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# Being cross pressured-parents' experiences of the transfer from paediatric to adult care services for their young people with long term conditions: A systematic review and qualitative research synthesis

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ABSTRACT

*Background:* Family members of young people (13–24 years) with long-term conditions tend to experience multiple challenges when their children transfer from paediatric to adult care, as do the patients themselves.
*Objectives:* To identify, interpret and theoretically conceptualise the meaning of parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions.
*Design:* A qualitative research synthesis.
*Data sources:* We obtained articles from Medline, CINAHL, PsycINFO, EMBASE, Scopus, and Web of Science. Unpublished theses and dissertations were searched for using Google Scholar, Mednar, and ProQuest Dissertations and Theses.
*Review methods:* Based on a previously published protocol, we followed the guidelines from the Joanna Briggs Institute. Sandelowski and Barroso's qualitative research synthesis approach guided the metasynthesis. Articles published between 1999 and March 2019 were systematically searched for.
*Findings:* Twenty-three reports from seven Western countries representing 454 parents including significant others such as aunts and grandparents of 462 young people with various diagnoses contributed to the review. 'Being cross-pressured' was the metasynthesis found to reflect parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions. The metasynthesis comprised four themes: 'Fluctuating between parental roles', 'Navigating contrasting healthcare contexts', 'Making decisions in the face of inner conflict', and 'Trusting their child's self-management ability'.
*Conclusions:* Our metasynthesis finding of parents' experiences of being cross-pressured provides a new way of thinking about the study phenomena which is supported by transitions theory holding that multiple transitions can take place simultaneously involving myriads of concurrent and conflicting demands. The cross pressure may overwhelm parents. The clinical implications are to recognise parents' experiences and distress in healthcare planning to promote safe and predicable transfers of their young people. Provision of healthcare to parents during transfer needs to be tailored to a collaborative decision-making process between parents, their young people, and involved practitioners across paediatric and adult healthcare services.

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Tweetable abstract: Parents experienced being cross-pressured when their young people with long-term conditions were transferred from paediatric to adult care.

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**What is already known about the topic?**

- Parents of young people with long-term conditions have serious concerns about their children's future during their transfer from paediatric to adult care.
- Knowledge about how to theoretically conceptualise parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions is sparse.

**What this paper adds**

- This systematic review and metasynthesis establishes the theoretical foundation for the concept of being cross-pressured which defines the experience of parents of young people with long-term conditions who are transferred from paediatric to adult care.
- This systematic review demonstrates how parents' experiences can be understood and interpreted in a theoretical context.
- We recommend that in planning the healthcare transfer of young people with long-term conditions, healthcare providers should acknowledge parents' experiences of being cross-pressured and support them during the transfer to help them experience a smooth transition.

## 1. Background

Parenting a child with a long-term condition as he/she transitions to adulthood has been described as a complex life situation evoking deep parental concern about the child's future (Heath et al., 2017; Waldboth et al., 2016). Advances in medical technology are helping children with long-term conditions reach adulthood (Beacham and Deatrick, 2013). Both the young adults and their family members may experience multiple challenges with repercussions and health risks for the whole family (Waldboth et al., 2016). Thus, a substantial number of parents are involved in their children's lives and the management of their long-term condition through adolescence and into adulthood. Parents are important figures in their young people's lives, and parents assume responsibility helping their young people with long-term conditions cope with the challenges that accompany their transition to adulthood.

Long-term conditions among young people is a growing global public health concern. Around 10% of all adolescents suffer from a long-term condition (Miller et al., 2016; Perrin et al., 2014; Suris et al., 2004). Living with a long-term condition during adolescence is especially demanding because of the additional developmental changes both physical (puberty, brain changes, growth, and sexual maturation), cognitive (thinking and reasoning, self and identity), and social (relationships with family, peers, and friends) (Coleman, 2011).

The influence of family, especially of parents, on the development of young people is important in relation to their quality of life (Heath et al., 2017; Soulis and Andreou, 2007). In the beginning of adolescence, parents continue to manage their children's long-term conditions (Kovacs and McCrindle, 2014), and the young people rely on their parents to manage their care, such as scheduling appointments and maintaining communication with healthcare providers (van Staa et al., 2011). Even when the young people have successfully transitioned to independence in managing their long-term condition, some regularly continue to consult their parents about their care and/or they continue living with their parents (Bemrich-Stolz et al., 2011). It has been observed that after young people's transition to adult healthcare, their routine outpatient healthcare utilisation tends to decline (Blinder et al., 2013) and an increase is seen in hospital admissions and emergency room visits (Brousseau et al., 2010; Dickerson et al., 2012). This may indicate that even after their transition to adulthood, young people find the experience of handling their long-term condition challenging. They still need their parents for support, comfort, reassurance, feedback, and guidance while growing up and becoming independent (Hanna and Guthrie, 2001; McNeilly et al., 2015).

Parents are concerned about their children's transfer from paediatric to adult care (Kovacs and McCrindle, 2014); they also worry about their children's ability to speak for themselves, manage their disease, and receive care in their transition to adulthood (Heath et al., 2017). Parents might be ambivalent about the transfer and reluctant to let go of their children (Eccleston et al., 2012; Kloep and Hendry, 2010; Vijayan et al., 2009).

During adolescence, the parent-adolescent relationship changes towards the adolescent becoming more autonomous and taking more responsibility (Heath et al., 2017; Magill-Evans et al., 2005). Additionally, the parental role is changing regarding monitoring and supervision, in setting limits and boundaries, and in regulating homework and free time (Coleman, 2011; Heath et al., 2017). Most parents believe that their adolescents will self-manage their care following transfer (Sawicki et al., 2014), and they seem concerned about whether they will become less involved in the care following the transfer (Rao et al., 2012). Besides, parents strive to find a balance between letting go and maintaining some control (Waldboth et al., 2016; Yamaguchi and Suzuki, 2015). These changes may lead to decreased parental self-confidence, increased anxiety, and less helpful parenting (Allen et al., 2011; Coleman, 2011).

Recent years have seen a growing research interest in understanding the transfer from paediatric to adult healthcare and the young people's transition (Coyne et al., 2012; Sattoe et al., 2017; Schultz and Smaldone, 2017). In a systematic review of the parental role during young people's transition to adulthood and adult healthcare, Heath et al. (2017) found that children's development towards adulthood was an incremental process that required parents adjusting their role in helping their child manage increased responsibility and self-care. Heath and colleagues conducted a systematic review and thematic synthesis of a broad range of studies (Heath et al., 2017); for example, they included studies on parental interactions with medical records (Østerlund et al., 2005) and self-management (Schilling et al., 2006). Our research interest is narrower and focuses exclusively on parents' experiences when their young people are transferred from paediatric to adult healthcare. Despite the wealth of research and numerous recommendations for improving transfer and transition of young people (Everitt et al., 2017; Okumura and Kleinhenz, 2016; Schultz and Smaldone, 2017), gaining an understanding of the transition process from paediatric to adult care from parents' perspective remains challenging. As no firm conclusions could be drawn about the robustness of the evaluated evidence, the overall strength of the synthesised body of evidence from a recent Cochrane review is low (Campbell et al., 2016). While nurse scholars agree that the adolescent-to-adult transition

is worthy of continued attention, research on the phenomenon has been largely focused on recommendations for healthcare providers with limited consideration of the perspectives of young people and parents who endure the transitions.

In a nursing transitions theory perspective (Meleis et al., 2000), each change in health initiates a transition process with critical events that have to be overcome; they may provide opportunities for enhanced health, growth, and well-being as well as introduce new roles and routines but may also carry risks of instituting an unhealthy transition process with clinging to former roles and routines, unrealistic expectations, and unnecessary discontinuity. Seen in this context, parents of young people with long-term conditions undergo multiple and simultaneous transitions while having their own experiences and concerns during their children's transfer and transition from paediatric to adult care. The purpose of this qualitative research synthesis study was to systematically review and synthesise qualitative findings from international studies to better understand parents' experiences of the event, that is, the transfer of their young people with long-term conditions from paediatric- to adult-oriented healthcare services. This understanding would allow us useful insight into parents' transition experiences during this event.

The research questions were, "What does the literature document about parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions?" and "How can parents' transition experiences be interpreted in a theoretical context?"

## 2. Methods

### 2.1. Design

The study involved a comprehensive systematic review of relevant qualitative literature from around the world and a qualitative research synthesis of the data from studies meeting our inclusion criteria. Based on *a priori* criteria, this review builds on a previously published protocol (Ludvigsen et al., 2014). To ensure a rigorous review process, we followed the guidelines from the Joanna Briggs Institute (Joanna Briggs Institute, 2014) and Sandelowski and Barroso's (2007) qualitative research synthesis approach. To ensure a thorough search process, an information specialist assisted in designing the comprehensive systematic search. The principles underlying the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework for data retrieval were adopted in terms of identification, screening, eligibility, and inclusion (Moher et al., 2009). From a phenomenological hermeneutic stance (Ricoeur, 1976), Lindseth and Norberg's (2004) modification of the interpretation theory guided the synthesis process in terms of data extraction, analysis, and interpretation. This design allowed us to incorporate our pre-understandings of young people's transfer and use literature of transitions theory (Meleis, 2010) to obtain a shared understanding of the phenomenon of interest. We immersed ourselves in the text in an attempt, as far as possible, to "enter the world" represented in these texts using Lindseth and Norberg's three-step analytical technique to ascribe meaning to the phenomenon of parents' experiences.

### 2.2. The review

We used a specialised framework, called PICo, to form the specific research questions and facilitate the literature search. PICo stands for Population (P), Phenomenon of Interest (I), and Context (Co) (Joanna Briggs Institute, 2014). The aim of the searches was to identify reports illuminating parents' (P) experiences of young people's transfer (I) from paediatric to adult care (Co).

Eligible for inclusion were qualitative studies focusing on (1) parents of adolescents aged 13–18 years and young adults aged 19–24 years living with a long-term condition, and (2) how the parents experience and manage their children's transfer from paediatric to adult care. Studies in English, German, Danish, Swedish, and Norwegian were considered, as these were the languages that the group collectively were able to read and understand. The time span of published reports from 1999 until 2019 was determined by our previous reviews exploring young people and healthcare providers' experiences (Fegran et al., 2014, 2016). For reasons of comparison, all three reviews follow the same year criterion of 1999.

Information sources were the databases Medline [PubMed], CINAHL [EBSCO], PsycINFO [Ovid], EMBASE [Ovid], and Web of Science. Unpublished theses and dissertations were searched for using Google Scholar, Mednar, and ProQuest Dissertations and Theses. Journal reports published in Danish, Swedish, and Norwegian, and relevant to this systematic review, are all indexed in the above-mentioned databases. The last updated search was performed in March 2019.

A stepwise search strategy was developed. First, an initial, limited search of Medline and CINAHL was undertaken using the following initial keywords: (Adolescent OR Teenager OR Young adult) AND Parent AND (Transition OR Transfer). This was followed by an analysis of the text words contained in titles and abstracts and of the index terms used to describe the articles. Second, a systematic search strategy was developed from identified keywords initially developed for Medline, including both a search using Medical Sub Headings and free text searches (Table 1). The search strategy was adjusted to the remaining databases. Third, the reference lists of the identified reports were searched for additional studies, and all identified reports were subject to citation searches in the databases CINAHL, Google Scholar, OVID SP (Nursing and Medline), Scopus, and Web of Science to reach an as complete as possible inclusion of studies.

After deleting duplicate reports, two reviewers (MSL and LF) independently screened the titles and abstracts for eligibility. Reports selected for retrieval were independently assessed (MSL, LF, and EH) for methodological quality prior to inclusion using the standardised Joanna Briggs Institute Qualitative Assessment and Review Instrument (Joanna Briggs Institute, 2014). This instrument (Hannes et al., 2010) is a tool that consists of ten questions (about rigour, considerations of the reflexive nature of qualitative research, and reflections on authors' relationship to the research setting) that are rated using a four-point Likert scale (yes, no, unclear, not applicable) (Ludvigsen et al., 2016). Disagreements between the reviewers were discussed among all authors until consensus was reached. One critical exclusion criterion was related to question eight of the QARI and concerned participants and their voices being adequately represented in the study. Adhering to Sandelowski and Barroso's (2007) advice, no report was excluded because of poor methodological quality as long as it provided data relevant for the study aim.

### 2.3. Analysis

Metasynthesis techniques were used to analyse and interpret the findings. All texts under the headings 'Results /Conclusions' were extracted electronically and entered into the computer software (NVivo version 11).

Following Sandelowski and Barroso's (2007) suggestion for metasummaries, we (MSL, LF, and EH) extracted the manifest data of the findings. In this process, study details such as author, culture, setting, publication year, aim, participants, methodology, method, and analysis were organised in tables to provide a general picture of study characteristics (Table 2).

**Table 1**
Full electronic search strategy for the Medline database.

| Database | Interface | Search string, including MeSH and free text words |
|---|---|---|
| Medline | PubMed | Search (((((((("Young Adult"[Mesh] OR "Pediatrics"[Mesh] OR "Adolescent"[Mesh])) AND "Chronic Disease"[Mesh]) AND "Patient discharge"[Mesh])) AND ((("Family"[Mesh] OR "Parents"[Mesh] OR "Single parent"[Mesh] OR "Mothers"[Mesh] OR "Fathers"[Mesh] OR "Single-Parent Family"[Mesh])) AND ("Attitude"[Mesh] OR "Comprehension"[Mesh] OR "Emotions"[Mesh] OR "Perception"[Mesh]))))) OR (((((relative* OR family OR families OR parent OR parents OR "single parent*" OR mother OR mothers OR father OR fathers OR "next of kin*" OR step-parent* OR "step parent*" OR stepparent* OR client*)) AND (experience* OR comprehension* OR attitude* OR emotion* OR view* OR opinion* OR perception* OR belie* OR feel* OR know* OR understanding* OR adaptation*))) AND ((((Adolescent* OR "young adult*" OR teenager* OR "young people" OR paediatric* OR paediatric* OR "young person*")) AND (Chronic* OR "chronic disease*" "condition*" OR "special health care need*" OR "long term illness*")) AND (Transition* OR transfer* OR discharge* OR "patient discharge*"))) Filters: Publication date from 1999/01/01 to 2014/12/31; Danish; English; German; Norwegian; Swedish. |

### 2.4. Metasynthesis

The NVivo software also assisted us (MSL, LF, and EH) in analysing and metasynthesising data. The first step in Lindseth and Norberg's (2004) three-step analytical technique was the naïve reading of findings across the included studies. This inductive analysis initiated a collective reading of the primary study findings and resulted in a preliminary thematisation. In the second step, the structural analysis of each study's findings (in light of the naïve reading) yielded several findings. We focused the data extraction on separating findings in the research reports' presentations of data coming from parents. In this part of the analytic process, we focused on presentations of data, quotations, incidents, stories, and case histories that researchers used to provide evidence for their findings, as proposed by Sandelowski and Barroso (2007). In addition, as suggested by Sandelowski and Barroso (2007), 'no data' text was extracted and coded. Then, where appropriate and meaningful, target findings concerning parental experiences of their young people's transfer were clustered into categories through an inductive analytical process that helped us develop the themes by reading across report findings and combining the categories. In this analytical step, we considered the study of Lindseth and Norberg (2004), in which they encourage the use of everyday talk or poetic and figurative language in the formulating process. In the third step, the critical comprehensive interpretation, the established themes were synthesised into a comprehensive whole. In this integrating process, we developed the final metasynthesis as an abstract integration of findings obtained via a synthesis of the *in vivo* themes and the imported concept (Sandelowski and Barosso (2007, p. 204) of cross-pressure borrowed from political science.

### 2.5. Effect sizes

The effect size statistical parameter was introduced in metasynthesis research by Sandelowski and Barroso (2003) and is used to illustrate different levels of understanding of a subject matter (Onwuegbuzie, 2003). We calculated the effect sizes that facilitated the transformation of the qualitative data, extracted more meaning from those data, and verified the presence of a pattern/theme. The effect sizes helped us avoid over- or underweighting findings in the metasynthesis.

## 3. Findings

As illustrated in Fig. 1, the systematic database searches identified 2215 reports, and 16 reports were identified 'through other sources', such as already known studies from previous reviews and email alerts from scientific journals. After removal of duplicates, 1276 unique reports remained; of these, 1248 were excluded based on title and abstract screening because they did not meet the inclusion criteria. The remaining 28 publications were assessed based on their full texts. The last updated search was performed during March 2019. Overall, 23 qualitative primary studies met the inclusion criteria and made up the data sources for the metasynthesis.

Table 2 specifies the characteristics of the included reports, representing 454 parents (including aunts and grandparents) of whom 258 were women, 58 were men, and 138 were unspecified. Only three articles were published between 1999 and 2005; another six articles were published between 2006 and 2012, and the remaining 14 articles were published between 2013 and 2018. This indicates a doubling of published articles every seven years. Thus, the review signifies increased research attention toward parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions. All 23 included studies were undertaken in the Western world. See Supplementary File 1 for an elaboration of Table 2).

The critical appraisal (Supplementary File 2) of the included studies revealed that 19 papers lacked reflexivity concerning their data collection (Question 7). However, the overall methodological quality of the included studies as to the remaining criteria was considered good. No study was excluded due to methodological quality.

Table 3 illustrates that the frequency effect sizes ranged between 17% and 70% for the sub-themes and between 61% and 83% for the themes. Intrastudy intensity effect sizes ranged between 10% and 80% for the sub-themes and between 25% and 100% for the themes. From ten sub-themes, four themes were integrated to form a single statement in the metasynthesis, substantiating the parents' experience of being cross-pressured.

### 3.1. Qualitative research synthesis

By *naïve reading*, we found that during transfer to adult care, parents of young people felt an inner conflict and felt sqeezed between conflicting demands for how to handle what was to come. They felt being cross-pressured and being caught between conflicting demands. The parents were still their children's advocates and partners in keeping track of daily matters and healthcare matters. The conflicting demands of transfer meant losing relationships with long-term healthcare providers in paediatric units and having to gain trust in new healthcare providers' proficiency. The inner conflict showed that parents were having difficulty letting their young people speak for themselves and that they did not acknowledge that their children needed to practise self-advocacy. Parents were uncertain about what would happen during the transfer and in the new environment; they felt unprepared, were insecure about the timing of the transfer; they did not know their parental role and felt sidestepped in decision-making. Yet, parents demonstrated confidence in their young people's ability to manage the transfer.

Through the *structural analysis*, we developed a comprehensive understanding of the entire parental experience of their young people's transfer as a critical event causing parents to experience an inner personal conflict. This interpretation derives from the four themes 'Fluctuating between parental roles', 'Navigating contrast-

**Table 2**
Study characteristics of included studies.

| Author(s), year/Geographical location | Culture/-setting/context | Phenomenon of Interest | Participants | Methodology and Method | Analysis |
|---|---|---|---|---|---|
| Allen et al., 2011, Cardiff, UK | Five different diabetes services | Experiences | 39 mothers | Semi-structured interviews at three time points (6 months intervals) | Thematic Analysis |
| Bratt et al., 2018, Gothenburg, Sweden | Four paediatric cardiology settings | Expectations and needs | 18 parents (15 women, 3 men) | Qualitative research design<br>Individual semi-structured interviews | Content analysis |
| Brodie et al. 2011, Sydney, Australia | Paediatric endocrine and neuroscience departments | Complexity underpinning process of transition | 10 parents (mainly mothers) | Critical creativity approach<br>Semi-structured interviews | "Critical creativity" |
| Burström et al., 2016, Stockholm, Sweden | University children's hospital | Needs | 12 parents (7 women, 5 men) | Semi-structured individual interviews | Content analysis |
| Fair et al., 2015, Southeast, USA | Paediatric disease clinic | Perspectives | 18 parents (17 women, 1 male) | Grounded theory<br>Semi-structured individual interviews | Grounded theory |
| Fredericks et al., 2011, Michigan, USA | Paediatric liver transplant clinic | Perceptions and attitudes | 31 parents | Open-ended questions of topical survey | Quantified results of open-ended responses |
| Gray et al., 2015, Alabama, USA | Paediatric care or recent transferred to adult care (inflammatory bowel diseases) | Needs, concerns, and practical suggestions | 16 parents (14 women, 2 men) | Social constructivists framework<br>Focus group interviews<br>Questionnaire | Qualitative content analysis within as social constructivist framework |
| Author(s), year/Geographical location | Culture/-setting/context | Phenomenon of Interest | Participants | Methodology and Method | Analysis |
| Hauser et al. 1999, Midwestern, USA | Sickle cell paediatric clinics | Concerns, expectations, and needs | 17 parents<br>4 grandparents<br>1 aunt<br>(17 women, 5 men) | Semi-structured focus groups interviews | Content analysis |
| Hillard et al. 2014, Baltimore, USA | Diabetes clinic care | Concerns, expectations, preferences, and experiences | 21 parents (12 women, 9 men) | Mixed method approach<br>Questionnaires<br>Semi-structured interviews | Identification of themes and development of a coding scheme |
| Knudsen et al. 2016, Aarhus, Denmark | One rheumatology clinic | Experience and aspects that could ease | 3 parents (2 women, 1 male) | Semi-structured individual interviews | Inductive Content analysis |
| Nguyen et al., 2016, Hamilton, Canada | 13 clinics at two major paediatric hospitals | Self-management | 7 parents (6 women, 1 male) | Interpretive phenomenology<br>Semi-structured telephone interviews | Inductive content analysis |
| Nicholas et al., 2018, Canada | Canadian paediatric nephrology programs | Perceptions, experiences, and perceived barriers and facilitators | 28 parents | Open exploratory research design<br>Long interview method | Coding, themes and categories were generated until concepts were saturated |

(*Continued on next page*)

**Table 2** (*Continued*).

| Author(s), year/Geographical location | Culture/-setting/context | Phenomenon of Interest | Participants | Methodology and Method | Analysis |
|---|---|---|---|---|---|
| Okumura et al., 2015, California, USA | Community settings recent transitioned to adult healthcare providers | Develop a theoretical understanding | 9 parents | Grounded theory<br>Semi-structured individual in-depth interviews and field notes | Grounded theory including situational analysis |
| Author(s), year/Geographical location | Culture/-setting/context | Phenomenon of Interest | Participants | Methodology and Method | Analysis |
| Porter et al., 2014, Tennessee, USA | A comprehensive paediatric sickle cell disease program | Perspectives and recommendations for improving | 12 caregivers (women) | Focus groups<br>interview<br>Theoretical framework of Bronfenbrenner's bio-ecological theory | Codes organized into categories. categories organized into themes |
| Reiss et al., 2005, Florida, USA | Children's hospitals outpatient clinics and treatment programs in community medical centres | Experiences | 44 parents (36 women, 8 men) | Focus groups and interviews | Content analysis<br>Narrative analysis |
| Sawin et al. 2013, Milwaukee, USA | Paediatric to adult health care (Spina Bifada) setting. | Qualitative evaluation | 16 parents (14 women, 2 men) | Semi-structured telephone interview | Content analysis to identify themes |
| Sharma et al., 2014, Boston, Massachusetts, USA | Paediatric special immunology (perinatally acquired HIV) program at the University of Miami | Preparedness and views | 8 caregivers (6 women, 2 men) | Separated structured interviews with open-ended questions | Grounded theory |
| Shaw et al., 2004, Birmingham, UK | Juvenile idiopathic arthritis (JIA) databases | Needs and how needs could be met | 23 parents (16 women, 7 men) | Focused group discussions | Interpretative phenomenology analysis |
| Author(s), year/Geographical location | Culture/-setting/context | Phenomenon of Interest | Participants | Methodology and Method | Analysis |
| van Nieuwenhuizen et al. 2014, Nova Scotia, Canada | One rheumatology clinic | Perceptions and strategies | 9 parents (6 women, 3 men) | Constructivist paradigm<br>Appreciative Inquiry<br>Semi-structured interviews<br>Focus group | Thematic data analysis |
| van Staa et al. 2011, Rotterdam, Nederland | Erasmus University Medical Centre – Sophia Children's Hospital. | Experiences and recommendations to improve | 24 parents (21 women, 3 men) | Semi-structured individual interview | Thematic analysis |
| Vijayan et al., 2009, New Haven, USA | Yale-New Haven Children's Hospital Paediatric AIDS Care Clinic | Challenges and barriers | 15 parents (12 women, 3 men) | Grounded Theory<br>Open-ended interviews | Constant comparative method |
| Wright et al. 2016, Birmingham & Manchester, UK | Four liver centre units | Views and experiences | 9 parents (6 women, 3 men) | Semi structured individual interview | Interpretative phenomenology analysis |
| Young et al., 2009, Toronto, Ontario, Canada | Canadian rural and urban children's treatment centre | Specific issue of transition | 30 parent pairs | Semi-structured individual interviews | Constant comparative method |

**Table 3**
Intrastudy intensity effect sizes and interstudy frequency effect of the Metasynthesis, Being cross-pressured.

| Metasynthesis | Being cross-pressured: Parents to young people living with long-term conditions in transfer and transition from paediatric to adult care are being cross-pressured | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Themes | Fluctuating between parental roles | | Navigating contrasting healthcare contexts | | | Making decisions in the face of inner conflict | | | Trusting their child's self-management ability | | Intrastudy intensity effect size[a] Subthemes | Intrastudy intensity effect size[b] - Themes |
| Subthemes Authors | Being their child's advocate | Feeling responsible for ensuring optimum growth and health | Crossing contrasting healthcare contexts | Gaining trust in healthcare providers' proficiency | Loosing and establishing relationships with healthcare providers | Deciding appropriate time for transfer | Feeling ill-prepared | Being uncertain | Gaining trust in their child's responsibility taking | Supporting their child in being independent | | |
| Allen et al., 2011 | X | X | X | X | X | | | | X | | 6/10 (60%) | 3/4 (75%) |
| Bratt et al., 2018 | | X | | | | X | | | X | X | 4/10 (40%) | 3/4 (75%) |
| Brodie et al., 2011 | | | | X | | | | | | | 1/10 (10%) | 1/4 (25%) |
| Burström et al., 2016 | | | | X | | | | | X | | 2/10 (20%) | 2/4 (50%) |
| Fair et al., 2015 | | | | | X | | | X | X | X | 4/10 (40%) | 3/4 (75%) |
| Fredericks et al., 2011 | | | | | X | X | | | | | 2/10 (20%) | 2/4 (50%) |
| Gray et al., 2015 | X | X | X | X | X | X | | | X | X | 8/10 (80%) | 3/4 (75%) |
| Hauser and Dorn, 1999 | | | X | | | | | | | | 1/10 (10%) | 1/4 (25%) |
| Hilliard et al., 2014 | X | | X | | | X | | | | X | 4/10 (40%) | 4/4 (100%) |
| Knudsen et al., 2018 | X | | X | X | | X | | X | X | | 6/10 (60%) | 4/4 (100%) |
| Nicholas et al., 2018 | | X | X | X | X | | | | X | | 5/10 (50%) | 3/4 (75%) |
| Nguyen et al., 2016 | | X | | | | | | | X | X | 3/10 (30%) | 2/4 (50%) |
| Okumura et al., 2015 | X | | | | | | | | | X | 2/10 (20%) | 2/4 (50%) |
| Porter et al., 2014 | | X | | | X | X | X | | X | | 5/10 (50%) | 4/4 (100%) |
| Reiss et al., 2005 | | | X | | X | X | | X | X | | 5/10 (50%) | 3/4 (75%) |
| Sawin et al., 2015 | | | X | X | X | X | | | X | X | 6/10 (60%) | 3/4 (75%) |
| Sharma et al., 2014 | | X | X | | X | | X | | X | | 5/10 (50%) | 4/4 (100%) |
| Shaw et al., 2004 | | X | X | | X | X | X | | X | X | 7/10 (70%) | 4/4 (100%) |
| van Staa et al., 2011 | X | X | X | | X | X | X | | X | X | 8/10 (80%) | 4/4 (100%) |
| van Nieuwenhuizen 2014 | | X | X | X | X | | X | X | X | X | 8/10 (80%) | 4/4 (100%) |
| Vijayan et al., 2009 | | | | | | X | | | | | 1/10 (10%) | 1/4 (25%) |
| Wright et al., 2017 | | | X | | X | | | | X | | 3/10 (30%) | 2/4 (50%) |
| Young et al., 2009 | X | | X | X | | | X | | | | 4/10 (40%) | 3/4 (75%) |
| Interstudy frequency effect sizes[a] -Subthemes | 7/23 (30%) | 10/23 (44%) | 14/23 (60%) | 9/23 (39%) | 13/23 (57%) | 11/23 (48%) | 6/23 (26%) | 4/23 (17%) | 16/23 (70%) | 10/23 (43%) | | |
| Interstudy frequency effect sizes[b] – Themes | 14/23 (61%) | | | 19/23 (83%) | | 15/23 (65%) | | | 18/23 (78%) | | | |

[a] Individual studies' contribution to subthemes or themes.
[b] Representation of subthemes or themes in individual studies.

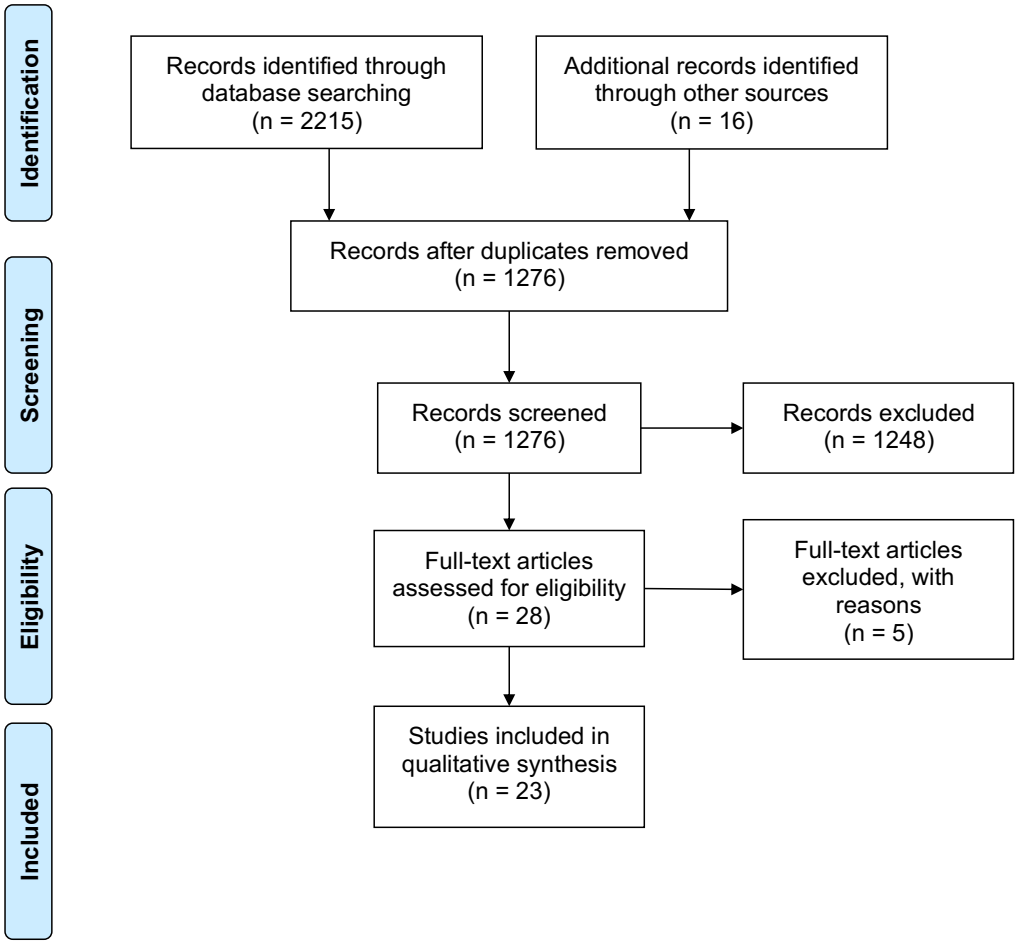


**Fig. 1.** PRISMA Flow Diagram. The search runs from 1999 to March 2019.

**Table 4**
Metasynthesis with themes and subthemes.

| Parental experience of their young peoples' transfer as a critical event that gives the parents an inner personal conflict with social meaning. | |
|---|---|
| Themes | Subthemes |
| Fluctuating between parental roles | Being their child's advocate |
| | Feeling responsible for ensuring optimum growth and health |
| Making decisions in the face of inner conflict | Deciding the appropriate time for transfer |
| | Feeling ill-prepared |
| | Being uncertain |
| Navigating contrasting healthcare contexts | Crossing contrasting healthcare contexts |
| | Gaining trust in healthcare providers' proficiency |
| | Losing and establishing relationships with healthcare providers |
| Trusting their child's self-management ability | Gaining trust in their child's responsibility-taking |
| | Supporting their child in being independent |

ing healthcare contexts', 'Making decisions in the face of inner conflict', and 'Trusting children's self-management ability' (Table 4).

A detailed interpretation of the four themes of the qualitative research synthesis is provided in the following paragraphs. The interstudy frequency effect sizes (Table 3) indicate the prevalence rate of each theme covered by the included studies, whereas the intrastudy intensity effect sizes indicate the concentration of findings in each report.

*Fluctuating between parental roles* relates to the diverse roles parents have during the transition process. Parents described how a multitude of roles were placed on them or how they took on these roles; they asked for structured information and relied on supportive healthcare providers to help them integrate old and new knowledge, skills, and habits. During the process of understanding their children's transfer and transition, parents were sharing stories with other parents, thus becoming at ease with the transition. One parental role described was to take the lead and be their child's advocate. Another role taken on was that of scheduling children's healthcare events. Intuitively, parents seemed to know or had learnt the meaning of collaboration. A parent-child relationship based on mutual trust was needed. The foremost priority was to ensure their children's optimum health and development. The parents felt a strong responsibility for their young people's successful transition. Their fluctuation concerned being attentive of when to take responsibility, when to be more hesitant, and when to gradually hand over tasks and responsibility to the young people.

*Making decisions in the face of inner conflict* involves parents' worries about their young people's crossing over from child to adult care, to a healthcare context that demarcates a new healthcare structuring; they worried about possible differences in medication and unfamiliar providers. Some parents expressed concerns over poor preparedness and they tended to be opposed to the time of transfer; they felt uncertain or deemed the transfer too

early. They believed that their young people were not yet ready for transfer, and they were accustomed to seeing the same physician in whom they had confidence, knowing that they could ask about anything. Other parents felt ready for the transfer in that moving to adult care was perceived as timely. Nevertheless, uncertainty was, to some degree, present because the parents did not always feel involved in the transition process, and they were insecure about treatment options in the adult healthcare setting. Parents were concerned that they might not achieve the same level of confidence in the new adult providers; and they were finding it hard to establish trust and familiarity with the new staff. All these concerns made parents uncertain; they were in conflict about how to make decisions during the transfer, and they expressed that lack of information was an issue that needed to be tackled, both in the preparation phase and in adult care. Parents acknowledged the expert role of their young people but also stressed that as parents their involvement during transition remained crucial. Their advice to other parents was: 'be alert, don't make yourself dependant upon providers, hang in there'.

*Navigating contrasting healthcare contexts* relates to the fact that their children had to transfer to adult care. Besides terminating relationships with paediatric providers and meeting new providers, parents expressed worries about gaining trust in adult healthcare providers' proficiency. Their worries concerned a reduction of services, the reduced intensity of monitoring and follow-up of their children's condition, and concerns about whether the adult providers would be knowledgeable enough about their children, their conditions, and medications. Parents expressed concern over their children leaving paediatric care given the close relationship they had with the paediatric healthcare providers. Concerns focused on the loss of both a long-term relationship characterised by trust and the loss of someone with background knowledge of their children's condition and clinical expertise. Trust had become so integrated a part of the relationship that families no longer reflected on it, and it was viewed as a natural part of the healthcare relationship. In addition, parents worried about coordination of care, lack of access to care, and possible financial distress.

*Trusting their child's self-management ability* denotes the processes of deciding the appropriate time for transfer to adult healthcare. Parents wanted to see their young people become self-sufficient and independent despite having a long-term condition, and they regarded independence to be a positive social value. Though parents discussed their concern over how their children would cope with becoming an adult, they also raised the importance of enabling young people to become independent. Parents explained that independent self-management does not necessarily mean withdrawal of all sources of social support. Mothers continued to support their children's decision-making and acted as a sounding board in situations wherein the correct course of action was unclear. Grandparents raising the young people were more likely than biological parents to describe incidents where they tried to teach their young people how to take care of themselves to prevent having to go to the hospital. Moreover, grandparents tended to convey wanting to prepare their grandchildren for the day when they would no longer be there to care for them. Many elements of the adult setting were out of parental control, which they found distressing. Most challenging for the parents was the role shift with respect to self-management, responsibility, and 'stepping aside'. They wondered whether their young people could assume full responsibility for their own treatment, as parents felt that they still had a rather active role in supporting their young people in managing their condition. Although parents expressed their desire to enable their young people to become independent, for many parents this was very difficult in practice; they felt they might not be privy to important information about their children's care. Parents worried that their young people either would not share information with them or would not listen or ask the right questions during their clinic appointments.

The analysis produced a *comprehensive interpretation* of parents' opposing experiences of their young people's transfer. The four themes with ten sub-themes (Table 4) revealed that parents fluctuate between different parental roles; they struggle to navigate in contrasting healthcare contexts and have to make decisions in the face of inner conflict while striving to build confidence in their young people's self-managing ability. Reflections on the developed themes and subthemes made us comprehend the wholeness of the parental experiences as a critical event that forces parents into an inner personal conflict characterised by a feeling of *being cross-pressured*. This expression became our metaphor for describing how it is to be a parent during young people's transfer from paediatric to adult care. This metaphor will be further discussed in the next section.

## 4. Discussion

In this systematic review of 23 qualitative reports from around the Western world, the analyses uncovered the complicated processes underlying parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions. The interpreted whole of the inner personal conflict was condensed into the metaphor *being cross-pressured.*

> Cross pressure refers to that social situation in which an intrapersonal conflict arises when the motives affecting a decision are incompatible. Two broad categories of such conflicts can be distinguished—attitudinal and affiliative. Attitudinal conflict may occur when a person is faced with a choice between alternative beliefs or courses of action under conditions which bring into play attitudes motivating different and opposing choices. Affiliative conflict can result from a person's attachment to several groups which have preferences for different alternatives (Cross Pressure, 2020).

These two types of conflict have previously been illustrated in the context of voting behaviour (see Brader et al., 2009, Scacco and Peacock, 2014). In this metasynthesis, they illustrate the conflict parents encounter while their young people transfer to adult care. The cross pressure they seem to be faced with is crosswise connected, suggesting that being a parent during transfer is complex and sometimes even conflicting; it requires compromise and patience in matters not always easy to deal with.

*Being cross-pressured* was the qualitative research synthesis developed to explain parents' experience of inner conflict and confusion, parental attitude, and responsibility. Although the final metasynthesis was an abstract integration of findings obtained via a synthesis of the *in vivo* themes, using the imported concept of cross-pressure borrowed from political science, we would argue that this synthesis extends our understanding of these parents' experiences. It captures parents' obligation to meet both their own child's and healthcare providers' expectations of support during their young people's transition to independence. The metaphor cross pressure is chosen because it captures both situations, i.e., the parents who were in a difficult internal and external social situation, and the transfer of young people to a new healthcare culture combined with them being teenagers. The parents were striving for consistency between what to feel and think, and how to act. Thus, the parents are pressured by a multitude of simultaneous transitions. From the perspective of Meleis and colleagues' transitions theory, this means that their identities are challenged (Meleis, 2010). The transfer might make parents aware of their roles, relationships, abilities, and behaviour; matters that are typical of the transition process. Successful transitions require one to incorporate new knowledge and alter behaviour and therefore

change the definition of self in social contexts (Im, 2011). For parents of young people with long-term conditions who are to be transferred to adult service, this might be easier said than done. The conflicting feelings, understood as being cross-pressured during the transition to a new parental role, might be strong, time-consuming, and hard to divorce; and such feelings need to be acknowledged and given time by healthcare providers from both healthcare contexts.

The fluctuation between parents' shifting roles in families with children and young people with long-term conditions might be a challenge not only for the parents; it may also challenge family dynamics and their children's self-management and development of independence; thus, discord may arise between parents and children in this transition process (Rapley et al., 2013). We agree with Flamm and Grolnick (2013) that parental shifting roles are common phenomena because family life involves repeated transitions. Furthermore, when healthy children reach adolescence, parental life becomes challenging, and parental practices influence their young people's wellbeing (Boudreault-Bouchard et al., 2013). Understanding the perspectives of patients and families, especially the psychological aspects of the transition to adult care, is imperative for attaining physical and mental wellbeing for all concerned parties when settling after a hospital transfer. Our comprehensive literature review finding of the existence of cross-pressure deepens our understanding of the special situation parents with children and young adults with long-term health conditions are facing. We believe that knowledge of this situation may help nurses facilitate the transition, which, in a transition theory perspective, is a main task in nursing.

Navigating contrasting healthcare contexts entails making decisions in the face of inner conflict. This finding confirms previous findings (e.g. Betz et al., 2015, Hopper et al., 2014, Reed-Knight et al., 2014, Yamaguchi and Suzuki, 2015) showing that parents of young people with long-term conditions are faced with multiple inner conflicts and ambiguities that may become more prominent during health service transfer. The transfer uncertainty may be due to a lack of preparedness, which prevents parents from anticipating prospects for their transferred young people. For example, in a Swedish survey (Sparud-Lundin et al., 2017), it was evident that the paediatric healthcare providers were more interested in preparing for transitional care than were the healthcare providers in adult care. We agree with Schlucter (2014) that to reduce the feeling of uncertainty, it is necessary to create opportunities for goodbyes as well as hellos. It is a matter of ending long-term relationships with paediatric staff in a proper way and commencing the adult care service in a welcoming way. Setting aside time for closure and opening for everyone involved, including the parents, could decrease uncertainty and strengthen continuity of care. Furthermore, a care gap between the two healthcare service units might result in refraining from outpatient visits and thus constitute a health risk for the young people (Goossens et al., 2016).

The finding of parents having trust in their children's self-management ability suggests that during the transition process parents gain confidence that their young people with long-term conditions can take care of themselves. This concords with Larsson et al. (2015) findings. Parents in their study were slowly altering their roles from being the ones who set limits to the ones available for support. Thus, they were balancing the need for control while maintaining a trusting relationship, thereby facilitating their children's journey towards independence. This, however, is not always easy for parents of young people; they might feel excluded when their children are receiving care from adult healthcare providers (Betz et al., 2015), and the young people might regress when being with their parents. In a study involving emerging adults (healthy and 17–29 years of age) (Arnett and Padilla-Walker, 2015), the participants felt less adult-like in the presence of their parents than in the presence of their co-workers or romantic partners. This mostly childlike relationship can be applicable to relationships between parents and young people. Both parents and adult healthcare providers might undermine a trusting relationship; they might underestimate the children's ability to assume responsibility. For example, Sonneveld et al. (2013) found that adolescents were more satisfied than parents about the co-ordination and communication of the transition process. The changing parental role during adolescence is challenging, as parents, similarly to their young people, are in a transition process.

Healthcare providers in paediatric and adult service (being the facilitators) are in a position to assist parents in their transitional cross-pressure journey by being open to their individual ways of coping with their roles, their trust and growing confidence in their child, their uncertainty, and their knowledge, skills, and resources. An open attitude signals that parents are important for their young people and that they want the best for them. However, in this process, parents are subject to cross pressure, which renders them ambivalent. Therefore, assisting parents' actions during this time of cross pressure is an important task for nurses and other healthcare providers.

In the context of transitions theory, facilitating transition (Chick and Meleis, 1986; Meleis et al., 2000) should be emphasised when adapting strategies to meet the needs of individual young people as well as their parents. As in a double helix, young people need closeness to their parents and supportive surroundings during the first phase of the transition (Björquist et al., 2015); and the parents themselves need to feel secure in managing this complex navigation. Both parties need tactful and compassionate help and support from the healthcare provider involved in the transfer. Our review confirms previous research (Farrant and Watson, 2004) that parents of young people with long-term conditions always desire the transfer to adult health services to be planned; and they expect the healthcare providers to possess good medical knowledge and genuine listening capabilities. Transitions theory suggests that parents are faced with several sorts of transitions that call upon them to master a mixture of roles, restructure life routines, create new choices, and find opportunities for growth and development. The nursing therapeutics at transfers thus involve establishing a trusting and therapeutic relationship with the parents and mobilising personalised parental resources. The issue is to ensure connectedness between the parties (parents, young people, and healtcare provider) and optimal functioning in the parent-child dyad. Any discord, tension, or feeling of ill-being should be resolved but preferably avoided. Our review demonstrates that there is more to transition than a transfer both for the young people (Sattoe et al., 2017) and for their parents.

### 4.1. Strengths and limitations

The number of eligible studies and the number of participants in this systematic qualitative review were sufficient to complete an in-depth metasynthesis of parents' experiences of the transfer from paediatric to adult care of their young people with long-term conditions. Effect size calculations indicated that the findings are relatively equally distributed across the themes, signifying that no single study or theme is over- or underrepresented. The overall methodological quality of the included studies was considered good; however, the sparse considerations by primary authors of their own relationship to the research setting must be considered when interpreting this metasynthesis. One limitation is the lack of studies from non-western contexts. The 23 studies with 454 participants are a strength; however, the predominance of female participants ($n = 258$) and the scarcity of male ($n = 58$) experiences

are limitations. Another strength is the heterogeneity of diagnoses representing 462 young people.

One limitation inherent in the metasynthesis might be the synthesising of qualitative health research into one concept (Ludvigsen et al., 2016). In this review, we interpreted our findings not as reflecting the concept of 'cross pressure' but as reflecting the expression 'being cross-pressured', which we deem to be a strength of our review. We argue that such an expression may be more relevant to practitioners and policymakers. A qualitative research synthesis is supposed to push the scholarship forward through interpretive syntheses of integrated and coherent descriptions or explanations of phenomena, events, or cases (Sandelowski and Barroso, 2003). We believe that we have achieved this in this review.

The calculation of effect sizes enables the transformation of qualitative data by extracting more meaning from those data and verifying the presence of a pattern and theme; and by calculating effect sizes, we may avoid the over- or underweighting findings (Sandelowski and Barroso, 2003). A limitation is that equal weight may be given to each study regardless of how many participants a study has. However, quality is not only associated with participant numbers but with what the study adds to the knowledge on the topic; in other words, how much rich data each study contains. According to Thorne (2017), metasynthesised results are presented as evident after studies have been re-validated, appraised, and organised in matrices and tables. Correspondingly, Thorne argues that the genesis of the qualitative research synthesis and the interpretative dialogue are often in the background, whereas the methods are in the forefront. Qualitative research then becomes technical reports stripped of meaningful context; it lacks scholarly depth and a qualitative language. Simply, the researchers are oversimplifying complex human phenomena (Thorne, 2017) instead of trusting their connoisseurship and taste when validating included reports and their own interpretation (Sandelowski, 2015). In hindsight, these critical views from seasoned qualitative research scholars might apply to our review. We have appraised data using standardised checklists, and we have presented our research process in a technical way using tables and figures. However, we have interpreted our data considering contexts, discussed the findings in light of relevant theory, and have been careful in making conclusions that do not go beyond our findings. Reflecting on these matters, we see ourselves as combining the best from both the original interactive theoretical traditions and the new, more technical traditions. We extracted and aggregated the manifest data of the findings. We reflected on the quantitative logic to extract, group, and edit the findings, thus offering novel interpretations that are more than mere accumulated summaries. We tried to accommodate our analyses in ways that made justice to both the parts and the whole of the metasynthesis. Although parents strived to gain trust in their child's self-management ability, we discovered no experiences of relationship breakdown between parents and children or instances where care responsibilities were accepted or rejected. This may be due to parents experiencing no or only minor issues relating to breakdown, or to the fact that they found it irrelevant to disclose such experiences while participating in the primary studies. In addition, reporting breakdown may be deemed socially less acceptable, so carers/parents may be presenting a socially acceptable face to the research team, which may or may not reflect reality. Another explanation for the absence of relationship breakdown could be that primary study authors were unaware of these issues in their conceptualisation of studies and creation of items for interview or observation guides.

A strength of this review is that it was prepared by a research team that is proficient in scrutinising qualitative research syntheses and immersed in transitions theory (Ludvigsen et al., 2016). The credibility of this review is strengthened by team discussions throughout the process while searching for and retrieving data; appraising, analysing, synthesizing, and theorizing findings; and presenting the findings in both tables and texts.

## 5. Conclusions

Being cross-pressured was the metasynthesis derived from this systematic review of parents' experiences of the transfer from paediatric to adult care of their people with long-term conditions. One implication is that clinicians should consider the young people's transfer as a critical transition event for the parents as well as the young people. Parents' needs during their young people's transition require more attention from nurses, healthcare providers, and health policymakers in both paediatric and adult healthcare services. Facilitating care for parents' feelings of being cross-pressured during transfer must be recognised and incorporated into transitional care programmes. Future research on parents' experiences of the transfer from paediatric to adult care services for their young people with long-term conditions could therefore benefit from research into relationship breakdown and how care responsibilities are accepted or rejected.

## Declaration of Competing Interest

None.

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## Data statement

Supplementary material associated with this article can be obtained from the corresponding author.

## Supplementary materials

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