative and supportive care during their child's illness.	Open interview	24 parents

Quality assessment results

Research	Q1	Q2	Q3	Q4	Q5	A6	A7	A8	A9	A10	Quality
Maha et al, 2017	Un clear	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	B
De Vos et al, 2015	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	B
Erin et al, 2013	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	B
Jane et al, 2015	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	B
Lisa et al, 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	A
Kari et al, 2011	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	A
Marijke et al, 2011	No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	B
Leanne et al, 2008	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	B
Shayna et al, 2010	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	B
Zengjie et al, 2017	Un clear	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	B
Jiao et al, 2019	Un clear	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	B

Meta-synthesis results

- Themes
  - Care challenge
  - care incentives
  - Experience in negotiation
  - parents' coping strategies

Meta-synthesis results

Pre-treatment	care challenges	Initial shock and disbelief Escape from the fact Learn about your child's illness Sudden financial burden
	care incentives	Be a "good parent" The hope of a cure God's will
	Experience in negotiating	Self game Consult with your family
	parents' coping strategies	For treatment Give up treatment

Meta-synthesis results

Middle treatment	care challenges	Accept the fact that your child is sick Get used to life Learn about disease and nursing Continued economic pressures
	care incentives	Don't want to lose Avoid sadness and guilt Self responsibility
	Experience in negotiating	Talk with kids Consult with your doctor
	parents' coping strategies	Family opinion The doctor in charge

Meta-synthesis results

Post-treatment	care challenges	How to say goodbye to your child The departure of a child Find new hope Ethical guidelines
	care incentives	Accompany children to the end Say goodbye to your children Ask for agency help
	Experience in negotiating	Refused to reality Have no choice but to
	parents' coping strategies	Live in the present and be positive How to say goodbye to your child

Part 04

Discuss

Discuss

1.Parental caregivers have different experiences of caring for their children at different stages of treatment.

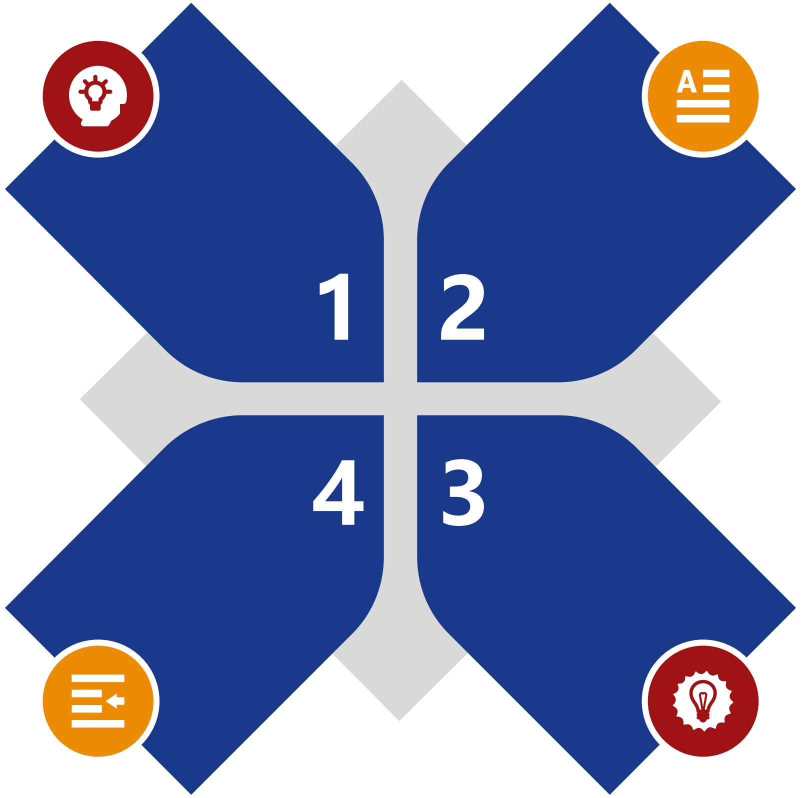
2.The parent caregiver becomes the "expert" of the child's disease.

3.Culture influences parents' experience of care.

Part 05

Conclusion

Conclusion



1

Understanding the different treatment stages of children is conducive to providing accurate services to patients and their families。

2

Taking into account their positive experiences in the process of providing support can help them better cope with the challenges they face.

3

Focus on Parent Focus: Child centered knowledge and skill learning needs.

4

The cultural strengths of parents in caring for their children, such as religious trust and a sense of responsibility, should also be taken into account by those involved.

Thank you for listening!