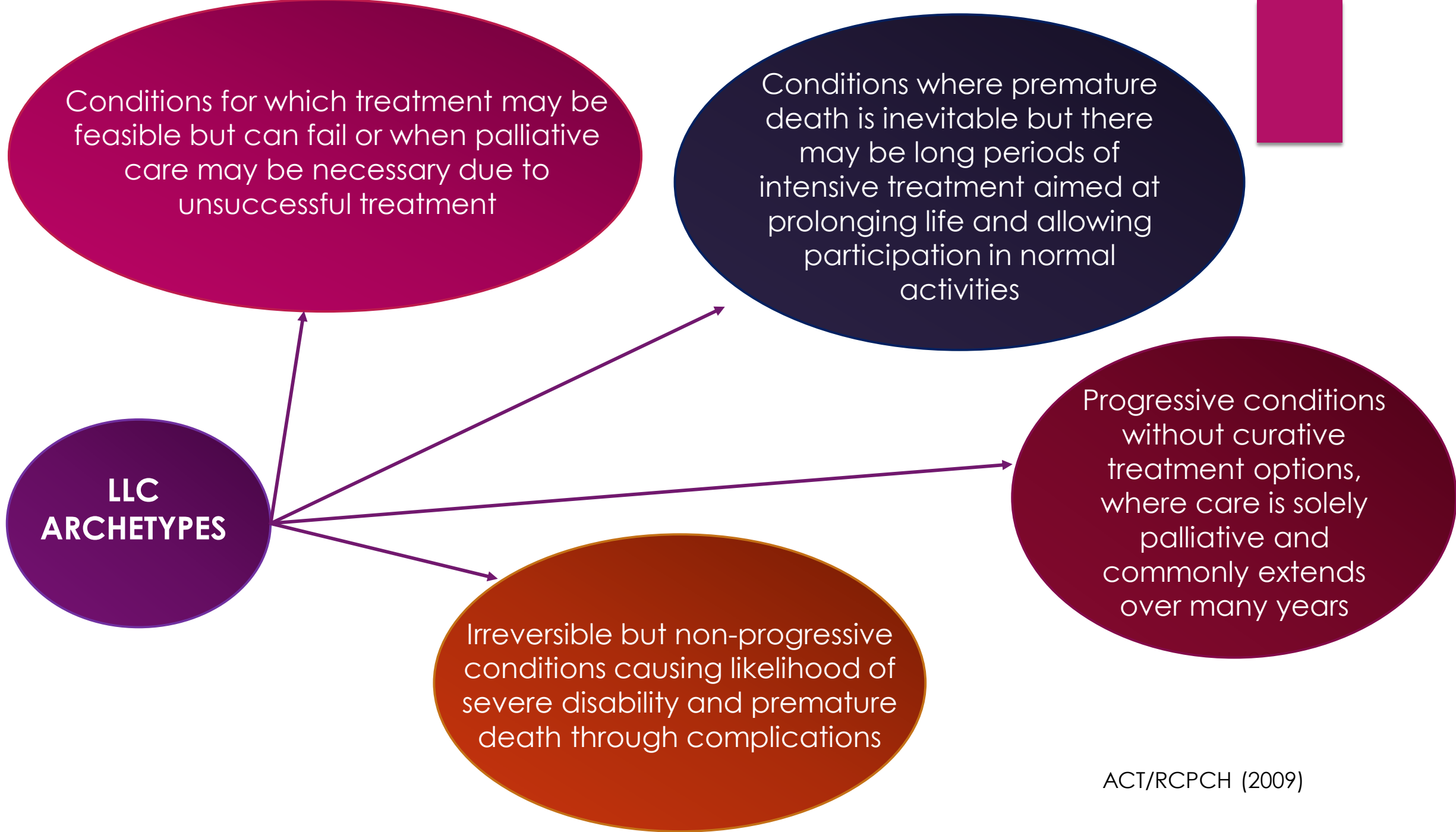# A meta-ethnography of parents' experiences of their children's life-limiting conditions

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ACT/RCPCH (2009)

Study aims & Method

i) To provide an in-depth assembly of the current state of knowledge around parents' experiences of their children's LLC

ii) To understand the impact of healthcare services on parents' experiences

iii) To contribute to the development of methods for IPA research synthesis

▶ Meta-ethnography is an interpretive form of knowledge synthesis, proposed by Noblit and Hare (1988) that aims to develop new conceptual or 'metaphorical' understandings.

Search strategy

-Four electronic databases: PubMed, PsycINFO, CINAHL and Science Direct

-Studies up until September 2017

-Search terms available from the InterTASC Information Specialists' Sub-Group (ISSG) Search Filter Resource (were used to develop the search syntax

-Hand searches of articles cited in reference lists and from relevant review papers

Study selection

-The archetypes set out in the ACT/RCPCH (2009) and the directory of LLCs developed by Hain et al. (2013)

-IPA studies exploring parents' experiences of their children's LLCs

-Full text papers published in peer-reviewed journals

-Studies that explored parents' experiences before and after the child's death were included if findings had been reported separately

-Only data relating to parents' experiences of illness while the child was alive were extracted (e.g. Reilly et al. 2008; Popejoy 2015)

► Followed by data screening, extraction and quality appraisal

Analysis

(1) getting started
(2) deciding what is relevant
(3) reading the studies
(4) determining how studies are related to each other
(5) translating studies into each other
(6) synthesising translations
(7) expressing the synthesis
             (Noblit and Hare, 1988)

Results

Titles of 910 papers were screened; 17 papers met the inclusion criteria

-12 studies in the UK
-1 study in Sweden
-1 study in different countries of Europe
-2 studies in Canada
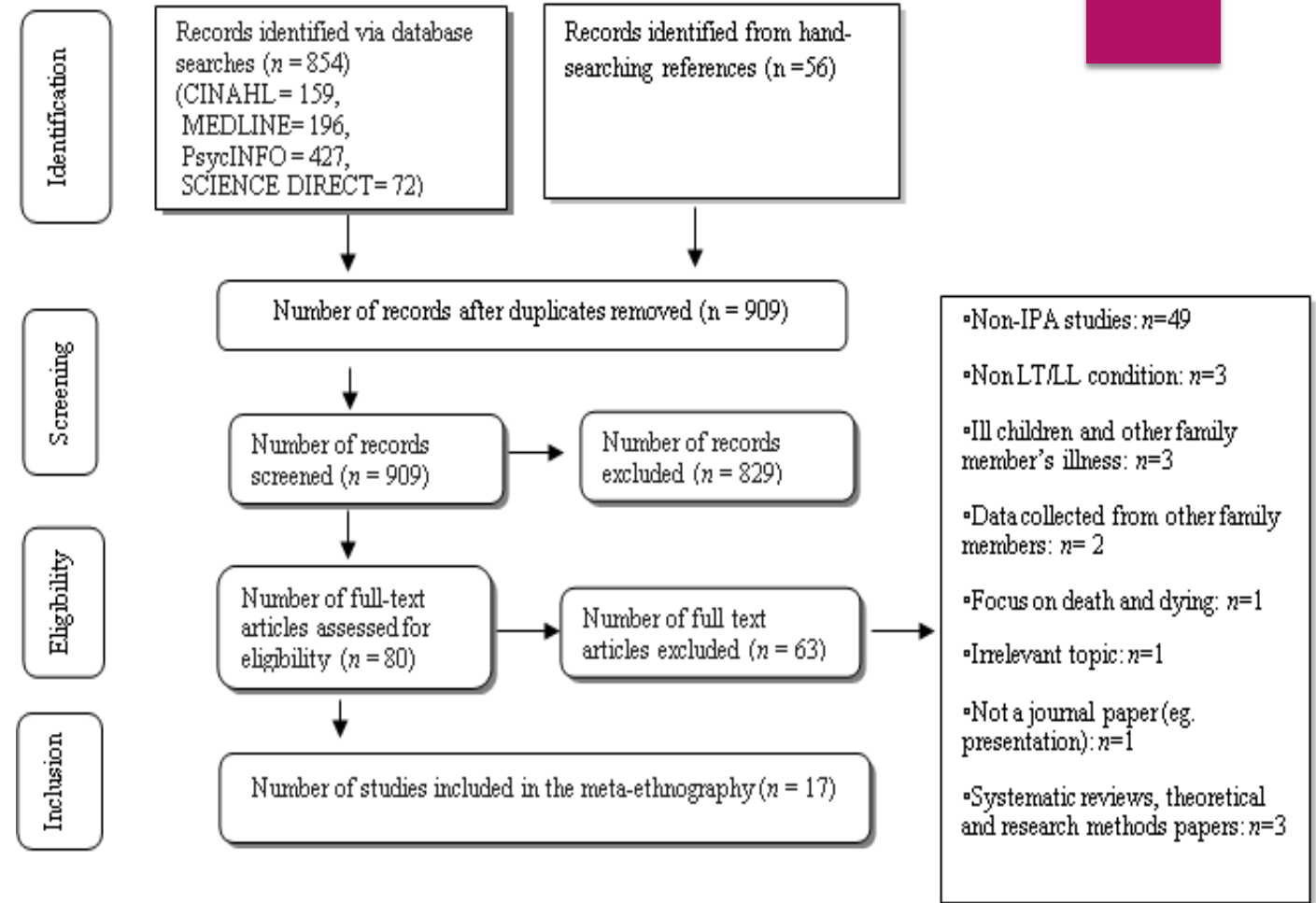-1 study in Australia

Results

Figure 1: PRISMA flow diagram summarizing the study selection stages

Characteristics of included studies

-235 parents were interviewed
-semi-structured interviews in all studies
-both parents interviewed in 10 studies
-mothers interviewed in 6 studies
-fathers only in 1 study

Children's LLCs:

- acute liver failure (Wright 2017)

- fetal alcohol spectrum disorders (Whitehurst et al. 2011; Coons et al. 2016a; Coons et al. 2016b)

- anorexia nervosa (Bezance et al. 2014; Thomson et al. 2014)

- cancer (Hannan et al. 2005; Schweitzer et al. 2012)

- stroke (Jones et al. 2012)

- cystic fibrosis (Glasscoe et al. 2008; Glasscoe et al. 2011)

- Juvenile Huntington's disease (Brewer et al. 2007; Eatough et al. 2013)

- coeliac disease (Cederborg et al. 2011)

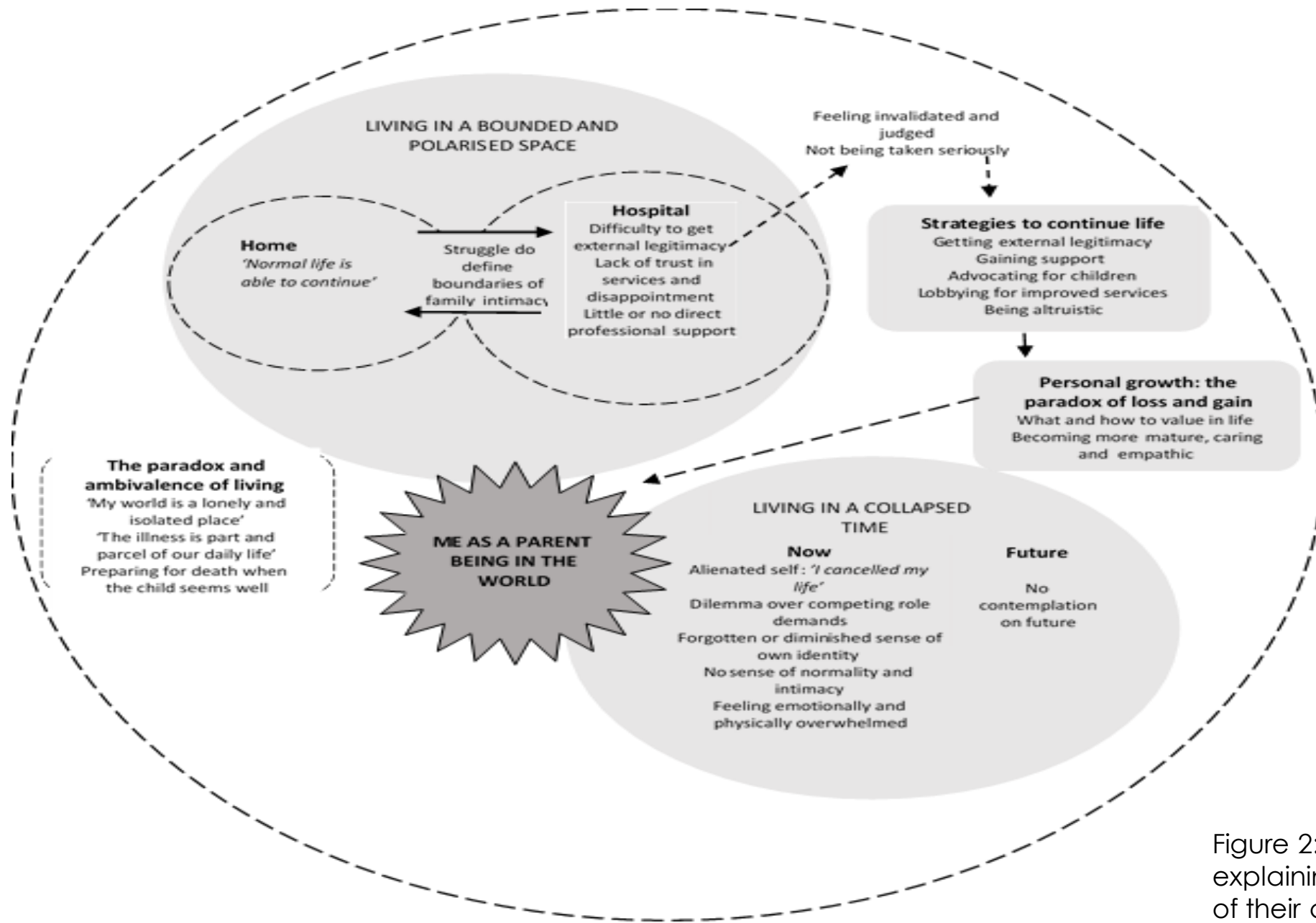- other conditions generally named LLCs (Ware et al. 2007; Popejoy, 2015)

LIVING IN A BOUNDED AND POLARISED SPACE

Home
'Normal life is able to continue'

Struggle do define boundaries of family intimacy

Hospital
Difficulty to get external legitimacy
Lack of trust in services and disappointment
Little or no direct professional support

Feeling invalidated and judged
Not being taken seriously

Strategies to continue life
Getting external legitimacy
Gaining support
Advocating for children
Lobbying for improved services
Being altruistic

Personal growth: the paradox of loss and gain
What and how to value in life
Becoming more mature, caring and empathic

The paradox and ambivalence of living
'My world is a lonely and isolated place'
'The illness is part and parcel of our daily life'
Preparing for death when the child seems well

ME AS A PARENT BEING IN THE WORLD

LIVING IN A COLLAPSED TIME

Now
Alienated self : 'I cancelled my life'
Dilemma over competing role demands
Forgotten or diminished sense of own identity
No sense of normality and intimacy
Feeling emotionally and physically overwhelmed

Future
No contemplation on future

Figure 2: Conceptual model explaining parents' experiences of their children's LLCs

Key concept 1:
Living in a bounded and polarised space

Feeling less independent, due to polarised needs for privacy

(Hannan et al. 2005; Brewer et al. 2007; Jones et al. 2012)

Parents' difficulty to get external legitimacy

- Their role in the care process being questioned (Brewer et al. 2007)
- Their concerns not being taken seriously (Cederborg et al. 2011; Bezance et al. 2014)
- Disapproving of how their situation was contained by primary care professionals (Thomson et al. 2014)
- Assuming authorship of the child's plan for future (Glasscoe et al. 2011)

You can't ignore the parent and the parent's feelings. They have to realize how powerless you are. That actually you don't necessarily want that power to be taken, to be further eroded. (Brewer et al. 2007)

Key concept 1:
Living in a bounded and polarised space

Parents' expectations regarding care not being fully met

- Lack of trust in services and disappointment (Ware et al. 2007; Thomson et al. 2014; Reilly et al. 2008; Hannan et al. 2005; Eatough et al. 2013; Coons et al. 2016b)
- Parents' need of trust in the care team (Glasscoe et al. 2011)
- Poor communication across services (Ware et al. 2007; Reilly et al. 2008)

> *No one was meeting me in that conversation (…) And because that, because I was finding difficulties in having that conversation with professionals I was feeling I couldn't really have it with my friends or family.* (Reilly et al. 2008)

- Parents' avoidance of conflict (Thomson et al. 2014)

Key concept 1:
Living in a bounded and polarised space

Parents' expectations regarding care not being fully met

- Delayed advice (Brewer et al. 2007)
- Struggle to access the right help (Bezance et al. 2014)
- The need of night-time respite and concerns around out-of-hours support (Hannan et al. 2005)
- Lack of provision from professionals that understood the diagnosis (Whitehurst et al. 2011)
- Bureaucracy, rare opportunities to discuss the diagnosis and its implications after the initial shock and insufficient support or follow-up following diagnosis (Ware et al. 2007)
- Fathers not being given equal opportunities to meet the healthcare team (Ware et al. 2007)

Key concept 1:
Living in a bounded and polarised space

Parents' strategies to continue life

- Getting external legitimacy (Glasscoe et al. 2011; Popejoy 2015; Thomson et al. 2014; Schweitzer et al. 2012; Reilly et al. 2008)
- Gaining support (Wright 2017; Ware et al. 2007; Reilly et al. 2008; Hannan et al. 2005; Eatough et al. 2013; Schweitzer et al. 2012)
- Advocating for children and lobbying for improved services (Ware et al. 2007; Glasscoe et al. 2008; Coons et al. 2016a)
- Being altruistic (Schweitzer et al. 2012; Ware et al. 2007)

Key concept 1:
Living in a bounded and polarised space

Parents' personal growth

- What and how to value in life (Ware et al. 2007; Popejoy 2015)
- Becoming more mature, caring and positive (Reilly et al. 2008; Thomson et al. 2014; Coons et al. 2016a)
- A new sense of what happiness meant (Schweitzer et al. 2012)

Key concept 2:
Living in a collapsed time

- Alienated self (Eatough et al. 2008; Glasscoe et al. 2008; Ware et al. 2007)
- Dilemma over competing role demands (Glasscoe et al. 2011)
- Forgotten or diminished sense of own identity (Bezance et al. 2014; Wright 2017; Ware et al. 2007; Whitehurst et al. 2011)
- No sense of normality and intimacy (Bezance et al. 2014; Ware et al. 2007; Brewer et al. 2007)
- Feeling emotionally and physically overwhelmed (Bezance et al. 2014; Wright 2017; Whitehurst et al. 2011; Ware et al. 2007; Thomson et al. 2014; Glasscoe et al. 2008; Eatough et al. 2013; Popejoy 2015; Jones et al. 2012; Schweitzer et al. 2012)
- No contemplation on future (Eatough et al. 2013)
- The paradox and ambivalence of living (Bezance et al. 2014; Ware et al. 2007; Thomson et al. 2014; Eatough et al. 2013; Glasscoe et al. 2008; 2011; Schweitzer et al. 2012; Cederborg et al. 2011; Popejoy 2015; Jones et al. 2012; Reilly et al. 2008)

Limitations and strengths

Strengths and limitations of the literature

-Only one study reported on fathers (Ware et al. 2007)

-Coons et al. 2016 reported on different family members, all referred to as parents

-Lack of cultural diversity (14 out of 17 studies were published in Europe -12 in the UK)

-No parents from minority ethnic communities

Strengths and limitations of the meta-ethnography

-English language a selection criterion; more than 50% of included studies were published in the UK

-Only nine LLCs were examined

-Potential recall bias due to children's age: (fetal alcohol spectrum disorder: 1-37 years, Coons et al. 2016a, b; stroke: 27-46 years, Jones et al. 2012; Juvenile Huntington's disease: 9-24 years, Eatough et al. 2013)

-A pragmatic approach required

Implications for practice

- Some parents accessed external support or furthered their education to understand the medical language and diagnosis.

   (i) YouGov survey (2016): almost 55% of cancer carers in the UK do not receive any support at all.

   (ii) A need for a multi-agency and collaborative approach to provide education and training in order to improve parents and clinicians' experience of care (ACT/RCPCH 2009).

   (iii) Potential areas of intervention: parent-healthcare provider communication, collaborative treatment and care decisions, family intimacy, validation as 'good parent', support to plan goals for future, and gender equality in support provision for parents.

Implications for practice

- Carers need to be cared for and interventions should fit with the philosophy and values of their family (Brewer et al. 2007).

- Palliative care should include services for carers who experience mental illness relating to their roles, mainly those who feel isolated or stigmatised.

- Equal opportunities for both parents to meet the healthcare team (Ware et al. 2007).

- End-of-life care discussions should take place prior to a life-threatening episode, as decisions at critical times are difficult and are influenced by emotions (Popejoy 2015).

The need for future research

- Currently the majority of studies including parents of children with LLCs have been descriptive(Heinze et al. 2012).

  (i) Expanding IPA applicability in more diverse racial, ethnic, socioeconomic, and geographic healthcare contexts

  (ii) Broader LLCs framework

Source: Postavaru, G. (2018). A meta-ethnography of parents' experiences of their children's life-limiting conditions. Special Issue for *Qualitative Research in Psychology* (forthcoming)