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**Title:** The Rural Mother's Experience of Caring for Child with a Chronic Health Condition: An Integrative Review

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## **Abstract**

**Aim and objectives.** The focus of the literature review was to identify and review the literature on rural mothers' experiences in caring for a child with a chronic health condition.

**Background.** Families living with a child who has a chronic health condition experience many challenges; these are often amplified for families living in rural areas, where issues such as the distance from services adds further challenges the family must manage. Like many children, rural children with chronic health conditions are primarily cared for by their mothers. The additional strain of geography creates its own unique experiences for mothers who need to access the high-quality care that their child requires.

**Design.** Integrative literature review using the Equator PRISMA guidelines.

**Methods.** A search of databases; Cochrane, CINAHL, Ovid, PubMed, ProQuest Health and Medicine, Informit and Scopus for studies published between 2005–2016 using an integrative review approach. 1484 studies were identified with an additional six studies found through snowballing. The search resulted in seven studies being meeting the inclusion criteria after using the Critical Appraisal Skills Programme.

**Results.** Data from the seven articles was analysed and the mothers' experiences were synthesised into five themes: 'struggling for resources', 'barriers in accessing services', 'strain of decision-making', 'mother's physical and emotional breakdown' and 'the daily management of family activities'. These five themes formed the basis of this article.

**Conclusions.** The findings indicate that mothers from rural areas face additional barriers related to their rurality, including transportation difficulties, socioeconomic status and social isolation, and are challenged by limited access to specialty medical services, educators and allied health professionals. The literature review outcome will assist in informing nursing practice through identifying and allocating resources to reduce these barriers rural mother experience will assist in enabling the child to reach their full developmental potential.

**Relevance to clinical practice.** There is a need for health professionals to understand the challenges and barriers rural mothers face in accessing services. Nurses can assist rural mothers to navigate and access the appropriate services in order to reduce health inequity, increase accessibility to services and reduce rural disadvantage for their child. Nurses and health professionals are in an ideal position to develop future models of care that optimise health outcomes and enable equity and access to services for rural children with chronic conditions similar to those experienced by their urban counterparts.

**Keywords:** children, chronic health condition, rural, mothers

**What does this paper contribute to the wider global clinical community?**

- Rural mothers experience unique challenges in accessing service for children with chronic health conditions compared with their urban counterparts.
- In rural areas there is a significant deficiency in the services required to assist and support mothers in providing optimal care for their child.
- Further research is required to assist nurses, doctors and other health care providers to develop guidelines, resources and models of care that assist rural mother in caring for their child with a chronic health condition to reduce the health inequity these children and their families experience.

**Introduction**

Chronic health conditions are increasing in children worldwide (Perrin, Bloom, & Gortmaker, 2007; Sodi & Kgopa, 2016; Strickland et al., 2015). Children usually do not choose where they live, the diet they eat or their ways of life; rather, these are determined in the main by their family circumstances (Riley et al., 2016). Further, children with chronic health conditions are reliant on their families to provide the care they require and may have a limited understanding of the long-term consequences of their health condition (Farmer, Clark, Sherman, Marien, & Selva, 2005; Riley et al., 2016). Families living in rural areas may be affected by factors that influence the care of a child with a chronic condition; for example, rural children are more likely to live in poor families, have unmet medical needs and have less access to local specialists (Allan, Ball, & Alston, 2010; Alston et al., 2006; Peltz et al., 2016; Skinner & Slifkin,

2007). While all family members are affected when a member of the family has a chronic health condition, it is usually the mother who shoulders the burden of care and the day-to-day management of the child's condition (Bar, Shelef, & Bart, 2016; Bilgin & Kucuk, 2010; Bourke-Taylor, Pallant, Law, & Howie, 2013; Carnevale, Rehm, Kirk, & McKeever, 2008). This literature review was thus conducted to investigate the unique experience of mothers of children with a chronic condition living in rural areas, providing **nurses with information to assist them to deliver and implement the required resources.**

## **Background**

Chronic illness creates a burden for both the person with the illness and those caring for him or her (Murphy, Christian, Caplin, & Young, 2007; Murphy, Kobayashi, Golden, & Nageswaran, 2012); similarly, when a child has a chronic health condition their families must adapt their lives to meet the needs of the affected child (Bessette Gorlin, McAlpine, Garwick, & Wieling, 2016; Carnevale et al., 2008; Skinner & Slifkin, 2007). **While the experience of families with a child with a chronic condition have been explored previously, little is currently known about this experience for rural mothers.** Rural mothers of children with a chronic condition encounter the same challenges as those living in metropolitan areas with respect to the social, financial and health implications of their child's illness, but for rural mothers, isolation and geography create additional challenges (Murphy et al., 2012; Peltz et al., 2016; Sodi & Kgopa, 2016).

Children experience many different chronic health conditions that can range from mild to severe, be common or rare, be present at or before birth or develop later in childhood. The management of these chronic conditions varies and can require minimal to complex specialist care and management. A chronic health condition has been defined as 'a physical or mental

condition or functional limitation that has lasted, or is expected to last, six months or more' (Australian Institute of Health and Welfare [AIHW], 2012, p. 17). Chronic illness is variously described as a chronic health condition, chronic disease, chronic illness, chronic condition, non-communicable disease and long-term condition, disease, disorder or syndrome.

### **Aims**

The aim of this integrative literature review is to address the research question: What are the experiences of rural mothers caring for a child with a chronic health condition?

### **Method**

A systematic, integrative review using the approach outlined by Whitemore and Knafl (2005), and guided by the Equator PRISMA framework, was used to identify what is already known about the topic and to synthesise this through interpretive translation of the evidence into identified themes. An integrative review process facilitates the inclusion of different research designs, including both quantitative and qualitative studies, which allows for a better and a more comprehensive understanding of the phenomenon under investigation (Whitemore & Knafl, 2005).

#### **Search methods.**

The terms used in the review are included in Table 1.

(Insert Table 1)

#### **Table 1.** Search terms.

With the assistance of the university health librarian, the following databases were searched: Informit, Scopus, the Cochrane Library, CINAHL, PubMed, ProQuest Health and Medicine, Ovid and Google Scholar. These databases were chosen to limit the review to studies that were relevant to nursing practice. The search was limited to research articles published in

peer-reviewed journals from 2005 to 2016 to identify articles that provide a contemporary understanding of the topic.

### **Inclusion criteria.**

The articles selected were required to be research-based, peer-reviewed and written in English. They also had to possess the following characteristics : a) relevant to nursing and family research and practice; b) related to the experiences of mothers (the study could be about parents, but the primary caregiver had to identify as a mother); c) about children with chronic conditions; d) include mothers who lived in a defined rural area; e) were studies of children with a chronic health condition, chronic disease, chronic illness, long-term disease, long-term conditions and/or lifelong illness, children with special health care needs who were medically fragile and children who were dependent on medical technology. Chronic health conditions included mental and physical health conditions, congenital anomalies and genetic diseases. Experiences included (but were not limited to) access to transport; access to specialist care; financial, parent and family stress; stigmatism, isolation and work/school absenteeism.

### **Exclusion criteria.**

Studies that focused on fathers exclusively or solely on childhood cancer were excluded, as the focus of care is more likely to be remission and/or cure rather than routine long-term management (Smith, Cheater, & Bekker, 2015). Studies were excluded if they focused on children's end of life care because maternal experiences of grief, anxiety and decision-making may be different to the experience of providing long-term care. Studies that took an *a priori* approach and used tools to assess a specified concept were also excluded as the focus was on the experience that emerged from a deductive approach. This included research that focused on psychological constructs that were measurable.



**Definitions.**

For this literature review, chronic health conditions included both mental and physical conditions, variously described as chronic illness, diseases, syndrome complex or disability, medically fragile and requiring special health care needs. Such conditions can be long-lasting, life-limiting and often progress slowly, affecting children in various ways (AIHW, 2012, p. 17; Van der Lee, Mookink, Grootenhuis, Heymans, & Offringa, 2007). The term 'chronic health condition' was chosen as an umbrella term to incorporate numerous conditions, rather than chronic disease or illness as these words may exclude children who may not have a disease or illness.

**Mothering and motherhood is defined as** being either biological or the result of legal adoption, including long-term foster mothers (Blythe, Halcomb, Wilkes, & Jackson, 2012) and included those who perceived themselves as being mothers or in a maternal role and providing care for a child with a chronic health condition.

**The term rural is defined differently in various countries, usually taking into account either population profile or the accessibility from urban areas. In developed countries, rural is often defined by accessibility (United Nations, 2008; Dolea, Stormont, Shaw, Zurn, & Braichet, 2009; Couper, 2003). The rural context for this literature review encompassed terms regional, remote, and country areas as these locations were geographically isolated from metropolitan areas, where travel was required to access to quality health care including, health professionals and specialised services (Versteeg, Du Toit, & Couper, 2013; Couper, 2003).**

**Process.**

The initial search was undertaken between May and September 2016. To avoid the risk of bias, the inclusion and exclusion criteria were established and agreed on by all authors prior to

the literature search being undertaken to ensure the aim of the literature review was aligned with the research question. The papers were screened for duplicates and subjected to quality appraisal. A meta-synthesis was conducted once the final papers to be included were agreed upon.

### **Quality appraisal.**

Quality appraisal was conducted using the Critical Appraisal Skills Programme (CASP) systematic review checklist tool (CASP, 2016). The CASP tool provided a systematic approach to evaluating the literature and its applicability for answering the research question. The tool was applied to each of the 12 papers that were finally selected. Five of the 12 papers were eliminated as they did not meet the quality requirements after applying the CASP tool. All authors were consulted to ensure there was consensus prior to the final seven papers being included in the review.

## **Results**

### **Search outcomes.**

(Insert Figure 1)

### **Figure 1: PRISMA Diagram.**

Through searching the chosen database 1,482 studies were found for potential inclusion, grouped as follows: Informit (19), Scopus (307), Cochrane Library (9), CINAHL (21) Pubmed (291), ProQuest Health and Medicine (675), Ovid (4) and Google Scholar (156). Duplicates were removed (19) and records were screened by title and those that did not meet the inclusion criteria were excluded (1,357). Those that met the inclusion criteria (113) were further screened by title and abstract, resulting in 55 studies that appeared to meet the inclusion criteria. The full

texts of these 55 studies were reviewed, with a final 12 studies selected as meeting the inclusion criteria. These were appraised using the CASP systematic review checklist (CASP, 2016), after which seven studies were assessed as suitable for the final analysis (Figure 1). From the final seven studies, one author was contacted to ensure that the children investigated in that study had a chronic health condition, and this was confirmed (Lauver, 2008). Of the seven studies included in the final analysis, three were quantitative and four were qualitative.

### **Synthesis.**

Each article was read and a summary of the key themes identified and documented (see Table 2). Each article was then read again with the aim of synthesising and transforming each of the studies' findings into the five identified themes listed in Table 2 using a thematic approach (Polit & Beck, 2006).

(Insert table 2)

**Table 2.** Themes identified from the literature.

### **Findings.**

In all seven studies, respondents were mostly mothers, although only one study involved mothers as the sole participants. In the six studies that focused on families, mothers were the majority (85–98%) of the respondents. Four studies focused on rural populations and the other three had a mix of both rural and urban respondents.

The challenges that the mothers faced when looking after a child with a chronic health condition related to the social, academic, financial and health factors putting these children at risk of failing to meet their developmental potential. The five overarching themes identified were: 'struggling for resources', 'barriers in accessing services', 'strain of decision-making',

‘mother’s physical and **emotional health**’ and ‘the daily management of family activities’; these are described in detail below.

*Struggling for financial resources.*

For mothers to effectively care for their child they require financial resources to allow them the time and ability to access transport and service providers (Farmer et al., 2005; Murphy et al., 2007). It was acknowledged that rural mothers needed to travel large distances to access care and that this had an effect on the entire family. Transport to and from appointments was more difficult for mothers who lived in rural areas where public transport was less easily accessed, or in some cases did not exist (Skinner & Slifkin, 2007). This was significant in rural areas, as often the specialist care their child required was not available locally, resulting in significant transport-related costs. Financial costs related to transport were compounded by additional factors including loss of wages due to work absenteeism or employment loss, the cost of fuel, and the costs associated with meals and accommodation (Farmer et al., 2005; Lauver, 2010; Murphy et al., 2007).

Through the literature, mothers were shown to be a constant care resource for their child with a chronic health condition. Often, mothers are required to leave paid employment to meet the care needs of their child (Murphy et al., 2007). The loss of employment, career progression potential as well as the inability to participate in paid employment often had significant financial and personal effects on these mothers and their families.

As a resource, time was also an issue, as a mother’s caregiving role was often seen as invisible work with no tangible link to the financial consequences (Farmer et al., 2005; Higgins, Bailey, & Pearce, 2005; Murphy et al., 2007). Caring time related to attending appointments, accessing and dealing with services, applying for financial reimbursement from medical

insurance, the additional everyday activities of caring for a child (grooming, dressing), communication, providing therapy and medical care, all impacted on the mother's time (Farmer et al., 2005; Hoogsteen & Woodgate, 2013; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005; Murphy et al., 2007). Mothers constantly juggled multiple roles to provide the care and resources that their child required for the best quality of life (Hoogsteen & Woodgate, 2013). All of these time issues affected mothers' ability to be engaged in paid employment and hence the family's financial position.

Personal characteristics, including income, health insurance and financial resources affected rural families' access to service providers. This was more evident in countries where health care access was reliant on a private health insurance system (Farmer et al., 2005). Rural families tended to be poorer, medically uninsured and had increased financial demands to enable access to services (Murphy et al., 2007; Skinner & Slifkin, 2007). Mothers often found it challenging to access appropriate service providers within their own private insurance and public health care entitlements, leaving them with large out-of-pocket expenses (Lutenbacher et al., 2005). In some countries, health insurance influenced the families' choice of services and ability to access services (Lutenbacher et al., 2005).

### ***Barriers to navigating service needs.***

Mothers reported how they had to advocate for their child with a chronic health condition across a number of systems and range of services. Specific services that mothers required for their children related to all aspects of their child's life, including academic, developmental and health. This involved numerous service providers: schools, education specialists, allied health services, including speech, occupational and physical therapies; counselling, mental health services, respite services and medical care to enable their child to reach their full health and

developmental potential (Hoogsteen & Woodgate, 2013; Lutenbacher et al., 2005; Murphy et al., 2007). For rural mothers, these systems were often more complex because of the limited access to these services in their local area (Farmer et al., 2005; Higgins et al., 2005).

Rural mothers were often confronted with limited places, long waiting lists, financial costs and large geographical distances to access care (Farmer et al., 2005; Murphy et al., 2007). Navigating various services to eliminate care gaps required challenging negotiation by the mother. Often there were no comprehensive services available in rural areas and a lack of communication between service providers created gaps in a child's care (Farmer et al., 2005). In rural areas, mothers reported that services were often disjointed and not coordinated, and these included health and non-health care services, thus affecting the quality of care children received (Lutenbacher et al., 2005). Mothers often found themselves in the role of communicator between service providers, despite having a lack of knowledge of the resources required, and were often placed in a difficult position trying to negotiate services and understand their legal entitlements (Lutenbacher et al., 2005). Mothers also reported they felt more vulnerable when their children were required to move between services, due to a lack of communication, fragmentation in the types of services and delays within the transition process between service providers, especially when large distances were involved (Farmer et al., 2005).

A further barrier for rural mothers was availability of appropriate after-hours emergency care when their children were acutely ill. In many cases, the required care was not available locally and the mothers were concerned when their treating primary health provider, either local or in the nearest major centre, could not see their child or advise on their treatment. This meant that the after-hours responder was often not familiar with the child's particular health issues and treated only one symptom or one element of the child's complaint rather than providing holistic

care (Lauver, 2010). In some cases, mothers reported that they preferred to drive further to access specialised care after hours in order for their children to be given what they felt was the appropriate care. For some mothers, this meant driving to a children's hospital in a tertiary centre over three hours away (Lauver, 2010).

Within rural settings, there were differences in practice patterns between local clinicians and specialists, which led to confusion, frustration and mistrust of local primary care providers (Hoogsteen & Woodgate, 2013; Lauver, 2010; Lutenbacher et al., 2005). This created stress and worry for the mothers, as a lack of specialist services may affect their child's future health. The opportunity for respite care was also limited in rural areas, and was sometimes not available (Lutenbacher et al., 2005; Murphy et al., 2007). In one study, a mother discussed the lack of competent respite services and indicated she did not trust the care that was available, stating it was easier to do it herself (Murphy et al., 2007).

Schooling was recognised in the literature as being a major stress for rural mothers, who were challenged by the need to locate appropriate services for their children's academic development where their additional health and support needs could also be accommodated. This became more challenging when children were transitioning between systems from early intervention through to primary and high school (Lutenbacher et al., 2005). The school as a place for fun, learning and socialisation for these children was often contrary to their experience (Lutenbacher et al., 2005). Mothers often had to provide education, knowledge and resources to their child's teacher to enable timely access to the appropriate academic and social support enabling them to have a positive and successful school experience. This required the teacher to have an understanding of the child's health condition and how it affect the child's school attendance, participation and behavioural and social needs to meet their developmental potential

(Hoogsteen & Woodgate, 2013). Within the literature, a child was denied access to an appropriate developmental level of schooling as services could not accommodate the child's behavioural needs (Lutenbacher et al., 2005). The lack of understanding of a child's behavioural characteristics by teachers was a major stress for rural mothers (Higgins et al., 2005), as schools in rural towns were often ill-prepared to accommodate the needs of children with challenging health conditions (Lutenbacher et al., 2005).

Alternative schooling options were often limited in rural areas, and specialised services were frequently not available, therefore mothers felt they were required to make compromises with regard to their child's education (Hoogsteen & Woodgate, 2013). In some studies, the school was not able to accommodate the required adjustments to meet a child's physical and emotional needs (Hoogsteen & Woodgate, 2013; Lutenbacher et al., 2005). Consequently, in one study, a child had to wait for access to school until the school could meet his or her needs (Lutenbacher et al., 2005). In addition, children from rural areas were often required to miss extended periods of school for appointments and therapies not available locally, and experienced greater school absenteeism than their urban counterparts due to the travel time and distances involved (Farmer et al., 2005).

For rural families, large amounts of time were spent arranging and organising care; they tended to provide more care at home and were able to improvise when accessing services locally (Lutenbacher et al., 2005). Compared to their city counterparts, rural children are less likely to be seen by a paediatrician and/or paediatric specialist to access specialty medical care (Skinner & Slifkin, 2007). Although families accessed services, the literature discussed a number of factors related to the types of support and health services available to them. In summary, rural families



tended to access more generalised services than specialist services, provided more care themselves, waited longer and had to travel further to access specialist care.

*The strain of decision-making.*

Mothers often lived with worry surrounding decisions around their children's health. When and where to seek medical help was challenging for mothers who needed to find out how to access the necessary services and supports (Farmer et al., 2005; Lauver, 2010). Mothers described inconsistency between local and specialist medical providers, making decisions even more difficult as any change in care could have a significant effect on the health of their child, as well as the family (Farmer et al., 2005; Lauver, 2010; Lutenbacher et al., 2005). Mothers acknowledged it was important to seek quality care where possible; this included decisions in when and where to take their children for treatment. They often knew intuitively when and what type of care was required for their child and also the barriers to accessing this care (Lauver, 2010). The decision of when and where to present for health care required the mother to develop strategies that included knowledge of the types of health care available across the primary, secondary and tertiary health systems; how to access these systems for both routine and specialised care; when to present for care; the choice to fund additional costs for health care, and travel and spending more time to access specialist care. In one case, it was reported that the mother knew the child was becoming unwell through very subtle signs, but also knew that she or he would not be admitted until the child's condition worsened, and so the mother delayed accessing care (Lutenbacher et al., 2005).

Other decisions related to prioritising care and the impact this may have on the family. Mothers had to make decisions related not only to the child with the chronic health condition but also the effects that their decision might have on the rest of the family. When making decisions,

mothers had to weigh up both the immediate and systemic needs of all of their children (Lutenbacher et al., 2005; Murphy et al., 2007). For rural mothers, there were limited care choices and navigating these was challenging.

***The physical and emotional impact on mothers.***

Rural mothers were stressed by caring for their children with chronic health conditions and having to look after their complex care needs (Farmer et al., 2005; Higgins et al., 2005; Hoogsteen & Woodgate, 2013; Lauver, 2010; Murphy et al., 2007). Mothers felt constantly stressed and the effect on families was overwhelming, as they were often ill-equipped to deal with the enormity of the diagnosis and the care required (Hoogsteen & Woodgate, 2013; Lauver, 2010). The unpredictability of the chronic health condition placed additional stress on mothers, as they felt they were constantly ‘on call’, even when their children were in school or in respite care; they could receive a phone call at any time to collect a child immediately (Murphy et al., 2007). This created caregiver strain in that they felt engulfed by the constant *noise* that surrounded caregiving and having to always be available regardless of their own needs (Farmer et al., 2005; Lauver, 2010).

The stress of caregiving led to rural mothers feeling frustrated and constantly worrying about their isolation from other mothers (Murphy et al., 2007). They suffered constant worry, not only for their current situation, but also their child’s future and the unpredictability of their chronic health condition and prognosis (Murphy et al., 2007). Mothers expressed concern about social isolation, reporting how they often found themselves prisoners in their own home, with little contact with other individuals and their communities (Higgins et al., 2005; Lauver, 2010). This differed from loneliness, as it was more permanent for these rural mothers, who have many more barriers and challenges to overcome just to be able to leave their homes (Lauver, 2010).

Although mothers knew that they were not to blame for their child's chronic health condition, they expressed feelings of blame, stigma, embarrassment, hostility and discrimination (Hoogsteen & Woodgate, 2013; Lutenbacher et al., 2005). Those who had support from family and friends within the community felt less isolated and more valued and supported in their caregiving role (Farmer et al., 2005; Higgins et al., 2005; Murphy et al., 2007). One mother said having a child with a chronic health condition was rewarding and gave her a sense of purpose (Murphy et al., 2007). However, this was not the case for all mothers.

Many mothers' physical health was affected as a result of their caregiving role. They reported experiencing back and shoulder pain from heavy lifting and pain inflicted by a children's sometimes violent outbursts. They were physically exhausted, had limited energy and in some cases, were sleep deprived from attending to their children's needs. In one study, a mother stated that she ate chocolate to relieve stress; such a strategy might affect the mother's emotional and physical health and wellbeing in the longer term (Murphy et al., 2007).

### ***Everyday struggles.***

For many mothers, life was all about their everyday activities, revolving around their child's chronic health condition (Lauver, 2010; Murphy et al., 2007) and caregiving was around the clock. Mothers typically spent time with other family members once the child with a chronic health condition was asleep (Higgins et al., 2005; Murphy et al., 2007). Family activities required additional planning beyond that of a family with healthy child, including shopping, entertainment and recreational activities. Family outings were often planned in advance or at a particular time of the day to suit the child's care requirements; this was often difficult and challenging when the child's condition was unpredictable and uncontrollable (Hoogsten & Woodgate, 2013; Murphy et al., 2007). A child's behavioural outbursts in public could mean an

activity had to come to an end for the entire family (Higgins et al., 2005; Lauver, 2010). For rural mothers, this required the consideration of time and distance for travelling to these activities, as well as the ability to access appropriate recreational activities locally.

Medical procedures and medication had to be planned throughout the day and holidays were often rare and challenging. Although respite care was available, rural mothers did not feel comfortable using these services, or there were limited service choices and/or long waiting lists (Murphy et al., 2007). The everyday activities of cooking, food choices, housekeeping, work and school all had to revolve around the child's chronic health needs. This weighed heavily on mothers, who tried to minimise interruptions to the family, in particular, on siblings (Murphy et al., 2007).

Marital strain was a common theme in the studies. Reasons included financial issues, missed work days or the mothers' inability to work, as they had to provide full time care for their children (Farmer et al., 2005). As care for children with chronic health condition has shifted from the hospital to the home, often more commonly in the rural setting (Lutenbacher et al., 2005; Skinner & Slifkin, 2007), the home environment has changed into a medicalised home with equipment and consumable stores for these families (Lauver, 2010; Lutenbacher et al., 2005; Skinner & Slifkin, 2007). This had a significant effect on mothers, increasing the time they spent at home arranging/coordinating and providing care interventions to manage their child's condition (Farmer et al., 2005; Murphy et al., 2007).

## **Discussion**

Rural mothers caring for a child with a chronic health condition are confronted with the same challenges as their urban counterparts, but also experience the additional challenges related to the requirement to travel large distances to access specialist services, and the lack of

appropriate and available local services (Peltz et al., 2016; Skinner & Slifkin, 2007; Tong et al., 2013). All of the seven studies included in this review examined rural communities, and the samples were diverse in many of the social determinants of health, including geography, socioeconomic status, health systems and children's chronic conditions. Five of the studies focused on the families' experiences but the central voices within these studies were those of the mothers. In one of the quantitative studies a mother's education level was the only identifiable data source that the mother was the primary care provider and responder to the survey data being examined; despite this, there were commonalities that could be identified across all of the studies.

Mothers were often the primary caregiver and played an integral part in meeting their child's health care needs. Within the literature the terms parents, families and household were mostly used to represent mothers (Mikkelsen & Frederiksen, 2010). Rural mothers found it more difficult to access the necessary care required locally than their city counterparts did, and were required to travel longer distances to access services, especially if hospitalisation was required (Murphy et al., 2012; Peltz et al., 2016). Geographical distance created both practical and personal barriers to accessing service needs, including financial, transport, lack of time, fatigue and feelings of isolation. These issues have been reported elsewhere (Gan, Gararo, Gerber, & Boschen, 2010; Tong et al., 2013), and all affected the mothers' physical and emotional wellbeing (Hoogsteen & Woodgate, 2013).

Mothers reported that they were often underprepared for the role of primary caregiver of a child with a chronic health condition (Hoogsten & Woodgate, 2013; Lutenbacher et al., 2005; Murphy et al., 2006). In this case, mothers reported making complex decisions that took time and effort, to ensure that they had the resources they required to successfully care for their child

while still maintaining everyday family functioning, as reported by others (Krista & Eyal, 2015; Peltz et al., 2016). Mothers learned and become knowledgeable in navigating complex care systems and making multifaceted decisions relating to their child's social, academic and medical needs to determine the priorities for their child's care needs within the family's resources (Hoogsten & Woodgate, 2013; Lauver, 2010; O'Connor, Howell-Meurs, Kvalsvig, & Goldfeld, 2015). They had to make decisions to ration and prioritise care efficiently when family resources were limited or insufficient. This left mothers fatigued and time-poor as they multitasked across the normal home boundaries to avoid the stress of family dysfunction (Krista & Eyal, 2015). This was all done within a defined rural environment, which for them was the home.

Mothers sacrificed their own health and wellbeing to prioritise their child's needs, leaving them physically and emotionally strained (Cousino & Hazen, 2013). Mothers were financially, physically and emotionally stressed by caring for, and worrying about, their children with chronic health conditions (Kuo, Cohen, Agrawal, Berry, & Casey, 2011, Lauver, 2008). Mothers did all of this as they loved and cherished their children and wanted the best for them to keep them healthy and to meet all their needs, to allow them to reach their full life potential (Bourke-Taylor et al., 2013). Their child's care needs were prioritised through constant advocacy, despite many frustrations and setbacks (Hoogsteen & Woodgate, 2013).

Rural communities offered support, although it differed to the support available in urban and metropolitan areas. Mothers tended to use the Internet, telephone services and local community members for support and to reduce their social isolation (Hoogsteen & Woodgate, 2013; Lutenbacher et al., 2005; Myers, Vander Stoep, Zhou, McCarty, & Katon, 2015).

There were also positive aspects for caregiving that rural mothers reported including a feeling of great satisfaction in the role of providing care to their child (Murphy et al., 2007). Services that were well coordinated, close to home and where communication systems were easily navigated also created great satisfaction for the mothers (Lutenbacher et al., 2005; Farmer et al., 2005). Where these positive experiences are in place, intervention to improve access to services and coordination would not diminish these positive experiences for rural mothers. Although mothers in three of the studies that included both rural and metropolitan areas had similar challenges, it was the time and distance to access service that created the biggest hurdle for rural mothers (Skinner & Slifkin, 2007; Lutenbacher et al., 2005; Farmer et al., 2005).

Rural children do not have the same health care equity and access to services as children living in metropolitan centres, highlighting rural disadvantage. At times, the services that they accessed were generalised rather than specialised, and this led to further stress for mothers as they tried to navigate many barriers in accessing resources needed for their child (Hoogsteen & Woodgate, 2013; Lutenbacher et al., 2005; Skinner & Slifkin, 2007). Having an understanding of how care is received enables nurses to be involved in planning and providing care that address the issues that have been identified by the rural mothers' own experience of the delivery of care. This places nurses in an ideal position to assist in reducing health care inequity and disadvantage for rural children with chronic health conditions through identifying service gaps and accessibility.

## **Limitations**

There are several limitations to this review. There were only seven final papers that met the inclusion criteria and all were written in English. All had mothers as the main respondent and

were conducted within a rural setting in the Western world. Not all databases were searched; only those that held nursing research literature and were relevant to family practice. The studies reviewed focused on different terms that included children with chronic health conditions, including special health care needs, disabilities and autism. One paper required personal correspondence with the author to verify that the children in the study actually had a chronic health condition.

### **Conclusion**

This integrative literature review provides evidence that rural mothers experience challenges in relation to caring for their children with a chronic health condition that are different to those encountered by their metropolitan counterparts. The rural environment creates unique challenges in relation to distance and is inequitable in terms of the services and resources available. Children with chronic health conditions are primarily cared for by their mothers within the family setting; despite this, mothers are often difficult to identify as the voice of the family or within the literature. More research is needed concerning Australian rural mothers' experiences to understand their unique environment and its effects on the care required to manage a child with a chronic health condition.

### **Relevance to clinical practice**

The literature review identifies the attributes and barriers rural mothers face in providing care for their child. Optimal care is necessary for a child to reach their full development potential including academic, social, physical and mental health enabling long term effects of their chronic health condition to be minimalised into adulthood. Rural mothers often have to find ways to advocate and access the required care their child requires within their local community. Primary health care and service providers in rural areas may not have the specialised skills, expertise and



knowledge to provide or coordinate care for the child and family (Dharmar et al., 2008; Miller, Nugent, Gaboda, & Russell, 2013). Nurses are often in an ideal position to coordinate care for these children with complex needs and to create supportive interconnected relationships that work across the health, education and other sectors. Nurses can assist rural mothers to navigate and access the appropriate services in order to reduce health inequity, increase accessibility to services and reduce rural disadvantage for their child.

This review aims to identify the need for health professionals to understand the challenges and barriers rural mothers face in accessing services and to assist in developing future models of care, services and resources that optimise health outcomes and access for rural children with chronic conditions. In developing new models of care and resources nurse require insights through evidence of the current care delivery for rural children with chronic health conditions in order to develop innovative ways of improving care delivery. Reducing the health care inequity and accessibility to services issues will help to overcome rural disadvantage.

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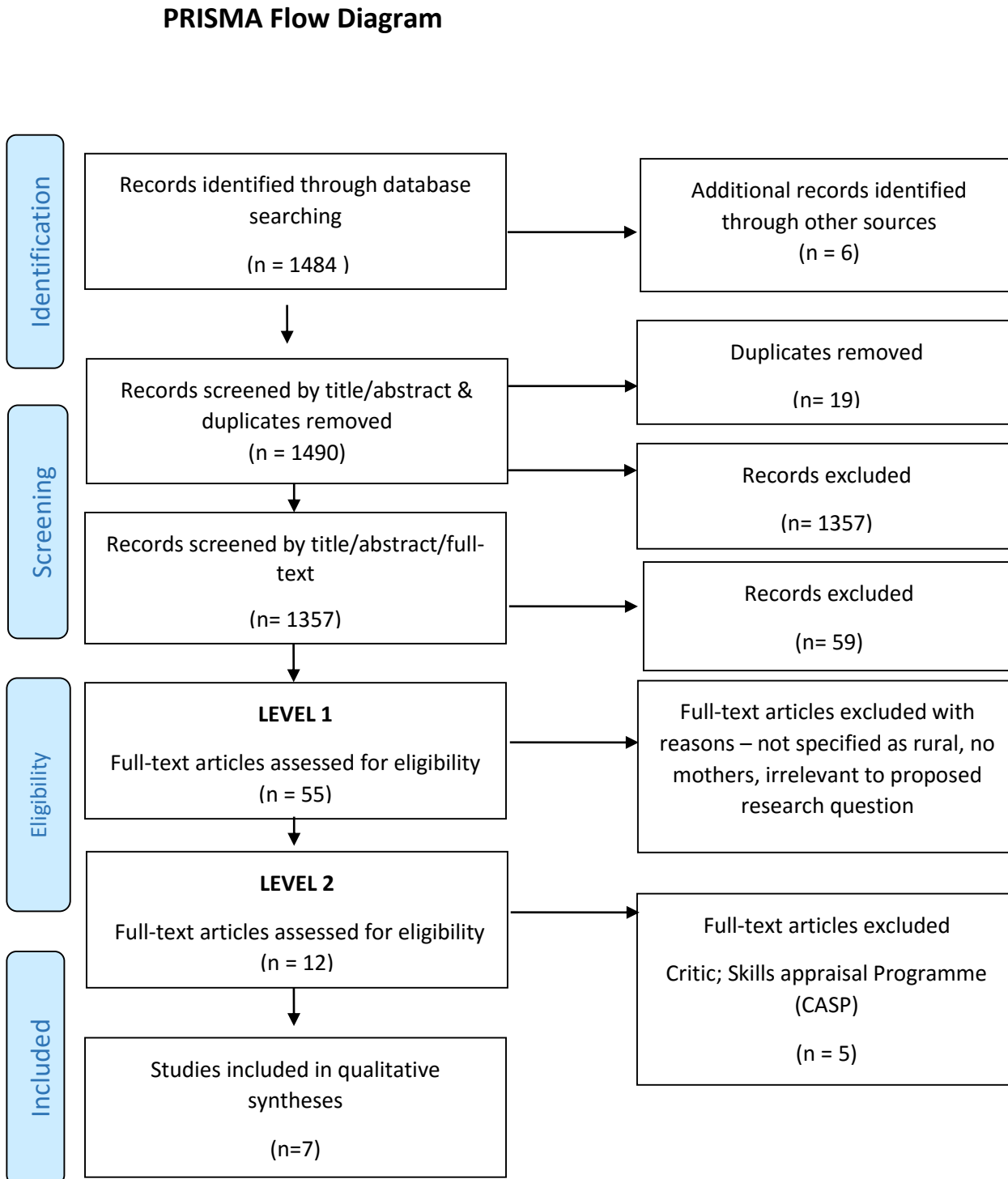
**Table 1.** Search terms.

chronic illness, chronic disease, chronic health conditions, rural, families, family, mothers, maternal, child and children. Each of these concepts included 'chronic' AND 'child' AND 'rural' allowing for truncation and Boolean operators. These three keywords were identified as the major search terms and were combined with the terms and 'mother experience', 'maternal experience', 'mother' and 'family'.

The final group of search terms included: Search 1. child\* AND chronic\* AND rural family; Search 2. child\* AND chronic\* AND rural Mother; Search 3. (mother\* experience) AND (child\* AND Chronic\*) AND rural; Search 4. (Maternal experience) AND (child\* AND Chronic\*) AND rural. These terms were searched for within the title, keywords and abstracts within the articles.



**Figure 1: PRISMA Diagram.**



Themes identified	Sample population and Setting	Struggling for financial resources	Barriers in navigating service needs	Strain of decision-making	Mothers' physical and emotional health	Difficulties in managing everyday activities
Author						
Farmer, Clark, Sherman, Marien, Selva, (2005)	98% mothers 51 participants  Rural United States	✓	✓	✓	✓	✓
Lauver (2010)	Foster mothers 10 participants  Rural United States		✓	✓		✓
Murphy, Christian, Caplin, Young, (2007)	85% mothers 40 participants  Rural & Urban United States	✓	✓		✓	✓
Lutenbacher, Karp, Ajero, Howe, Williams, (2005)	92% mothers 37 participants  Rural & Urban United States	✓	✓	✓		✓
Hoogsteen, Woodgate, (2013)	85% mothers 26 participants  Rural United States	✓	✓	✓		✓
Higgins, Bailey, Pearce, (2005)	97% mothers 53 participants  Rural Australia				✓	✓
Skinner & Slifkin, (2007)	mother identified in statistics data 38866 participants	✓	✓	✓		✓

	Rural United States					
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**Table 2.** Themes identified from the literature.