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## Glossary

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<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>FCC</td>
<td>Family-Centred Care</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>NICU</td>
<td>Neonatal Intensive Care Unit</td>
</tr>
<tr>
<td>PICU</td>
<td>Paediatric Intensive Care Unit</td>
</tr>
<tr>
<td>RM</td>
<td>Ronald McDonald</td>
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<tr>
<td>RMHC</td>
<td>Ronald McDonald House Charities</td>
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Executive Summary

The Social Policy Research Centre (SPRC), UNSW Australia, has conducted a review of the literature on the evidence base on the value of family resource rooms in hospitals. These are clinical-free spaces that offer support away from the ward to families of children who are hospitalised, outpatients or undergoing same day surgery. The review was commissioned by Ronald McDonald House Charities (RMHC) Australia, which is an independent non-profit organisation consisting of a National Body and local House Chapters that support families with seriously ill children via a suite of programs, including funding a Ronald McDonald Family Room program (Family Rooms) in some hospitals in Australia. This document reports the findings of the literature review.

The analytical framework for the literature review search and analysis was designed following short visits to the Family Rooms of three hospitals in NSW – Gosford Hospital, John Hunter Hospital (Newcastle), and the Sydney Children’s Hospital – aimed at engaging in informal observations of and conversations with staff and families. The review includes a summary of administrative data on the use of Family Rooms in Australia. A purposive review methodology was used to provide a comprehensive understanding of the outcomes and perspectives about family resource rooms in hospitals, regardless of their funders. Literature was sought on the needs, experiences, and possible benefits of using family resource rooms for five main stakeholders: children, families, hospital/clinical service providers, the health and social system, and the wider community, e.g. the volunteers who help in the Ronald McDonald Family Room program. The first three of these outcome groups were identified by previous RMHC Global research, and the addition of the health care system and community placed the review in a wider social policy framework.

The review of the literature on the needs of families with hospitalised children shows that these families have a wide variety of needs, including financial, social, emotional, and personal care needs, which often are not met directly by hospitals, health care staff and the welfare system. In particular, families of hospitalised children prefer to be with their child almost constantly and worry about leaving the care area for even short periods. This entails that often parents find it difficult to meet their own personal care needs, including taking a break, washing, eating and sleeping, and they experience lower well-being. Qualitative research shows that parents would be more likely to take a break if: a) they trust that, although they are not there, their child will get the best available care, and b) they have access to facilities nearby the care area where they can eat, wash, and sleep.

Many families caring for children who are hospitalised face high out-of-pocket costs (with travel and meals being the two major costs), potential earning losses, and often high costs related to specialised care for their child. Often families’ financial costs include direct losses of income, in particular when the hospitalisation of the child occurs as an emergency, and

1 In this report, Family Rooms written capitalised refers to the Ronald McDonald Family Room program. The expression ‘family resource room’ is used to refer to family room spaces that are not funded by RMHC or, more generally, to all family room spaces, regardless of their funders.
parents have limited possibilities to arrange leave from work. For many parents, the financial cost of the time spent in the hospital includes the use of a substantial proportion of their annual holiday entitlement. These costs negatively affect all families, in particular those of lower socio-economic background. The reviewed evidence shows that parents of hospitalised children would benefit from the availability of low cost options for food and accommodation in hospitals, as well as from increased access to amenities such as shower facilities, phones, internet, television, and secure storage of personal belongings.

Family areas in hospitals can provide support and respite from the ward to families with hospitalised children. Qualitative research shows that families and visitors need both communal areas and private spaces in which to rest and have some time on their own. Family resource rooms offer a variety of services that research shows are appreciated by families and their visitors. These services include kitchen, shower and laundry facilities, lounges and sitting areas. Some Family Rooms provide sleeping rooms to address families’ sleep deprivation and disruption. Research shows that family resource rooms are spaces that families tend to use more frequently, and which provide higher restorative experiences to families compared to other communal hospital spaces, for example waiting rooms, lobbies, and cafeterias.

The review found literature suggesting that use of evidence-based design in hospital and care facility environments can improve families’ and children’s well-being and healing processes. Nevertheless, there is scant research specifically aimed at investigating how family resource rooms help to support families and whether they have a positive impact on their health and well-being. In particular, no studies were found on the views and experiences of hospital staff in relation to family resource rooms, nor on the role of volunteers in Family Rooms (volunteers are a characteristic of the Ronald McDonald Family Room program).

The review found no direct evidence that the restorative experiences from family resource rooms decrease families’ and children’s stress as measured by anxiety, depression, and mental health functioning. However, there is a lack of research undertaken within a more comprehensive well-being framework aimed at assessing whether family resource rooms help to meet families’ and children’s needs and have any impact on real-time happiness. Real-time measures of happiness ask people how they feel at a certain moment. Consequently, they are less likely to be affected by the ongoing, major source of worry and anxiety represented by a child’s illness and hospital stay, which is likely to affect families’ answers to questions that ask them to offer a summative judgment of their past experiences of family resource rooms.

We conclude by suggesting that the research gap on the role and impact of family resource rooms on families and children can be addressed by embracing a comprehensive theoretical framework (Figure 16) which:

- Identifies the needs of families of hospitalised children, and how they relate to the services provided through family resource rooms and alternative interventions.
• Contextualises families’ needs in relation to the role, resources and needs of other main stakeholders, e.g. the hospital setting including the hospital service providers, the health and social system, and the wider community (e.g. volunteers).

• Explores how family resource rooms’ physical characteristics (e.g. size, distance from the ward, layout, and decoration), social characteristics (e.g. family-volunteer-health care staff interactions) and symbolic characteristics (e.g. the use of the McDonald’s branding) promote or hinder the delivery of their goals, relative to alternative interventions.

Such a framework can help researchers to identify what the main research gaps are in the literature and what research design and methods would best address them.
1 Introduction

The Social Policy Research Centre (SPRC), UNSW Australia, was commissioned by Ronald McDonald House Charities (RMHC) to undertake a review of the literature on the evidence base on the value of family resource rooms in hospitals. These are clinical-free spaces that offer support, away from the ward, to families of children who are hospitalised, outpatients or undergoing same day surgery. The RMHC is an independent non-profit organisation consisting of a National Body and local House Chapters that support families with seriously ill children via a suite of programs, including funding a Ronald McDonald Family Room program (Family Rooms) in some hospitals in Australia and internationally. This document reports the findings of the literature review.

There is an extensive body of literature that shows that caring for a sick child can be a source of considerable stress, both emotional (Kars, Duijnstee, Pool, van Delden, & Grypdonck, 2008; Power & Franck, 2008; Shields, Young, & McCann, 2008) and financial (George, Vickers, Wilkes, & Barton, 2011; Wasserfallen, Bossuatt, Perrin, & Cotting, 2006), and that such stressors can have a negative impact on the carers’ quality of life and mental well-being (Boling, 2005; Klassen, et al., 2008; Lawoko & Soares, 2003). In this review, we refer to families to include parents, other family members, and other significant informal carers supporting the child in hospital.

Research shows that social support is positively related to both physical health, i.e. lower risk of all-cause mortality, and mental health, e.g. lower risk of depression, both in the general population and, in particular, among carers (Holt-Lunstad, Smith, & Layton, 2010; Uchino, Bowen, Carlisle, & Birmingham, 2012; Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2014). Social support is a broad term which ‘includes the supportive ways that different people behave in the social environment’ (Helgeson, 2003, p. 25). The literature discusses different types of social support; however, this concept is usually associated with emotional, informational, and tangible support. Emotional support refers to people who can listen, care, sympathize, provide reassurance and make one feel valued, loved and cared for. Informational support involves the provision of information or guidance, and tangible support entails people providing help with practical issues, such as running errands or providing respite.

Family resource rooms are areas in hospitals aimed at offering support to families. They provide shared facilities, such as lounge, kitchen and laundry areas and, in the case of the Family Rooms, have volunteer staff. Although family resource rooms can be a source of tangible, emotional and informational support, no previous study has reviewed the evidence on the health and well-being outcomes on their users and service providers, their economic costs and benefits, and best practices in their construction and use.

This review aims to provide a comprehensive account of the Australian and international literature on the ways in which family resource rooms or alternative facilities can have a positive impact on all parties involved, i.e. the children and their families, House Chapters, volunteers, hospital staff members and the overall health care effectiveness.
1.1 Objectives

The objectives of the review were:

1. To briefly observe the experience of the children, adults, and staff members about the use, advantages and disadvantages of the family resource rooms to orient the literature review.

2. To identify academic literature and research reports commissioned by government and other agencies on
   a. the value and unique characteristics of family resource rooms, including their economic costs and impact on the well-being of children, families, and hospital staff members
   b. the views and expectations of families and hospital staff members regarding help and support in family resource rooms
   c. alternative models of support for the family resource rooms and how they compare.

3. To summarise routinely collected administrative data on the use of the family resource rooms in Australia (data to be provided by RMHC).

4. To tabulate, map and summarise the identified evidence with reference to the international and Australian national contexts, and any other relevant objectives emerging from the review, e.g. children, adults, and staff members.

5. To identify gaps in the reviewed literature and suggest priorities for improving the evidence base.

6. To identify preferred research and evaluation methodologies to determine the effectiveness of family resource room type interventions.

1.2 Methodology

The methodology was designed to provide an inclusive, transparent and reproducible review of the literature across all relevant fields, including child development, family support, health care, health service organisation, health economics, psychology, and social services. It consisted of three key methods:

- Brief observations and informal conversations in the Family Rooms of three hospitals in NSW — Gosford Hospital, John Hunter Hospital (Newcastle), and the Sydney Children’s Hospital — to inform the analytical framework for the literature review search and analysis.

- A narrative literature review informed by a purposive review methodology.

- A summary of administrative data on the use of Family Rooms in Australia.
The project received ethics clearance from the Human Research Ethics Advisory Panel at the University of New South Wales (application number 9_14_021).

1.2.1 Site observations

The literature review was designed following brief informal observations and conversations with staff and families in the Family Rooms of three hospitals in NSW: Gosford Hospital, John Hunter Hospital (Newcastle), and the Sydney Children's Hospital. These site observations were informed by participant observation, a method used in research on community and health care service delivery (Fudge, Wolfe, & McKeivitt, 2008). This entails observing what happened in the Family Rooms and how the relationships among family members, between family members and volunteers, and between family members and hospital staff members unfolded. The researchers were introduced to the staff members at each site by a representative of the RM House Chapters. Site visits included informal discussions with House Chapter staff and volunteers on their experiences of running the Family Rooms and their views on the needs of the families.

1.2.2 Literature review

The narrative literature review was informed by a purposive review methodology, which aimed to offer a comprehensive panorama of the outcomes and perspectives associated with the use of family resource rooms. The review specifically looked for literature on the needs, experiences, and possible benefits of using family resource rooms for five main stakeholders: children, families, hospital/clinical service providers, the health and social system, and the wider community, e.g. the volunteers who help in the Family Rooms. The first three of these stakeholders were identified by previous RMHC Global research (Lantz, Pollack, & Franck, 2012), whereas the last two, i.e. the health care system and the wider community, placed the review in a wider social policy conceptual framework, and were confirmed as relevant from the three site observations that took place in June 2014.

Table 1 shows the five stakeholders and the keywords for each group together with three other thematic groups of keywords aimed at focusing the literature searches specifically on family resource rooms and alternative facilities, the settings in which they can be met, i.e. hospitals, and the process factors that can generate outcomes in the five outcome groups, e.g. support. In particular, the keywords on process factors were used as a complementary search strategy to the keywords on family resource rooms and alternative facilities in order to cast as wide a net as possible in relation to relevant literature. The keywords for the stakeholder group children were chosen in such a way to include children from birth to 18 years. No keywords for outcomes were included in order to keep the searches as inclusive as possible.
<table>
<thead>
<tr>
<th>Thematic groups</th>
<th>Keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholders</td>
<td></td>
</tr>
<tr>
<td>Families</td>
<td>Famil*, parent*, carer*, guardian*, relative*, sibling*, guest*</td>
</tr>
<tr>
<td>Children</td>
<td>Hospital?ed child*, newborn*, neonate*, infant*, teenager*, adolescent*, minor, kid*, boy*, girl*</td>
</tr>
<tr>
<td>Hospital/clinical service provider</td>
<td>Hospital, doctor*, nurse*, hospital staff, NUM</td>
</tr>
<tr>
<td>Community</td>
<td>Volunteer*, voluntary worker*, charit*, unpaid, altruist*, activis*, peer or self-help group, budd*</td>
</tr>
<tr>
<td>Health and social system</td>
<td>Corporat*, non-government, NGO*, public, private, voluntary, social policy, ethic*, public health, politic*, interest*, implication*</td>
</tr>
<tr>
<td>Family resource rooms and alternative facilities</td>
<td>Family room, Ronald McDonald, family space, design, construction, room*, lounge*, play area*</td>
</tr>
<tr>
<td></td>
<td>area/room/facility*, starlight, sitting area, waiting area, inpatient area*, amenity*, facility*, kitchen*, dining area/room*</td>
</tr>
<tr>
<td></td>
<td>facilt*, eating, refresh*, vending machine*/area/room/facilit*, kettle, tea and coffee, snack*, refrigerator, microwave, shower, bathroom*, toilet*, laundry, washing machine, dryer, overnight stay, lodging, sleep*, wall bed*, hospital stay, guest house*, accommodation, residence, inn, cottage*</td>
</tr>
<tr>
<td>Setting</td>
<td>Hospital*, clinic, ward, unit, health centre, hospice, asylum, infirmary, sick bay, dispensary, surgery centre, emergency room, sanitarium</td>
</tr>
</tbody>
</table>

Note: The asterisk and the question mark are ‘wild cards’ that entail respectively all possible endings of a word and different spellings.

All the keywords related to each thematic group in Table 1 were searched together using the Boolean operator OR – e.g. (famil* OR parent* OR carer* etc.) – and then combined with each other, using the Boolean operator AND, as in the following examples:

- **Family resource rooms and alternative facilities keywords AND Setting keywords**
- **Target population keywords AND Setting keywords AND Process factors keywords**
- **Target population keywords AND family resource rooms and alternative facilities keywords AND Setting keywords**

These search strategies allowed us to address the following type of research questions related to the study objectives 1a, 1b, and 1c: What are the characteristics of family resource rooms and similar alternative facilities? What forms of help and support are available to families with hospitalised children? What outcomes do families and children experience from using family resource rooms or alternative facilities? What is the role of the different mechanisms that can generate such outcomes?

Similarly the keywords for hospital and clinical service providers, the health and social services, and the wider community, were searched together using the Boolean operator OR,
and subsequently combined with the keywords of the thematic group ‘family resource rooms and alternative facilities’ using the Boolean operator AND, as in the following examples:

- Hospital/clinical service provider keywords AND family resource rooms and alternative facilities keywords
- Health and social system keywords AND family resource rooms and alternative facilities keywords
- Community keywords AND family resource rooms and alternative facilities keywords.

This set of search strategies allowed us to address the following research questions related to the study objectives 1a, 1b, and 1c: What outcomes do hospital staff members experience from using family resource rooms or alternative facilities? What are the policy and public health implications of having family resource rooms in hospitals? What are those of alternative facilities?

The searches were undertaken in the following databases relevant for the social study of health and illness in hospital settings:

- MEDLINE
- PsycINFO (for psychology)
- CINAHL Plus (nursing)
- Social Sciences Citation Index (for Sociology and economic disciplines)
- APAIS-Health (Australian Public Affairs Information Service).

Keywords were searched as Subject Headings, where available, and in all fields of each database in order to get an idea of the amount of literature available. The searches covered January 2004 to June 2014.

Grey literature (informally published material) was identified using similar search strategies in the search engine Google, which allows using limiters to search across specific web sites or domains and limiting to PDF format (most grey literature is made available in PDF). Relevant national websites, such as FAMILY: Australian family & society abstracts, Australian Government departments, RMHC, and hospital websites were also trawled and the following two databases dedicated to grey literature were searched:


Titles and abstracts of studies identified by the searches in each of the databases were downloaded in an Endnote library (a powerful reference manager program). The Titles and Abstracts of the retrieved literature were screened based on their relevance with regard to the research objectives. In order to be as inclusive as possible, there were no exclusion criteria based on the study design, e.g. randomised controlled trials or qualitative studies.
However, the type of evidence available in relation to the relationship between family resource rooms or relevant alternatives is exemplified in the review.

The full text of the selected studies was retrieved, read and summarised in ‘note cards’ style summaries in a Word document, which included the types of setting investigated, the main study findings, i.e. the outcomes, needs, views, and relationships of the five stakeholders mentioned above.

1.2.3 Routinely collected quantitative data

Routinely collected data on visits to Family Rooms in Australia was provided to the research team by RMHC and analysed to illustrate the main trends in the use of the Family Rooms in Australia. The data consisted of the number of visits to nine Family Rooms across Australia. This data is recorded through door sensors (Beonic Technologies Ltd) that count each single time someone enters the room. This way of counting visits generates an overestimation of the number of people who use the rooms because multiple entries by the same person are counted as different individuals. Bullen (2013) compared the door sensors’ data with that from signing-in books of the Family Rooms at the Monash Children’s Hospital and at the John Hunter Hospital and found that “42% of the weekly Beonic data count of the Family Room at the Monash Children’s Hospital and 47% of the weekly Beonic data count of the Family room at the John Hunter Hospital is a good indicator of the total number of real guests entering each respective Family Room in 2013” (p. 2). In this report we used 44 per cent of the door sensors’ data as a conservative average of the estimate percentages found at the Family Rooms at the Monash Children’s Hospital and at the John Hunter Hospital (respectively 47 per cent and 42 per cent). This provides an estimate of the number of visits at the nine hospitals (Section 3.2)

1.3 Report structure

The rest of the report is structured in the following way. Chapter 2 sets the background for the analysis of family resource rooms by reviewing the literature on the needs and experiences of parents and carers with a sick child in hospital. Chapter 3 reviews the literature on family resource rooms. It starts by offering statistics on their availability and the frequency of use of the Ronald McDonald Family Room program in Australia. It then describes the main characteristics of family resource rooms, including the Ronald McDonald ones. The outcomes associated with the provision and use of family spaces in hospitals are then reviewed prior to discussing the literature on their implications for hospital staff members and the wider health and policy system. The report concludes by offering a discussion of the evidence reviewed against the needs of families with hospitalised children, and by suggesting areas for future research projects.
This chapter reviews recent research on the needs and experiences of families with sick children when the children are in hospital. There is strong evidence that shows that having a child in hospital is a major source of stress and anxiety for the whole family (Board, 2004; Board & Ryan-Wenger, 2000, 2003). Further, research shows that such stress and anxiety can have lasting effects even months after discharge from hospital (Board & Ryan-Wenger, 2002; Colville, et al., 2009).

Understanding the needs of families of hospitalised children is a fundamental element in the promotion of their health and well-being, and in supporting families' presence at the hospital with their children. Overall, research shows that participation by families in their child’s care promotes positive outcomes for both the family unit and the child (Chapter 3). From this point of view, information on the needs of parents in hospitals is relevant regardless of the specific model of care adopted, be it a traditional disease-based model of care (in which patients and their families are seen as passive recipients of care); a parent participation or partnership in care model (which places the child at its core and calls for parents to participate in the care of their child in hospital); or a family-centred care model of care. Family-centred care has the family as a whole at its core, can extend beyond the hospital setting, and does not necessarily entail family participation in the care of the child if this would not be conducive to healthy family functioning (Power & Franck, 2008; Shields, 2010; Shields, Pratt, & Hunter, 2006; Shields, et al., 2012).

The rest of this chapter is organised around the two main sets of needs that are discussed in the literature on the needs of families of hospitalised children: financial needs and personal care and emotional needs, e.g. sleep and communication with health staff members. The chapter ends with a bullet point summary of the main findings.

2.1 Financial needs

There are many studies on the financial costs of caring for children with chronic conditions (e.g. Galbraith, Wong, Kim, & Newacheck, 2005; George, et al., 2011; Kuhlthau, Hill, Yucel, & Perrin, 2005; Newacheck, Inkelas, & Kim, 2004; Su, Kemp, Varigos, & Nolan, 1997; Thyen, Kuhlthau, & Perrin, 1999), but only scant research on the costs borne by families when their children are hospitalised (Callery, 1997; Wasserfallen, et al., 2006). Overall, both sets of literature report consistent evidence that parents caring for children with a chronic condition, or who are hospitalised, face high out-of-pocket costs, potential earning losses and often high costs related to specialised care for their child (Callery, 1997; Wasserfallen, et al., 2006). The costs of caring for a child with a chronic condition are more likely to affect low income families negatively (Galbraith, et al., 2005; Newacheck, et al., 2004). However, as research from Australia shows, full-time working parents who care for a child with chronic illness also struggle financially to care for themselves and their child, and may need special support to help them balance their dual roles (George, et al., 2011).
2.1.1 Financial costs of having a child hospitalised

In a study of 16 families whose children totalled 695 hospital days in the paediatric intensive care unit (PICU) of the University Hospital of Lausanne, Switzerland, Wasserfallen et al. (2006) found that families experienced a very heavy financial burden. Travel and meals were the two major costs\(^2\). In particular, Wasserfallen et al. (2006) found that the 16 families spent an average out-of-pocket amount of CHF 86 (\(\sim\)AUS$ 100\(^3\)) per day, or CHF 2,616 (\(\sim\)AUS$ 3,058\(^3\)) per month, on travel and/or meals and communication costs. Eight families (53 per cent) also experienced various levels of earning losses directly related to the hospitalisation of their child, which ranged from CHF 1,175 (\(\sim\)AUS$ 1,373) to CHF 3,346 (\(\sim\)AUS$ 3,911) during the hospital stay. The families most severely affected by income losses were those with other children (67 per cent) and with jobs allowing less flexibility in the working schedule, whereas the travel distance was not found to play an important role. The amount of lost earnings was variable and was found to be markedly different if the hospitalisation occurred as an emergency or was elective surgery. In the former case, parents had limited possibilities to arrange leave from work, whereas in the latter case, professional leave could be arranged in advance. Non-travellers spent more on meals and communication on a daily basis than travellers. Although Wasserfallen et al. (2006) found a wide variation in the amount of incurred costs between the individual families and between the different cost categories, these differences were not statistically significant; in other words, they could have been due to chance rather than to actual differences between the families.

Similar findings were reported in two qualitative studies, one from England (Callery, 1997) and one from Canada (Stremler, Dhukai, Wong, & Parshuram, 2011). Callery (1997) interviewed the parents of 24 children discharged from a surgical ward of a children’s hospital about the financial, social, and personal costs that they experienced. Callery (1997) found that families’ financial costs included direct losses of income or holiday as for some parents the cost of the time spent in the hospital was the use of a substantial proportion of their annual holiday entitlement. Food and drink were also reported as onerous expenses by some parents who experienced difficulty providing themselves with adequate and affordable food and drink while they were in hospital (Callery, 1997). Some parents were able to ask their relatives to bring sandwiches when they visited the hospital; however, others had to rely on the hospital canteen. Callery (1997) emphasises the ambiguous position of parents in the hospital, whereby they were partners in the care of their child, but not entitled to free meals or the discount offered to hospital workers in the canteen.

Similarly, in a qualitative study on sleep experiences of 118 parents with children staying in a PICU, Stremler, Dhukai, Wong and Parshuram (2011) found that participants reported the financial demands of parking, lodging away from home, lost time from work, and eating away from home as the main issues affecting their sleep. Parents suggested seeking financial support when available from social programs and family members, and recommended that

\(^2\) Meals costs were computed on the basis of incurred costs whereas travel costs were computed on the basis of price lists available from the French speaking consumer association. Both meals and travel costs were computed as the amount of parental out-of-pocket costs in excess of usual expenses (Wasserfallen et al., 2006).

\(^3\) Currency conversion last calculated at www.xe.com on 27/08/2014.
hospital programs better provide families with low cost options for food and accommodation as well as increased access to amenities such as phones, internet, television, secure storage of personal belongings, and shower facilities (Stremler, et al., 2011).

These latter findings raise the issue of the communication between hospitals and families in relation to their financial and other support needs. An American survey of 484 adult outpatients and 133 general physicians explored patient-physician communication in relation to health care related out-of-pocket costs (Alexander, Casalino, & Meltzer, 2003). It found that 63 per cent of patients wanted to talk about their out-of-pocket expenses with their physicians, and 79 per cent of physicians believed that patients in general want to discuss these costs. Nevertheless, only 35 per cent of physicians and 15 per cent of patients reported ever having discussed out-of-pocket expenses. This study shows that there is an important gap between what patients and physicians believed as important and what actually happened in their interactions.

### 2.2 Personal care and emotional needs

In a systematic review of the literature on parent participation in the care of hospitalised children, which explored studies published from January 1994 to June 2006, Power and Franck (2008) identified three primary parents’ needs from ten descriptive studies, both qualitative and quantitative:

- to be with their child in hospital;
- to receive information about their child’s hospital care;
- to receive practical and emotional support for participating in the care of their child.

Parents’ need to be with their child was similar across all hospital settings, including general acute paediatric medicine and surgery wards, paediatric intensive care, and day surgery (Power & Franck, 2008). ‘Being there’ (Kars, et al., 2008) is a particularly central need which is consistently reported across the literature on the experiences of parents with a child in hospital (Dampier, Campbell, & Watson, 2002; Shields, et al., 2008; Wigert, Berg, & Hellström, 2010). However, Power and Franck (2008) report that ‘parents of chronically ill children also expressed a need to take a break with assurance that nurses would assume their parental responsibilities’ (Power & Franck, 2008, p. 636).

The importance of a break for parents of chronically ill children also emerged from a study aimed at exploring the environmental needs of 33 parents of 26 children who were hospitalised and died in a PICU (Meert, Briller, Schim, & Thurston, 2008). Meert et al. (2008) report that ‘to cope with ongoing stress, parents often recalled their need to get away’ (p. 625) and to find ‘a different four walls to look at’ (p.625). Participants reported fulfilling this need by going to different places including the Ronald McDonald House, the hospital chapel, the cafeteria, the gift shop, the pharmacy, smoking and outdoor areas, which helped them to fulfil the need to get a break while also meeting other needs, such as resting, reflecting, praying, eating, smoking, or getting some fresh air (Meert, et al., 2008). Overall, participants spoke about their need for items, activities, and facilities that allowed them to care for themselves while being at the hospital. The need for food nearby was mentioned by many parents, who still, however, worried about leaving the care area even for short periods.
Meert et al. (2008) also report that during their child’s hospitalisation parents needed rest and many wanted to sleep in their child’s room. This need came with other practical ones, such as having access to bed linens when spending the night at the hospital. Lack of provisions to sleep, for example pillows, blankets and comfortable surfaces were also reported as factors contributing to poor sleep in the qualitative study by Stremler et al. (2011) on the sleep experiences of 118 parents with children staying in a PICU. Meert et al. (2008, p. 626) summarise the critical need for rest by the following extract from a father’s interview: So I was feeling run down, my wife was feeling run down . . . when she finally died [referring to the daughter], I felt that they should hospitalize us . . . I was absolutely exhausted and it was physical.

Similar needs in relation to personal care, nutrition, and sleep were also reported in a qualitative study of 15 families of children who were critically ill and admitted to a PICU in England (Dampier, et al., 2002). In this latter study, the lack of facilities to accommodate families’ basic needs, such as having a snack near the bedside, was particularly emphasised. The topic of rest and sleep is further discussed in section 3.2.1.

Similar results were found in an Australian study by Shields et al. (2008) that aimed to compare the views of 127 parents and 79 health staff members (including nurses, doctors and allied health staff, e.g. physiotherapists and play therapists) in relation to the list of 51 needs of parents of hospitalised children contained in the Needs of Parents Questionnaire (NPQ). This study was part of a wider cross-cultural research project that was also undertaken in Sweden and England. Shields et al. (2010) state that in the three countries, staff and parents reported that their most important needs were, in descending order:

1. being trusted
2. communication
3. support and guidance
4. having their physical needs met
5. trusting that their child would get the best care possible.

Needs relating to other family members were ranked the least important (Shields, 2010).

Shields et al. (2008) found that although parents and staff mostly agreed on the priority of needs, there were major differences with regard to the degree of assistance that parents required to have their needs met. Below, we summarise the findings in relation to 15 needs that are relevant for this review, and which, for practicality, we group in four main themes – social support, personal care, caring, and privacy – including the need of parents to:

**Social support:**

- have a scheduled meeting with other parents to share and discuss the experience of their children’s hospitalisation

- be able to meet with parents an ill child with similar experiences of
• have contact with a social worker to obtain information about financial assistance.

**Personal care:**

• ensure sufficient rest and sleep
• have a nurse assisting them to recognize their own needs, e.g. meals, sleep
• have a place to sleep in the hospital
• have private bath and shower facilities.

**Caring:**

• stay with their child 24 hours a day if they wish
• have meals with their child on the ward/unit
• be able to ‘room in’ with their child
• be encouraged by staff to come and stay with their child
• feel that they are important in contributing to their child’s well-being
• know that their child will receive proper schooling to avoid falling behind in educational development
• have time to be with their other child/children.

**Privacy:**

• have a special place in the unit where parents can be by themselves.

The majority of both parents and staff indicated that 14 out of the 15 needs listed above were important (table in Appendix 1). The only exception was the need for a scheduled meeting with other parents, which the majority of parents indicated as not important (58 per cent, n= 127), whereas the majority of staff reported as important (73 per cent, n=75). Nevertheless, the majority of both parents and health care staff reported that being able to meet with parents with similar experiences of an ill child was an important need for parents of hospitalised children (95 per cent of the health staff reported this as an important need as opposed to 67 per cent of the parents, p <0.001). In some cases, a higher percentage of health care staff reported the listed needs as important compared to parents, resulting in statistically significant differences (table in Appendix 1). Shields et al. (2008) interpreted these differences as a high level of recognition by the health care staff of parents’ needs. Alternatively, the differences in the perceived importance of certain needs between parents and health care staff may be interpreted as an example of health care staff being out of
touch with the parents’ needs and perceived level of independence, as will be discussed below.

Similarly, the majority of both parents and staff indicated that 14 out of the 15 needs listed above were met. The only exception was the need to meet with parents with similar experiences of an ill child, which 52 per cent of parents reported as not met, whereas the majority of the health care staff respondents (76 per cent) viewed it as a need that was met for parents of hospitalised children.

Finally, the majority of both parents and staff indicated that parents of hospitalised children needed help to meet the 15 needs listed above. However, compared to parents and in reference to all 15 needs, a higher proportion of the health care staff reported that parents needed assistance in having their needs met (table in Appendix 1). Shields et al. (2008) interpreted these results as a lack of knowledge by parents of assistance available to them, or possibly as a paternalistic attitude of staff towards the parents, whereby parents of hospitalised children were in fact more independent than staff perceived them to be.

2.2.1 Sleep

There is growing research on the sleep patterns of parents of hospitalised children, and how they relate to their health and well-being. These research findings consistently show that parents with hospitalised children experience sleep deprivation and disruption resulting in fatigue, sleepiness, increased stress and reduced well-being in the form of a decline in optimism, sociability and psychosocial functioning (Jee, et al., 2012; McCann, 2008; Meltzer, Davis, & Mindell, 2012; Stremler, et al., 2014). However, the literature reports contrasting findings on the benefits of sleeping in the proximity of the child as opposed to more comfortable locations away from the hospital, such as hotels, a relative’s or friend’s home, designated parent room in hospital, or residences such as RM Houses. For example, in a study aimed at comparing the sleep quality and quantity of 38 parents who slept at their hospitalised child’s bedside with parents who slept at a hospital’s onsite RM House in the UK, Franck et al. (2014) found that parents who slept at the child’s bedside experienced more sleep disruption (wake after sleep onset), reported poorer sleep quality and feeling less rested than parents who slept at the RM House.

However, Stremler et al. (2014) highlighted some methodological limits in the study by Franck et al. (2014) and performed a prospective observational study of 118 parents of critically ill children using objective measures of sleep (i.e. actigraphy4) and validated scales to assess fatigue and sleepiness. They found that sleeping in a hotel, parent room, or residence, e.g. a RM House, was associated with 3.2 more wakes per night than sleeping in a hospital lounge or waiting room. They concluded that parents are better able to achieve sleep when in closer proximity to their child, as opposed to an environment with amenities

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4 ‘Actigraphs are wrist watch like devices that record motion data with a battery-operated microprocessor that senses motion [...] Detected movements are translated into digital counts across 1-minute intervals and stored in internal memory so that they can later be analyzed to determine objective sleep-wake times. Parents wore Octagonal Basic Motionlogger actigraphs (Ambulatory Monitoring, Ardsley, NY) on their non dominant wrist for five consecutive days and nights beginning at enrolment’ (Stremler, et al., 2014, p. e57).
for sleep but distant from the child (Stremler, et al., 2014). Different preferences and experiences among parents about sleep locations were also discussed in the qualitative study by Stremler et al. (2011) on the sleep experiences of parents with children staying in a PICU. Stremler et al. (2011) report that parents described being at the bedside and sleeping away from their child as both facilitating and interrupting sleep, and describe how parents had different preferences in relation to when and where to sleep.

Overall, Stremler et al. (2011) found that although parents acknowledged the importance of caring for themselves in order to achieve good sleep – for example through exercise, healthy eating and taking opportunities for rest – they reported finding it difficult to do so, and thought that they may need permission and assistance from health care professionals to access these opportunities. Stremler et al. (2011) concluded by suggesting to health practitioners that communicating to parents ‘that others in their situation found that self-care helped them better support their child may be more effective than simple admonishments to get sleep or take a break from the hospital’ (p. 43). Similarly, in a study aimed at evaluating and comparing the needs, stressors, and coping strategies of 182 parents in a PICU, Jee et al. (2012) found that the main coping strategies employed by parents were related to trust, assurance, and outcomes, including ‘believing my child is getting the best care available’, ‘talking to medical/nursing staff’, ‘believing my child will get better’, ‘believing that the hospital has my family’s best interest in mind’, and also ‘spending long periods of time at my child’s bedside’. However, coping strategies relating to parental comfort, support from nonclinical people, and access to facilities, such as eating well and sleeping, were used to a lesser extent (Jee et al., 2012).

2.3 Summary

Families caring for children with a chronic condition, or who are hospitalised, face high out-of-pocket costs, with travel and meals being the two major costs. They often also face potential earning losses and high costs related to specialized care for their child. These negatively affect all families, in particular those of lower socio-economic background. Health care providers and policy makers need to review their approach to this issue by providing more low cost options for food and accommodation as well as increased access to amenities such as shower facilities, internet, secure storage of personal belongings, and television.

Many families of hospitalised children prefer to be with their child almost constantly and have a strong need to receive regular information regarding their child. However, family members also need to be able to meet their own personal care needs, including taking a break, eating, and sleeping. Research shows that although parents acknowledge the importance of taking care of themselves while caring for their child at the hospital, they find it difficult to do so because they worry about leaving the care area even for short periods. Qualitative research shows that parents would be more likely to take a break if they trust that although they are not there, their child will receive the best available care and if they have access to facilities nearby the care area where they can eat, wash, and sleep. Overall, these findings show that parents need assistance and support from health care professionals to access opportunities for sleep, healthy eating, and exercise.
Research shows important communication gaps between patients and health care professionals. An American survey found a major discrepancy between the importance both patients and physicians gave to discussing out-of-pocket expenses and the fact that these were hardly ever actually discussed during their interactions. Qualitative research suggests that communication regarding the importance to get sleep or take a break for family members caring for hospitalized children can be more effective if based on the experiences of self-care of other families rather than if based on admonishments from health care staff.

Parents of hospitalised children experience sleep deprivation and disruption resulting in lower well-being. However, the research findings are conflicting in terms of whether parents sleep better when spending the night near their children or in more comfortable locations away from the hospital.
3 Family resource rooms and alternatives: Characteristics, role, and outcomes

When a child is admitted into hospital, the whole family is affected and this needs to be considered by the hospital, nurses, and doctors (Shields, et al., 2008). In recent extensive reviews of the literature that included hundreds of studies based on different research designs, Ulrich et al. (2004; 2008) report a growing body of evidence that family presence generates reciprocal benefits for both paediatric and adult patients and their families across different health care settings. Research shows that family presence can benefit patients by contributing to reducing their stress and anxiety, alleviating pain, improving clinical outcomes, reducing length of stay, and increasing patient satisfaction (Davies, 2010; Hopia, Tomlinson, Paavilainen, & Åstedt-Kurki, 2005; Shields, et al., 2008; Ulrich, Berry, Quan, & Parish, 2010; Ulrich, Quan, Zimring, Joseph, & Ruchi, 2004; Ulrich, et al., 2008). Similarly, family members’ capacity to visit and stay with patients during hospitalisation can meet families’ emotional needs and increase their satisfaction, particularly for families of hospitalised children (Kars, et al., 2008; Meert, et al., 2008; Shields, et al., 2008).

Children’s hospitals and wards in Australia, and in many other Western countries, have adopted family-centred care (FCC) as their primary model of care delivery to children and families (Davies, 2010; Mikkelsen & Frederiksen, 2011; Shields, 2010). FCC is defined as:

…a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognised as care recipients’ (Shields, et al., 2006, p. 1138).

Effective FCC requires the provision of ongoing support to families to enable them to be involved in the care of their child, should they wish to (Shields, 2010; Shields, et al., 2006).

Family resource rooms are hospital spaces aimed at providing support to parents and carers with hospitalised children through the provision of services and amenities, such as kitchen, shower and laundry facilities, lounges and sitting areas. Their purpose is to provide some respite from the ward and, thereby, to help meet some of the families’ financial and personal care needs, for example by saving money on accommodation and dining out (Chapter 2).

Although studies are yet to establish a direct link between psychological outcomes of children’s hospitalisation and specific hospital design features (Section 3.4), overall, the literature suggests that:

… health care environments that are appropriate for children (a) allow children to function at the peak of their abilities in many domains (such as making adaptive technologies available to do schoolwork) and (b) provide opportunities for social and emotional support for both children and parents (like private hospital rooms or easily accessible family meeting areas) (Cartland, 2013, pp. 4-5).

Similarly, Ulrich et al. (2010, p. 103) assert that:
... a health care building that supports family presence typically incorporates certain features specifically designed for the comfort of family and other visitors. Such features include quiet waiting rooms with flexible, comfortable group seating; an overnight bed in patient rooms; internet access; work spaces; personal storage; and private bathrooms' (Ulrich, et al., 2010).

In a qualitative study with 51 hospital inpatients in the elderly and maternity wards at Salford Royal Hospitals NHS Trust, in the UK, Douglas and Douglas (2004) found that many participants stressed the importance of having homely environments where 'they could offer visitors a cup of tea, or for long stay patients, somewhere they could go for a meal with friends or family' (p. 71). The participants in this study suggested that this need could be addressed by including in future design models ‘the provision of cafe’ bars, restaurants, gardens and leisure facilities that they could use with families and friends (p. 71). The importance of communal spaces for patients and visitors was also emphasised in Harris, Shepley, White, Kolberg and Harrell’s (2006) multi-method study aimed at exploring the implications on family experience, neonate outcomes, staff perceptions, cost and environmental design of single family room, open-bay, combination and double-occupancy configurations of neonatal intensive care units (NICU). Harris et al. (2006, p. s45) concluded that:

… designated congregate family space is important, regardless of configuration type. Providing space for family members to step away from the infant station for respite and the opportunity for family-to-family social support are valuable activities that can be supported by the design of the unit, regardless of configuration'.

Similarly, in a systematic review of the evidence on the relationships between paediatric hospital environments and the health outcomes of children and adolescents, Watts and Wilson (2009) report that the findings from three of the eight studies that focused on teenagers showed that although privacy was a dominant theme, teenagers wanted ‘to balance this with facilities that allow them to interact with their fellow patients and friends’ (p. 919). Such facilities included:

…access to cooking facilities or a kitchen where they can cook or make snacks […] which not only helps adolescents maintain independence but also provides opportunities to interact with their peers/friends. A separate soundproof activity room also meets this need as well as a space they can share with peers but not with staff.

These findings show the importance of communal spaces where both families and patients can have a break from the hospital routine. In particular, Watts and Wilson (2009) show the importance for teenage patients to have a space where they can socialise with their peers/friends and exercise some form of independence.

The rest of this chapter reviews the literature that has explored the processes and outcomes related to family resource rooms in hospitals. There is a lack of studies aimed at investigating these specific hospital areas. However, some findings are reported in evaluations of hospital services and in studies on families’ experiences of hospital visits and stays.
3.1 Family resource rooms

We did not find any official statistics on the number of family or parent rooms in hospitals in Australia; however, it is likely that most Australian hospitals provide some space dedicated to parents and families, as in other Western countries. The Department of Human Services Victoria (2014, p. 52) refers to family resource rooms as ‘patient lounges’ and describes them as providing:

... a change of environment away from clinical areas for patients and visitors. It is an area where family groups can visit and patients can socialise. The Patient Lounge shall have a minimum floor area of 15 m². Depending on the patient population, number of single rooms and access to other sitting areas, a ratio of 0.8 m² per patient may be used to calculate the area of a Patient Lounge ... It should be on an external wall to take advantage of natural light and outlook [and] should be located away from patient bedrooms but staff should be able to observe and monitor its use by patients, with direct access to the Unit corridor. Where possible, direct access to a secure landscaped area offering partial covering against sun, wind and rain should be provided ... Low window sill heights promote access to a view from a seated position.

In an online survey of managers of neonatal units undertaken between November 2007 and April 2008 in the UK (n=173, response rate 72 per cent), Redshaw et al. (2010) note that almost all units had rooms in which parents could stay (Table 2). In a similar online survey of American and Canadian Child Life Departments in major paediatric hospitals (defined as having an inpatient census >200 patients) undertaken between May and August 2007 (n=109, 50 per cent response rate), Newton, Wolgemuth, Gallivan and Wrightson (2010) found that 52 per cent of the surveyed hospitals offered a family resource room, and 49 per cent a room for teenagers. It is, however, unclear what these family resource rooms looked like, and what services were offered.

It can be expected that many Australian hospitals offer similar facilities although the standard may vary greatly among hospitals. For example, the observations undertaken for this study showed differences in the spaces available for families at the John Hunter Children’s Hospital in Newcastle and at the Gosford hospital children’s ward. Although both rooms were painted in the same neutral colour as the rest of the ward and had no wall decorations, the family resource room at the John Hunter Children’s hospital had a table, laundry facilities, and a kitchenette. The family area at the Gosford’s hospital children’s ward, however, consisted of a waiting room with a few chairs and, in a corner, a small sink and a wall-mounted hot water boiler (the room was in the process of being restructured and the kitchenette facilities discontinued as a result of the opening of the Ronald McDonald Family Room near the entrance to the children’s ward).
Below we provide two examples of family resource rooms, one from the United States and one from Australia. We then introduce the Ronald McDonald Family Room program.

### 3.1.1 Family great rooms and Family Life center (Ann & Robert H. Lurie Children’s Hospital of Chicago)

The Ann & Robert H. Lurie Children’s Hospital of Chicago, Illinois (formerly Children’s Memorial Hospital) was established approximately 130 years ago, and has recently been moved into new premises (Cartland, 2013). The new hospital was built following the evidence-based hospital design literature on the impact that building design can have on patients’ stress, patient and staff safety, staff effectiveness, and care quality. For example, the new hospital includes a number of respite spaces for family members which were not available in the previous hospital. The two main examples of such spaces are:

- The Family Life Center (Figure 1), which is ‘the main respite area for all inpatients and their families, providing a variety of helpful activities, work spaces and rest areas’ (Ann & Robert H. Lurie Children’s Hospital of Chicago, 2014b). The Family Life Center is located near the Family Learning Center, which is another resource for families and the Sleep Rooms. Both are operated by RMHC and contain bedding and decorations donated by Denihan Hospitality, which are the operators of the Mile North and James hotels (Ann & Robert H. Lurie Children's Hospital of Chicago, 2014b). The Family Life Center includes an interactive TV studio sponsored by an IT health care company (Figure 2).

<table>
<thead>
<tr>
<th>Facility</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>All units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfortable chairs at the cotside</td>
<td>100.0</td>
<td>96.0</td>
<td>97.2</td>
<td>97.4</td>
</tr>
<tr>
<td>Toys/play area</td>
<td>100.0</td>
<td>98.0</td>
<td>93.0</td>
<td>96.0</td>
</tr>
<tr>
<td>Kitchen facility for making tea and coffee</td>
<td>83.9</td>
<td>95.9</td>
<td>87.1</td>
<td>89.3</td>
</tr>
<tr>
<td>Sitting room for parents</td>
<td>80.6</td>
<td>87.8</td>
<td>84.3</td>
<td>84.7</td>
</tr>
<tr>
<td>Parent rooms for overnight stay</td>
<td>93.5</td>
<td>98.0</td>
<td>95.8</td>
<td>96.1</td>
</tr>
<tr>
<td>% Parent rooms with double or sofa bed</td>
<td>69.8</td>
<td>62.3</td>
<td>76.0</td>
<td>71.0</td>
</tr>
<tr>
<td>% Parent rooms with shower and toilet en suite</td>
<td>12.7</td>
<td>28.9</td>
<td>30.2</td>
<td>26.9</td>
</tr>
<tr>
<td>% Parent rooms with kitchen facilities nearby</td>
<td>76.2</td>
<td>90.3</td>
<td>83.2</td>
<td>84.2</td>
</tr>
</tbody>
</table>

Source: Redshaw, et al. (2010, Table 2, p. F366)
Figure 1 Family Life Center at the Ann & Robert H. Lurie Children’s Hospital Chicago

Figure 2 Family Life Center – Skylight TV Studio at the Ann & Robert H. Lurie Children’s Hospital Chicago
The ‘family great rooms’, which are present on each inpatient floor and consist of comfortable community spaces where patients and their families can get away from the hospital room, cook meals together, play board games, or watch a movie (Cartland, 2013) (Figure 3).

**Figure 3 ‘Family great room’ at Ann & Robert H. Lurie Children’s Hospital Chicago**

![Image of a family great room at Ann & Robert H. Lurie Children’s Hospital Chicago](source: Ann & Robert H. Lurie Children's Hospital Chicago (2014c))

These family facilities were designed ‘with the hope that they will help parents restore their energy and reduce their stress’ (Cartland, 2013, p. 30) and so expand their capacity to be effective co-carers during their child’s hospitalisation (Cartland, 2013).

Cartland (2013) used parent interviews and photo questionnaires to collect the reactions of parents and children to six specific design features in the hospital: the Family Life Center, the Siragusa Lobby (Figure 12) – which, like the Family Life Center, has many activities for children to engage in – the cafeteria, the chapel, the hallways, and hospital art. Parents were asked to indicate their own and their child’s emotional responses to these six spaces by choosing from 20 adjectives (10 positive and 10 negative). One point was given for each chosen positive adjective, with a total possible score of 10. Cartland (2013) reports that very few respondents chose negative adjectives, making negative responses unscorable. In order to measure the extent to which children experienced stress and anxiety during hospitalisation, Cartland (2013) also administered two questionnaires to parents. These were a modified version of the Emotional Functioning Scale, which is a brief tool that offers an initial screening for depression and anxiety (including separation anxiety) and a modified version of the Columbia Impairment Scale (CIS), which measures general social and mental functioning. Cartland (2013) hypothesised that children’s social and mental functioning might degrade as a result of chronic illness and multiple hospitalisations and, therefore, might mediate their experiences of anxiety and their perceptions of the hospital facilities.
Cartland (2013) reports that the hospital hallways, the art hanging in the hospital (could be anywhere), the Siragusa Lobby and the Family Life Center were the most frequently used among the six spaces assessed. However, regardless of the frequency of use, the Family Life Center and the chapel achieved the highest restorative experience scores (Cartland, 2013). Hospital art and the Siragusa Lobby achieved middle-level restorative experience scores, and the cafeteria and the hallways received the lowest restorative experience scores.

No association was found between restorative experience scores and child anxiety, child anxiety difference score, or parent stress (Cartland, 2013). However, Cartland (2013) found a correlation between the CIS and the child’s restorative experience scores for the Family Life Center and the art in the hospital, which suggests that the more mental/social impairment a child is reported to have, the more the Family Life Center and hospital art provided a restorative experience for them.

Overall, boys were more likely to find features/spaces to be more restorative than girls, and children who were able to play at least a little by the time of the interview had more restorative experiences reported by their parents than those who could not yet play. Cartland (2013, p. 25) states that:

children experienced more restorative experiences if their parents reported that the staff was concerned about putting their child at ease and if the parent reported that the child’s pain was adequately controlled.

This latter finding suggests the importance of the communication between parents and health care staff, and how it can impact on the views of parents in relation to the health and well-being of their children.

Finally, children aged five and older were offered the opportunity to participate in the study by photographing features of their room and the Family Life Center that elicited different emotions, their favourite and least favourite things (Cartland, 2013). In the Family Life Center, art was the most photographed favourite thing, followed by activities and the space itself, that is, photos of a section of the whole room or the signs at the entrance. Interestingly, Cartland (2013, p. 27) reports that:

in the Family Life Center, children were quite unlikely to report that using medical equipment was a least favorite thing (even though many children bring their IVs [intravenous therapies] to the center).

However, not all children enjoyed the Family Life Center. According to Cartland (2013, p. 27), ‘a minority of children reported not liking the space or the activities that could be done in the space’.

Overall, the results of Cartland’s (2013) study do not support the hypothesis that the restorative experiences provided by family resource rooms can help to decrease parents’ and children’s stress as measured by the Emotional Functioning Scale and the Columbia Impairment Scale. However, here we question whether the benefits of family resource rooms can be measured through clinical measures of mental health functioning and of common
mental health problems such as anxiety and depression. Research shows that well-being and mental ill-health are two independent continua (Huppert, 2009; Huppert & Whittington, 2003; Keyes, 2007) which need to be measured using different tools.

We suggest that a comprehensive approach to well-being is most suited to measuring the impact of family resource rooms on families and children, considering the literature reviewed in Chapter 2, and that attending family resource rooms does not remove the main source of stress for parents and children, that is, their illness and hospital stay. A comprehensive approach entails evaluating both whether family resource rooms help to meet families’ and children’s needs and their real-time happiness (Kahneman, 1999). Satisfaction of financial and personal care needs can be evaluated using retrospective, summative judgments given over a specific period of time (for example ‘over the last two weeks’ or ‘in your last visit to the family resource room’), which are contained in most well-being questionnaires. However, these types of question would not help to capture the short-term, immediate impact that the respite provided by hospital family areas can have on children and families. Real-time measures of happiness ask people how they feel at a certain moment, providing a snapshot of people’s mood and feelings while they experience them. By so doing, they are less likely to be affected by the ongoing, major source of worry and anxiety represented by the child’s illness and hospital stay and more likely to capture whether the respite that families and children experience in family areas impact on their feelings and mood.

3.1.2 The family resource centre at the Royal Children’s Hospital of Melbourne

An example of a family resource room in Australia is given by the Family Resource Centre at the Royal Children’s Hospital of Melbourne (Figures 4, 5 and 6). We have, however, not found any literature evaluating this space.

Figure 4 The Family Resource Centre at the Royal Children’s Hospital of Melbourne

Source: The Royal Children’s Hospital Melbourne (2014b)
Figure 5 The Family Resource Centre at the Royal Children’s Hospital of Melbourne

Source: The Royal Children’s Hospital Melbourne (2014b)

Figure 6 The Family Resource Centre at the Royal Children’s Hospital of Melbourne

Source: The Royal Children’s Hospital Melbourne (2014b)
3.2 The Ronald McDonald Family Room Program

The Ronald McDonald Family Room program provides rooms (from here onwards ‘Family Rooms’) for families and carers with child patients in the hospital where they can take a break whilst still being near their children. Family Rooms are proposed as a ‘home within a hospital’ and as a place where carers can go when they cannot go home (RMHC, 2014).

There are currently fourteen Family Rooms in hospitals around Australia. The Ronald McDonald Family Room program guidelines suggest a size not smaller than 40㎡, which is more than twice the minimum size suggested by the Department of Human Services Victoria (2014). Although all the Family Rooms share the same principles and goals, they present different characteristics and facilities (Figure 8, Figure 9, Figure 10, Figure 11), including: a lounge area, washer, dryer, iron and ironing board, kitchen and dining facilities, tea and coffee facilities, shower and baby change area, games and toys for children and, in some, a sleep room and portable cots (RMHC, 2014). A characteristic of Family Rooms is that they are attended by volunteers who welcome the visitors and help them with a number of services, such as doing their laundry or simply preparing a hot drink.

The nine rooms analysed in Table 3 and Figure 7 have door sensors (Beonic Technologies Ltd) which count each single time someone enters the room (Section 1.2). Table 3 shows that some rooms have many more visits than others (the Family Rooms at the Canberra Hospital, Nepean Hospital, and Sydney Children’s Hospital started to operate the door sensors over the last year). Figure 7 shows that the number of monthly visits tended to be consistent from July 2013 to July 2014 across the nine Family Rooms, with some of them experiencing an increase of visits over the last year. However, because of a lack of further information on local practices and experiences, it is not possible to provide explanations of why these increases occurred. We did not find any studies that evaluated the Ronald McDonald Family Room program. The informal conversations with some visitors and nursing staff during the observations undertaken in the Family Rooms at the Gosford Hospital, John Hunter Hospital (Newcastle), and the Sydney Children’s Hospital showed a high level of appreciation for those rooms. The visitors mentioned different reasons for which they found the Family Rooms helpful, from being a comfortable place to spend some waiting time or taking a break from the ward environment, to offering valuable services such as help with the laundry, shower facilities and snack facilities. Some visitors stressed how the kitchen area helped them to save money on beverages and meals during their visits at the hospital. The visitor book at one of the Family Rooms included comments showing visitors’ gratitude and praise for the practical and emotional support they received from the volunteers.
Table 3 Summary statistics of estimated individual visitors from July 2013 to July 2014 at nine Family Rooms

<table>
<thead>
<tr>
<th>Family Rooms location</th>
<th>Total number</th>
<th>Average</th>
<th>Maximum</th>
<th>Minimum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Princess Margaret Hospital, WA</td>
<td>52,683</td>
<td>4,053</td>
<td>5,045</td>
<td>3,275</td>
</tr>
<tr>
<td>John Hunter Hospital</td>
<td>100.0</td>
<td>98.0</td>
<td>93.0</td>
<td>96.0</td>
</tr>
<tr>
<td>Monash Children’s Hospital, VIC</td>
<td>19,021</td>
<td>1,463</td>
<td>2,045</td>
<td>191</td>
</tr>
<tr>
<td>Nepean Hospital, NSW</td>
<td>13,873</td>
<td>1,067</td>
<td>3,851</td>
<td>140</td>
</tr>
<tr>
<td>Peel Health Campus, WA</td>
<td>8,138</td>
<td>626</td>
<td>834</td>
<td>237</td>
</tr>
<tr>
<td>Wodonga Hospital, VIC</td>
<td>7,794</td>
<td>600</td>
<td>755</td>
<td>400</td>
</tr>
<tr>
<td>Centenary Hospital for Women and Children, ACT</td>
<td>4,237</td>
<td>326</td>
<td>1,297</td>
<td>565</td>
</tr>
<tr>
<td>Northern Hospital, VIC</td>
<td>1,812</td>
<td>139</td>
<td>331</td>
<td>17</td>
</tr>
<tr>
<td>Sydney Children’s Hospital, NSW</td>
<td>1,379</td>
<td>106</td>
<td>1,197</td>
<td>106</td>
</tr>
<tr>
<td><strong>Grand total</strong></td>
<td><strong>130,596</strong></td>
<td><strong>1,116</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Figure 7 Estimated number of monthly visits from July 2013 to July 2014 at nine Family Rooms**
Figure 8 Family Room at Wodonga Hospital

Figure 9 Family Room at Monash Children’s Hospital, VIC

Source: RMHC
Figure 10 Family Room at the Centenary Hospital for Women and Children, ACT

Source: RMHC

Figure 11 Family Room at the Centenary Hospital for Women and Children, ACT

Source: RMHC
3.3 Alternative facilities

Apart from family resource rooms, hospitals provide other spaces and facilities aimed at offering respite to families and carers, including gardens, child play areas, areas/rooms for teenagers, learning resources, lounge areas, waiting rooms, shopping areas and lobbies (Cartland, 2013; Kotzer, Zacharakis, Raynolds, & Buenning, 2011). Important family areas are also those provided within the patients’ rooms, for example, single family rooms, which research shows can increase parent privacy and presence, support Health Insurance Portability and Accountability Act (HIPAA) compliance, increase staff satisfaction, and reduce staff stress (Flacking, et al., 2012; Harris, et al., 2006). In this report, we discuss two spaces that, similarly to family resource rooms, can offer some respite from the ward environment to both families and visitors: hospital lobbies and waiting rooms.

3.3.1 Hospital lobbies

The architectural characteristics of hospital lobbies and, more generally, hospital buildings, have changed over time driven by prevailing cultural models and social power relations (Adams, Theodore, Goldenberg, McLaren, & McKeever, 2010; Bromley, 2012; Gesler, Bell, Curtis, Hubbard, & Francis, 2004) (Section 3.6). Adams et al. (2010) report that whilst hospital lobbies between the two world wars resembled hotel entrances and the grand halls of railway stations, those in the post-war period resembled sleek office building lobbies. In particular, late-twentieth-century hospital lobbies design has been influenced by the concept of multi-storey shopping malls, which are seen ‘as a building type for health care that makes patients comfortable because of its familiarity’ (Devlin & Arneill, 2003, p. 669) (Section 3.6 has a more in depth discussion of this point). Devlin & Arneill (2003) note that in the late 1980s, ‘the dramatic atrium (influenced by the architecture of hotels and malls) was described as the defining characteristic of the hospital’ (p. 670). However, according to Verderber and Stephen (2000, cited in Devlin & Arneill, 2003) this dominance was brief because of the need to contain costs and the changes brought into the US health care market by Health Maintenance Organizations (HMOs) and Preferred Provider Organizations (PPOs) restrictions, which entailed fewer choices for patients and therefore hospitals not needing to try as hard to attract them.

Hospital lobbies designed after the multi-storey shopping mall prototype consist of large public spaces which become the hubs through which patients, staff, and visitors reach all sections of the hospital. Figures 12, 13, and 14 show examples of hospital lobbies based on the multi-storey mall model in Australia and in the United States.
Figure 12 ‘Main Street’ - Lobby of the Royal Children’s Hospital of Melbourne

Source: The Royal Children’s Hospital Melbourne (2014b)

Figure 13 Boettcher Atrium, Children’s Hospital Colorado, Denver, US

Source: Children's Hospital Colorado (2014)
In this section we report the findings of the study by Adams et al. (2010), in which they explored how designers and patients understand and use the Atrium, an eight-storey lobby constructed in 1993 at the Hospital for Sick Children (SickKids), Toronto (Figure 153). The study interviewed a total of 80 hospital patients (35 inpatients and 45 outpatients) aged 5 to 18 years, reviewed archival material, and interviewed the projects’ architects.

Adams et al. (2010) report that once construction was underway, the hospital marketed the Atrium as its most innovative feature. The project’s master plan called for ‘a happy environment’, so that children and their families would experience a ‘place of relief, of courage, of tender love, of laughter and even great joy’ ... and ‘a green space of hope during all seasons’ (Adams, et al., 2010, p. 661). In summary, the Atrium was designed to engender pleasure and indulgence, rather than fear and pain, for children (Adams, et al., 2010).

Adams’ and colleagues’ analysis of archival documents and of the interviews with the architects show that the Atrium was explicitly intended to resemble a shopping mall, in particular the Toronto’s Eaton Centre. The architects argued that the shopping mall model constituted an appropriate, enjoyable public space, and that their intention was not to create an atmosphere of consumption. A design architect who took part in an interview said:

We don’t really see it as a shopping mall. There is a cross-fertilisation that goes on between different building types. [We took from the shopping mall] the entire idea of having public space that is appropriate for our climate and that brings in natural light (Adams, et al., 2010, p. 654).

When asked what building types the Atrium resembled:
participants mentioned shopping malls (29), hotel (10), condominium (5), school (4),

distinctive characteristics of the Atrium which were pointed out by most participants were the

jungle (3), CN Tower (3), Air Canada Centre/Sky Dome (sports entertainment facility)

coliseum (2)' (Adams et al., 2010, p. 664).

When participants were asked about the functions of the Atrium, about 10 per cent explicitly

adopts the shape of cars and were painted in yellow to recall children’s

noted the Atrium’s potential to distract patients from the medical reason for their visit or stay.

most participants spent time shopping or window shopping in the Atrium, and their comments
did not sustain reservations that shopping is inappropriate in hospitals, or that the shopping

mattress atmosphere is stressful (Adams, et al., 2010). However, Adams et al. (2010) noted the

limits of their study, which did not cover the complete range of children’s views and may have

ericited what the children thought were correct or expected answers for the adult

interrogators. They concluded by pointing out the need for and importance of including

children’s views in hospital planning and ‘to think expansively about how to determine the
effect of design on well-being’ (Adams, et al., 2010, p. 666)
3.3.2 Waiting rooms

There is some research on families' experiences of waiting rooms in hospitals. These studies suggest a few features that can make waiting rooms more comfortable and supportive environments. For example, Ulrich et al. (2004) report findings from a study showing that waiting patients experienced improved mood, altered physiological state, and greater reported satisfaction as a result of a number of changes to the general layout, colour scheme, furniture, floor covering, curtains, and ways to provide informational material in a hospital waiting room. The importance of waiting rooms in hospitals can be understood from the findings of Olausson, Ekebergh and Lindahl’s (2012) qualitative study (based on a phenomenological hermeneutical method) aimed at exploring the views of 14 next of kin of
patients in Intensive Care Units (ICU) in Sweden about the design, interiors, and furnishing in the patients’ rooms.

Olausson et al. (2012) generated three themes in relation to the participants’ experiences in the patients’ rooms: the meaning-making processes involved in becoming accustomed to the room feeling like ‘home’ and their experiences of the wider services and spaces in the hospital. This latter theme shows how the participants’ stories and experiences of the patient’s room did not end in the room, but also involved the corridors and the waiting room. Waiting was a defining characteristic of the hospital experiences of the study participants, causing them major concerns. Olausson et al. (2012) stressed how the design of the waiting areas was a potential source of rest for the participants, but could also generate strong feelings of sadness through inappropriate decorations and furnishings. The participants described the waiting room as narrow, and therefore too small to be able to always offer enough seating for everybody, forcing people to sit close to each other. Being in the waiting room was associated with ambiguous experiences, as it meant both ‘a therapeutic and/or involuntary involvement with strangers’ (p. 181). For many participants, the waiting room often entailed being exposed to interactions with others, including participating in their suffering, without the possibility to escape due to the public nature of the place. Participants needed to balance the public nature of the waiting room with the availability of a quiet and peaceful place. However, participants mentioned that being in the waiting room also meant having the opportunity to share similar experiences with others; ‘someone to talk to as the days pass’ (p. 181). At times, participants found insight and hidden hope in their situation from sharing stories and witnessing others’ situations, which gave them feelings of gratitude and eased their loneliness (Olausson, et al., 2012). Characteristics of the waiting rooms which were appreciated were the availability of a public telephone, beverages, coffee, and a seat.

Similar findings were found by Meert et al. (2008), who report participants’ views on a PICU waiting room in the context of their social support needs, i.e. receiving comfort and emotional support from families and visitors, and personal care needs, i.e. having a place to sleep and generally spend a lot of time in. The participants reported having to constantly negotiate their personal places in the PICU waiting room, which at times was empty and at others was crowded with visitors. An important point raised by some participants was the lack of supervision in the waiting room, which was mentioned as a factor contributing to the erratic behaviours that could be experienced in it. The size of the waiting room was also often mentioned as too small to accommodate extended families and sensory characteristics such as its temperature at night were recalled as making it as an uncomfortable place in which to sleep.

The importance of environmental amenities in the ICU waiting room, such as chair comfort, adequate lighting, and access to food and drink, was also found in the quality improvement evaluation of the ICU waiting room at Lehigh Valley Hospital, PA, undertaken by Deitrick et al. (2005). An important finding was the importance of the waiting room receptionists in defining the participants’ experiences of it. The waiting room was open 24 hours a day, and was staffed by one of four paid receptionists between 11am and 9pm. The receptionist answered the phone, greeted the visitors and controlled access to the locked ICU via a
buzzer activated entry door (Deitrick, et al., 2005). Deitrick et al. (2005) noted that the most frequent open-ended comments concerned the lack of availability of food and drink; the second most frequent comments concerned the helpfulness of the receptionist.

The experience of waiting was explored in depth in a qualitative study by Kutash and Northrop (2007) on the perspectives and experiences of waiting rooms in adult intensive care units of six family members. The study generated six categories that included structural and subjective aspects of waiting: ‘close proximity’ referred to the importance of a close physical distance to their family member; ‘caring staff’ captured the comfort family members felt when staff showed caring behaviours towards their relative; ‘need for a comfortable environment’ represented the impact of the design of the waiting room on family members’ well-being; ‘emotional support’ referred to the waiting room as a place where comfort was found by sharing with others; ‘rollercoaster of emotions’ captured the range of emotions experienced by family members; ‘information’ referred to the importance of receiving information about their relative. Kutash and Northop (2007) conclude by proposing that future research ‘should focus on how cultural and spiritual beliefs influence waiting and on specific interventions intended to ease the waiting period’ (p. 388).

3.3.3 Outcomes

The research is sparse on the relationships between hospital environments, in particular family resource rooms, and the health and well-being outcomes of the five stakeholders that we address in this review: families and children, hospital staff members, the wider community, and the wider health and social system. Below, we summarise the evidence identified for each of these stakeholders of hospital family resource rooms.

3.3.4 Families and children

Little research is available about how the physical environment of hospitals impact on children’s and teenagers’ well-being (Cartland, 2013; Watts & Wilson, 2009). There is also very little information on the relationships between families’ capacity to cope with their child’s hospitalisation, and their use of respite services, spaces, and amenities in the hospitals (Cartland, 2013). However, a growing body of literature shows that spaces such as common garden areas and communal areas in which children and parents can socialise when they wish can generate restorative experiences and, therefore, possibly improve their well-being (Section 3.1 and Section 4).

For example, in a recent literature review on the impact of paediatric physical environments on the psychological outcomes of hospitalised children, Cartland (2013) lists the following findings on which there is a growing body of evidence applicable to children (pp. 3-4):

- Sleep space for parents of paediatric patients can reduce parental and child stress
- Children’s experiences of design elements vary by age, stress level, and gender
- Children who experience repeated hospitalisations are able to find ways to use the hospital environment to improve their ability to cope
• Children and parents who use a common garden area in a hospital setting find the experience to be restorative and healing.

• Children and families can experience positive emotional meaning from art within health care settings.

• Family-friendly paediatric environments (e.g., where families can be private together and have adequate furniture in the room on which to rest and relax) as well as child-friendly paediatric environments increase parents’ satisfaction (and presumably reduce stress).

• Making mobility easier for children or giving children play spaces in the hospital may help them exercise control, reduce their sense of powerlessness, and possibly improve their post-hospitalisation psychological response.

Similarly, in a systematic review of the literature on the evidence of the impact of the physical paediatric hospital environment on the health outcomes of children and adolescents, Watts and Wilson (2009, p. 909) identified eight studies which show that:

• Single room design for paediatric intensive care units significantly reduced nosocomial infections as did the addition of negative pressure ventilation to single rooms in an isolation unit.

• Specially designed gardens had very low usage rates, but children who did visit them were actively engaged with both natural and structural features.

• A play centre designed to encourage symbolic play successfully did so and it also generated statistically significantly more total play and less unoccupied time or wandering.

• Nature art was not found to be effective in reducing stress in hospitalised children.

Although these results suggest some positive elements of physical design that can promote a healing environment within paediatric hospitals or paediatric wards in general hospitals, the small number of studies identified did not allow Watts and Wilson (2009) to propose firm conclusions on this topic (for some findings one study only was found).

Ulrich et al. (2010) proposed a conceptual framework which aimed to capture existing domains of evidence-based design in health care. The framework represents the built environment through nine design variable categories:

• Audio environment

• Visual environment

• Safety enhancement

• Way finding system
• Sustainability
• Patient room
• Family support spaces
• Staff support spaces
• Physician support spaces.

The variable family support spaces include:

• comfortable waiting rooms (movable seating, quiet, uncrowded)
• convenient access to toilets
• access to food
• overnight bed in patient room
• personal storage
• computer/work space; internet access
• private meeting room
• gardens
• availability and proximity of parking.

In an extensive review of the literature, Ulrich et al. (2008) found only a moderate level of evidence linking design features to the level or quality of social support in hospitals. They refer to four studies conducted in 1958, 1972, 1977, and 1981 as source of evidence recommending:

…the provision of lounges, day rooms and waiting rooms with comfortable, movable furniture arranged in small, flexible groupings, in order to facilitate social interactions’ (p. 98).

In a previous review, Ulrich et al. (2004, p. 25) reported that environmental satisfaction is a significant predictor of overall satisfaction, ranking only below perceived quality of nursing and clinical care. In particular, they presented study findings where:

…patients in well-decorated and well-appointed hotel-like rooms rated their attending physicians, housekeeping and food-service staff, the food and the hospital better than patients in standard rooms (typical hospital beds, inexpensive family sitting chairs and no artwork) in the same hospital. Also, they had stronger intentions to use the hospital again and would recommend the hospital to others.

Ulrich et al. (2004, p. 26) report how some studies show the importance of tacit, as well implicit, staff and organizational practices and policies which can influence how an environment actually functions and is perceived by patients and staff members. They concluded that:
…future research that looks at satisfaction among hospital patients should consider using … multi-method post-occupancy evaluations that use different methods to obtain objective and subjective evaluations of use and satisfaction’.

Despite the findings of these studies, as Ulrich et al. (2010) state, ‘much remains to be learned about specific design features that contribute the most to encourage family social support’ (p. 103).

3.3.5 Health care staff members

We did not find any studies that explored the views of health care staff members in relation to family resource rooms. However, literature is available on the views of nurses in relation to family-centred care (FCC) policies and practices (e.g. Coyne, Murphy, Costello, O’Neill, & Donnellan, 2013; Cruickshank, Wainohu, Stevens, Winskill, & Palladellis, 2005; Merighi, de Jesus, Santin, & de Oliveira, 2011). Coyne et al. (2013) report that previous studies have shown that nurses value FCC and enjoy the opportunities for teaching and supervising parents who participate in the care of their children. However, nurses can experience difficulties related to poor communication and inadequate negotiation skills. In a survey of 750 nurses from 7 of the 19 paediatric units in Ireland which aimed at investigating paediatric nurses’ perceptions and practices of FCC, Coyne et al. (2013) found that nurses with a higher academic qualification (e.g. baccalaureate) had higher mean scores on the activities perceived to be necessary for FCC compared to nurses who held a certificate-level qualification. The authors report that this finding was consistent with previous surveys of nurses which also found that positive attitudes to FCC were associated with high levels of education, senior positions, being older and more experienced, being married, and being a parent. Overall, Coyne et al. (2013) found that nurses felt that elements of FCC were present in their current practice although there were significant differences between their practices and perceptions of FCC, which suggested that nurses did not consistently apply the FCC elements in their actual practice. Coyne et al. (2013) conclude that nurses support FCC but perceive the design of the health care system and parent–professional collaboration as barriers to FCC practice.

Although research on the views and practices of nurses and other health care staff members can provide a background to understanding their attitude towards family resource rooms, more research is needed to specifically investigate their views and practices in relation to family resource rooms and other family spaces in hospitals.

3.3.6 Volunteers

We have found only one study that explored the role and impact of volunteers in a Ronald McDonald House (Haski-Leventhal, Hustinx, & Handy, 2011), but no studies that investigated their role and views in relation to Family Rooms. Haski-Leventhal et al. (2011) undertook a mixed-method study to explore the impact that volunteers at the Philadelphia Ronald McDonald House had on the guest families. The study shows that volunteers had a positive impact on the guest families in three aspects: ‘tangible impact (providing services), attitudes (satisfaction and perceived altruism), and future behaviour (willingness to volunteer)’ (p. 155).
Volunteers are a fundamental component of the delivery of Family Rooms, and often in the delivery of care of hospitals in general. For example, the Royal Children’s Hospital in Melbourne reports having more than 400 people volunteering in various roles (The Royal Children’s Hospital Melbourne, 2014a). The Ann & Robert H. Lurie Children Hospital of Chicago claims that in the calendar year of 2012, more than 1,200 volunteers gave 62,000 hours of their time for play activities, respite to parents, and other services (Ann & Robert H. Lurie Children's Hospital of Chicago, 2014a). There is, however, no research relating to who these volunteers are, what they do, and how they contribute to the health and well-being of families and children.

Specific research on the role of volunteers in the context of Family Rooms is needed in order to understand how they contribute to the functioning of the Family Rooms and the delivery of their outcomes.

### 3.3.7 Costs

We did not find any studies that reported the costs or return on investments of family resource rooms in hospitals. However, there is some indication in the literature of the costs related to the construction of family resource rooms and of their potential return on investments.

In their 2008 review of the literature on evidence-based design in children's hospital, the National Association for Children's Hospitals and Related Institutions (NACHRI, 2008) reports the costs, timing and main beneficiaries of a list of evidence based design strategies for which they suggest there is enough evidence to show their effectiveness respectively in paediatric and adult settings (Table 4). The list of design strategies specific to paediatric settings includes ‘space for families in all patient rooms and all units’, which is reported as relevant for the general population, having moderate to high costs, that is, costs ranging from $100,000 to over $1,000,000, and to be introduced during building renovations or new constructions.

In a discussion of the benefits of hospitals involved in Pebble Projects5, Berry et al. (2004) conclude that ‘one-time incremental costs of designing and building optimal facilities can be quickly repaid through operational savings and increased revenue and result in substantial, measurable and sustainable financial benefits’ (p. 4). In support of this, they offer a theoretical case study of the total replacement of a hypothetical 300-bed hospital called the ‘Fable Hospital’, which they propose would cost US$240 million to build (US$800,000 per bed). The authors suggest that the evidence-based design innovations introduced in the new building would save the hospital a conservative estimate of US$11,575,406 at the end of the first financial year after the replacement. The cost-saving strategies at the basis of those savings did not refer directly to family resource rooms; however, they included ‘reduced drug

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5 Pebble projects consist of health care organizations that in 2000 started to voluntarily come together with The Center for Health Design to evaluate their new buildings, including hospital replacements, critical care units, cancer units, nursing stations and ambulatory care centres (Berry et al., 2004).
costs’, which Berry et al. (2004) propose could come from a reduction in use of pain medication owing to the distractions built in the new hospital environment, including art, music, landscape and family involvement. The other cost-saving strategies and increased revenues at the basis of the hypothesised savings at the end of the first financial year included: reduced patient falls; reduced patient transfers; reduced nosocomial infections; reduced nursing turnover; increased market share and increased philanthropy.

Table 4 Impact, construction costs, and timing of evidence-based design strategies

<table>
<thead>
<tr>
<th>Evidence Based Design Strategies</th>
<th>Relevance to population</th>
<th>Construction cost</th>
<th>When to incorporate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategies from pediatric settings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single family room NICU</td>
<td></td>
<td>Low</td>
<td>New construction</td>
</tr>
<tr>
<td>Gynecian lighting in the NICU</td>
<td></td>
<td>Moderate</td>
<td>Renovation</td>
</tr>
<tr>
<td>Incubator noise reduction in the NICU</td>
<td></td>
<td></td>
<td>Existing</td>
</tr>
<tr>
<td>Sound absorbing ceiling tiles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Space for families in all patient rooms and on all units</td>
<td></td>
<td></td>
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<tr>
<td>Patient and family control over privacy and environmental conditions</td>
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<tr>
<td>Calming music distractions before/during procedures</td>
<td></td>
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<tr>
<td>Positive distractions to reduce anxiety</td>
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<tr>
<td>Access to nature through gardens</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Age appropriate play areas</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Overall ambience and attractiveness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Applicable strategies from adult settings</td>
<td></td>
<td></td>
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<tr>
<td>Effective way finding systems</td>
<td></td>
<td></td>
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<tr>
<td>Single patient rooms for all patients</td>
<td></td>
<td></td>
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<tr>
<td>Hand washing dispensers and sinks in every room</td>
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<td></td>
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<tr>
<td>Access to natural light</td>
<td></td>
<td></td>
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<tr>
<td>Ceiling lifts</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Noise audits</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Visual access and accessibility to patient</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Positive distractions</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>HEPA filtration for immune-compromised patients</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Promising high impact strategies not fully substantiated by research</td>
<td></td>
<td></td>
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<tr>
<td>Acuity adaptable patient rooms</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Increased standardization through same-handed patient rooms</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Increased standardization through consistent room and unit layout</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Source: (NACHRI, 2008, p.6)

Note. Low = less than $100,000. Moderate = $100,000 to $1million. High = more than $1million.
3.4 Health and social system: Ethical and policy issues

The literature reviewed in the previous sections has primarily focused on the relationships between hospitals’ physical environments and some health and well-being outcomes of patients and their families. However, in the context of their analysis of the Private Finance Initiative (PFI), a major programme of hospital building in the UK, Gesler et al. (2004) propose that a full analysis of hospitals as ‘therapeutic environments’ needs to explore them as ‘physical environments (both natural and built), social environments and symbolic environments’ (p. 119). In particular, by symbolic environments the authors refer to a broad range of elements, from the naming of hospitals or wards, to the language used in the interactions between carers, patients, and health staff members, to the use of colour schemes in waiting rooms, which can evoke positive or negative feelings. Gesler et al. (2004) propose a matrix in which they relate the three mentioned dimensions of therapeutic environments – i.e. their physical, social, and symbolic character – to the four design goals underpinning the PFI projects: hospitals should be clinically efficient, integrated within the community, be accessible to consumers and the public, and encourage patient and staff well-being (Table 5). This matrix is proposed as a heuristic tool to help explore specific design intentions and types of therapeutic space, even though some aspects of hospital design might figure in more than one cell (Gesler, et al., 2004). Although Table 5 is specifically designed to evaluate the PFI goals, this matrix represents a good framework that could be used to explore the goals of family resource rooms as therapeutic places in relation to their physical, social, and symbolic characteristics.

Table 5 Therapeutic environments / design goal matrix

<table>
<thead>
<tr>
<th>Environment / Design goal</th>
<th>Clinical efficiency</th>
<th>Community integration</th>
<th>Public access and consumerism</th>
<th>Promoting well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical environment</td>
<td>e.g. physical layout of wards/facilities, clear patient pathways</td>
<td>e.g. wheel chair ramps, clearly defined entrances</td>
<td>e.g. comfortable wards and waiting areas</td>
<td>e.g. external landscaping, internal lighting and ventilation</td>
</tr>
<tr>
<td>Social environment</td>
<td>e.g. surveillance of patients, lines of communication</td>
<td>e.g. multi-language or graphic signage</td>
<td>e.g. patient-centred spaces</td>
<td>e.g. appropriate designation of public/private space</td>
</tr>
<tr>
<td>Symbolic environment</td>
<td>e.g. hygienic design</td>
<td>e.g. hospital naming, public symbols</td>
<td>e.g. patients as consumers, hospitals as health supermarkets</td>
<td>e.g. use of natural materials, warm colours</td>
</tr>
</tbody>
</table>

Source: Adapted from Gesler et al., 2004, p. 125.
Of particular interest is the column ‘public access and consumerism’ of Table 5, which covers an important element of family resource rooms, that is, their social support function for families and carers of hospitalised children. With regard to this, the matrix in Table 5 provides an opportunity to explore not only how the physical characteristics of family resource rooms can promote or hinder social support of families and carers, but also the role of volunteers and health staff members (social environment) and the symbolic characteristics of family resource rooms. For example, in the case of the Family Rooms, an important symbolic element to be investigated is their unique feature of being part of Ronald McDonald House Chapters, which have a corporate relationship with McDonald’s Australia Ltd (McDonald’s). As McDonald’s preferred charity, RMHC receives significant funding from the corporation.

The connection between RMHC and McDonald’s can attract criticism because of the association between fast food and increasing obesity among children (McDonald, 2012). With regard to this, a survey was conducted of 386 outpatients in three hospitals in the US, one with an on-site McDonald’s restaurant, one without a McDonald’s on site, but with McDonald’s’ branding, e.g. a RM house and one with neither on-site McDonald’s nor branding (Sahud, Binns, Meadow, & Tanz, 2006). The study found that respondents from the hospital with an on-site McDonald’s were four times more likely to have purchased McDonald’s food on the survey day, and to rate McDonald’s food healthier than respondents at the other hospitals. Visitors to hospitals with McDonald’s branding only and those from the hospital with an on-site McDonald’s restaurant were more likely to believe that McDonald’s supported the hospital financially than those at the hospital without any reference to McDonald’s. Overall, these results do not support the hypothesis that the presence of RMHC branding through Family Rooms or RM Houses increases the consumption of McDonald’s food.

However, the symbolic value of Family Rooms is also understood within a wider historical and theoretical framework compared to the one offered in the study by Sahud et al. (2006). We now turn to introduce this framework, drawing on health geography and sociological literature on the experiences of health and illness.

As mentioned in Section 3.3, the design of hospitals has changed over time, driven by cultural models and shaped by complex social power relations among various stakeholders, including patients, staff, administrators, architects, construction engineers, policy-makers, politicians and the public in the wider community within which a hospital is situated (Adams, et al., 2010; Bromley, 2012; Gesler, et al., 2004). Whilst there was an emphasis on change related to growth and technology in the 1970s and 1980s, from the mid-1980s to early 1990s there was a growing push towards creating a more welcoming environment for the patient (Gesler, et al., 2004). Gesler et al. (2004) explain this change in the contexts of the growth of interest in well-being and healing therapies in Western countries as alternatives to biomedical approaches, and of a ‘consumerist’ approach to health care in which health care users exercise active choice in relation to the type of therapy they utilise and the time and place in which they prefer to use health services’ (p. 118). Gesler et al. (2004) conclude that health care providers respond ‘to these consumerist pressures by introducing to clinics and hospitals consumption spaces similar to those of private, commercial outlets including shops and hotels’ (p. 118). Similarly, Adams et al. (2010) propose that these arguments have led
architects to design paediatric hospitals intended to de-emphasize connotations associated with institutionalized medicine and to foster a sense of enchantment, which has been pursued through features associated with non-threatening, therapeutic fantasy environments, including ‘bright colours, natural light, indoor foliage, park benches, water fountains, juvenile artwork, nursery images, mascots, film and television characters, stores and fast food franchises with easily recognizable aromas’ (p. 658).

This historical trend towards the creation of non-threatening, familiar and homelike hospital environments provides the physical, policy, and practice context within which sick children and their families experience the health care system in most Western countries. With regard to this, sociologists have long studied the consequences of living with chronic conditions, introducing the concepts of ‘biographical disruption’ (Bury, 1982; Williams, 2000) and ‘biographical accommodation’ (Sartain, Clarke, & Heyman, 2000). The first refers to the experience of the assault that the onset of chronic conditions brings to the physical self, leading to a loss of confidence in social interactions. The second consists of the phase subsequent to the biographical disruption and refers to the work that people engage with to maintain their personal biography, including keeping a sense of balance and control, adapting and allowing the illness to become part of the biography of both the child and their family (Strauss & Glaser, 1975; Stremler, et al., 2014).

The role of the RM branding in Family Rooms can be understood within this wider framework that hinges on the two conceptual axes given by the consumerist context that characterise contemporary health care delivery and building design, and the meaning-making processes of normalisation experienced by children and families living with chronic conditions. Within this framework, the RM branding can be seen as an element of the wider consumerist health care context that becomes part of people’s experiences and the meaning-making processes of normalisation of their illness. It therefore allows us to generate a new set of questions, such as: does exposure to the RM branding during visits at Family Rooms affect children’s and families’ experiences of ‘biographical accommodation’, that is, the work that they engage with to adapt to their illness and allow it to become part of their biography? If so, what does this entail? Does it change their eating behaviours or views on McDonald’s restaurants? If so, how does this happen? What are the consequences on children’s and families’ coping and illness strategies (Bury, 1991), i.e. what they do in the face of illness? What are the consequences on their illness style (Bury, 1991), i.e. the way they present important features of their illness or treatment regimens? These and other research questions aimed at exploring the physical and social characteristics of family resource rooms can help to undertake a comprehensive evaluation of Family Rooms in hospitals relative to alternative facilities.

3.5 Summary

Families’ presence at the hospital with their children generates reciprocal benefits for both paediatric and adult patients and their families. Hospitals, nurses, and doctors need to consider the impact of the child’s admission on all family members.
Children’s hospitals and wards in Australia, and in many other Western countries, adopt family-centred care (FCC) as their primary model of care delivery to children and families. This approach entails planning health care around the whole family, not just the child.

Family resource rooms are hospital spaces that aim to provide support and some respite from the ward to families with hospitalised children through the provision of services and amenities, such as for example kitchen, shower and laundry facilities, lounges and sitting areas.

There is no direct evidence that the restorative experiences from family resource rooms decrease families’ and children’s stress as measured by anxiety, depression, and mental health functioning. However, the impact of respite on families’ and children’s well-being could be measured within a more comprehensive well-being framework aimed at assessing whether family resource rooms help to meet families’ and children’s needs, and how they impact on their real-time happiness.

Hospital lobbies and waiting rooms are two examples of spaces that, similarly to family resource rooms, can offer some respite from the ward environment to families and visitors.

Hospital lobbies consist of large public spaces designed after the multi-storey shopping mall prototype. They are the hubs through which patients, staff and visitors reach all sections of the hospital.

Waiting rooms can be a source of rest, but also generate feelings of sadness if the rooms have inappropriate decorations and furnishings. Improvements of the layout, colour scheme, furniture, floor covering, curtains, ways to provide informational material, and availability of a public telephone, beverages, hot drinks and food can make waiting rooms more comfortable and supportive for families and visitors. Optimally, hospital spaces should aim to offer both public space to share with other families and private space for recovery and rest.

Hospital common garden areas and communal areas are spaces in which children and parents can socialise when they wish. They can generate restorative experiences and, therefore, possibly improve their well-being.

There are no studies on the views and attitudes of health care staff members towards family resource rooms. Research on family-centred care shows that nurses enjoy the opportunities for advising and supervising families who participate in the care of their children. Nurses can, however, experience difficulties related to poor communication and inadequate negotiation skills.

Volunteers are a fundamental component of the delivery of Family Rooms, and often in the delivery of care of hospitals in general. However, there are no studies on the role of volunteers in Family Rooms, and whether and how they affect families’ and children’s experiences. More research is needed to understand the role and impact of volunteers on the guest families.
There are no studies on the building and running costs of family resource rooms, or on their return on investment. The literature on evidence-based design argues that building spaces for families can lead to improvements in patients’ and families’ well-being and therefore also potential cost savings, for example through reduction in the use of pain relief medication.

A full analysis of family resource rooms requires exploring how their physical characteristics (e.g. layout and decoration), social characteristics (e.g. family-volunteer-health staff interactions), and symbolic characteristics (e.g. the use of the McDonald's branding) promote or hinder the delivery of their goals.
4 Conclusions

The experience of hospitalisation can be a major source of stress and anxiety for both the children and their families. Children’s hospitals and wards in Australia, and in many other Western countries, adopt family-centred care as their primary model of care delivery, which entails planning health care around the whole family, not just the child. Families caring for children who are hospitalised have a wide variety of needs, including financial, social, emotional, and personal care needs, which research shows are not always fully met by hospitals, health care staff, and the welfare system.

Many families of hospitalised children prefer to be with their child almost constantly and find it difficult to leave the care area even for short periods to eat, wash, and have some rest. Evidence from qualitative studies show that parents would be more likely to take a break if:

a) they trust that although they are not there, their child will get the best available care, and
b) they have access to facilities nearby the care area where they can eat, have a shower, and sleep.

Families of hospitalised children, particularly those from a lower socio-economic background, face high out-of-pocket costs, with travel and meals being the two major costs. Often families’ financial costs include direct losses of income, in particular when the hospitalisation of the child occurs as an emergency and parents have limited possibilities to arrange leave from work. For many parents, the financial cost of the time spent in the hospital includes the use of a substantial proportion of their annual holiday entitlement. The reviewed evidence shows that parents of hospitalised children would benefit from the availability of low cost options for food and accommodation in hospitals. Further, evidence from qualitative studies shows that parents would benefit from increased access to amenities such as phones, internet, television, secure storage of personal belongings, and shower facilities.

The reviewed literature suggests that family areas in hospitals can provide support and respite from the ward to families with hospitalised children. Qualitative research shows that families and visitors need both communal areas and private spaces in which to rest and have some time on their own. Family resource rooms offer a variety of services, which research shows are appreciated by families of hospitalised children and their visitors, including kitchen, shower and laundry facilities, lounges and sitting areas. Some Family Rooms provide sleeping rooms to address families’ sleep deprivation and disruption. The review found quantitative evidence from one study (Cartland, 2013) that family resource rooms are a space that families tend to use more frequently, and which provide higher restorative experiences to families compared to other communal spaces in hospitals. However, Cartland (2013) found no association between the restorative experience from family resource rooms and reduction in stress as measured by anxiety, depression, and mental health functioning. With regard to these latter findings, we suggest that the investigation of the impact of family resource rooms can also be evaluated within a comprehensive approach to well-being to assess whether family resource rooms help to meet the wide variety of families’ and children’s needs and their impact on real-time happiness. Real-time measures of happiness ask people how they feel at a certain moment. Consequently, they are less likely to be
affected by the ongoing, major source of worry and anxiety represented by the child's illness and hospital stay, which is likely to affect parents' and carers' answers to questions which ask them to offer a summative judgment of their past experiences of family resource rooms.

Overall, although a growing body of literature suggests that evidence-based design can improve the impact that hospital and care facility environments have on people's well-being and healing processes, there is a lack of research on the outcomes that communal family areas in hospitals, in particular family resource rooms, can have on the well-being of families and children. We conclude by suggesting that the research gap on the role and impact of family resource rooms on families and children can be addressed by embracing a comprehensive theoretical framework (Figure 16) which:

- identifies the needs of families of hospitalised children and how they relate to the services provided through family resource rooms and alternative interventions
- contextualises families' needs in relation to the role, resources, and needs of other main stakeholders, e.g. the hospital setting, including the hospital service providers, the health and social system, and the wider community (e.g. volunteers)
- explores how family resource rooms' physical characteristics (e.g. size, distance from the ward, layout, and decoration), social characteristics (e.g. family-volunteer-health care staff interactions), and symbolic characteristics (e.g. the use of the McDonald's branding) promote or hinder the delivery of their goals, relative to alternative interventions.

Such a framework (Figure 16) can help researchers to identify what the main research gaps are in the literature and what research designs and methods would best address them. In particular, Figure 16 shows that:

- There is a lack of research on whether and how family resource rooms meet some of the main needs of families of hospitalised children, i.e. financial needs, personal care needs, nutrition, and social support.
- There is some evidence on the positive relationships between physical characteristics of hospital environments, for example, room decoration and layout, and improved well-being of both patients' and visitors. However, there is no research that has specifically investigated the relationships between the physical and spatial characteristics of family resource rooms, for example, their size, distance from the ward, and services provided, and well-being outcomes of families and hospitalised children.
- There is a lack of research on the social characteristics of family resource rooms, for example, whether and how they favour or hinder social interactions between families, between families and health care staff, and, where available (e.g. in the Ronald McDonald Family Room program), between families and volunteers. Further, there is no research on whether and how the social characteristics of family resource rooms
relate to their physical and symbolic characteristics and affect the well-being outcomes for families and hospitalised children.

- There is a lack of research on the symbolic aspects of family resource rooms, for example, how families and hospitalised children perceive them in relation to other parts of the hospital and what role, if any, the family resource rooms’ funders have in relation to these perceptions. There is also a lack of research on how the symbolic meanings of the family resource rooms relate to their physical and social characteristics and affect well-being outcomes of families and hospitalised children.

- There is some quantitative, cross-sectional evidence (we found only one study) that the respite that families and hospitalised children experience in family resource rooms is not related to stress reduction. However, there is no research investigating the relationships between visits to family resource rooms and positive measures of well-being, such as real-time happiness (see above).

- There is a lack of research based on a comprehensive framework that investigates the relationships between visits to family resource rooms and both their short term and medium- to long-term outcomes for families and hospitalised children: improved personal well-being, needs satisfaction, personal and family support, improved clinical journey.

Investigating these research gaps would generate important knowledge on the Ronald McDonald Family Room program. Although these research gaps are all important, considering the lack of research in this area, we suggest that it would be helpful to start with a research program aimed at providing a solid body of evidence on the main functions, characteristics, and outcomes of Family Rooms. Such as solid body of evidence could be pursued through cross-sectional mixed-method studies (e.g. individual interviews and surveys) aimed at exploring:

How families of hospitalised children use Family Rooms. This entails asking questions such as: What needs of families with hospitalised children do Family Rooms address? Do families find respite in them? Do they find support? If so, what types of support? Are Family Rooms a form of financial support to families? If so, how much can families save by using them on a regular basis over the average length of hospitalisation of children with different pathologies?

The views of families with hospitalised children on the physical, social, and symbolic characteristics of Family Rooms. This entails asking questions such as: Are there any (physical, social, symbolic) characteristics of the Family Rooms that people think favour or hinder the satisfaction of their needs? What is the role of volunteers in the Family Rooms? How do families with hospitalised children relate to them? What do families think of the Family Rooms in relation to the rest of the hospital? What do they think of the fact that Family Rooms are funded by RMHC?

The measurement of the short term well-being outcomes that are expected to be achieved through the Ronald McDonald Family Room program. This entails asking questions such as:
Is there a relationship between visits to Family Rooms and improved well-being? If so, what types of well-being are Family Rooms more likely to improve, e.g. real-time happiness (see above), subjective well-being (i.e. how people feel about life), social well-being (i.e. how family members interact with each other and with their social networks), or their mental health (i.e. anxiety and depression)?

Such a research program would provide fundamental knowledge for more complex investigations aimed at exploring causal relationships between Family Rooms and their short- and long-term outcomes across different groups of users and compared to alternative interventions. These latter investigations would require longitudinal studies with comparative groups across different sites. They could draw on clinical and administrative data as well as self-reported data, and would address research questions such as: Do Family Rooms with different physical characteristics, for example size and distance from the ward, achieve different outcomes in terms of number of visits, satisfaction of needs, and improved well-being? Do families of hospitalised children who use Family Rooms have better well-being outcomes compared to families of hospitalised children who use family resource rooms run by the hospital and/or those who do not visit family resource rooms? Do children of families who use Family Rooms recover quicker compared to children of families who use family resource rooms run by the hospital and/or those who do not use Family Rooms?
Figure 16 A model of the relationships between the needs of families with hospitalised children, hospital respite areas, and the mechanisms that link them to families’ and children’s outcomes

Note: Dotted lines indicate lack of studies. Dashed lines indicate the existence of some evidence. Continuous lines indicate the existence of a substantial body of evidence. Connections between needs and hospital respite areas other than family resource rooms are greyed to help emphasising the focus of the graph on family resource rooms.

A ‘+’ sign indicates a positive relationship. A ‘0’ indicates no relationship. A ‘−’ sign indicates a negative relationship.
References


Appendix A List of needs of parents with hospitalised children, by Shield et al. (2008)

Percentage of parents (P) and health care staff (S) that reported the listed needs as important, met and that believed that parents needed help to have them met.

<table>
<thead>
<tr>
<th>Parents’ needs</th>
<th>Importance</th>
<th>Fulfilment</th>
<th>Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Important</td>
<td>Not important</td>
<td>p</td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have a planned meeting with other parents to share and discuss the experience of their children’s hospitalisation</td>
<td>P</td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be able to meet with parents with similar experiences of an ill child</td>
<td>P</td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A social worker to get information about financial assistance To help ease problems</td>
<td>P</td>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Parents’ needs

<table>
<thead>
<tr>
<th>Importance</th>
<th>Fulfilment</th>
<th>Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Important</td>
<td>Not important</td>
<td>p</td>
</tr>
<tr>
<td>Personal care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Get sufficient rest and sleep</th>
<th>P</th>
<th>94 (119)</th>
<th>6 (8)</th>
<th>NS</th>
<th>91 (101)</th>
<th>9 (10)</th>
<th>NS</th>
<th>69 (72)</th>
<th>31 (32)</th>
<th>.001</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>S</td>
<td>97 (77)</td>
<td>3 (2)</td>
<td>88 (69)</td>
<td>12 (9)</td>
<td>89 (68)</td>
<td>10 (8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have a nurse assisting them to recognize their own needs, e.g. meals, sleep</td>
<td>P</td>
<td>73 (94)</td>
<td>27 (34)</td>
<td>&lt;.001</td>
<td>75 (85)</td>
<td>24 (27)</td>
<td>&lt;.001</td>
<td>66 (63)</td>
<td>34 (33)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td>97 (76)</td>
<td>3 (2)</td>
<td>96 (74)</td>
<td>4 (3)</td>
<td>92 (68)</td>
<td>8 (6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have a place to sleep in the hospital</td>
<td>P</td>
<td>94 (118)</td>
<td>6 (7)</td>
<td>.03</td>
<td>94 (102)</td>
<td>6 (7)</td>
<td>&lt;.001</td>
<td>82 (84)</td>
<td>18 (18)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td>100 (78)</td>
<td>0</td>
<td>99 (76)</td>
<td>1 (1)</td>
<td>100 (75)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stay with their child 24 hours a day if they wish</th>
<th>P</th>
<th>99 (127)</th>
<th>1 (1)</th>
<th>NS</th>
<th>99 (114)</th>
<th>1 (1)</th>
<th>NS</th>
<th>74 (71)</th>
<th>26 (25)</th>
<th>&lt;.001</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>S</td>
<td>98 (76)</td>
<td>2 (2)</td>
<td>100 (76)</td>
<td>0</td>
<td>96 (71)</td>
<td>4 (3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents’ needs</td>
<td>Importance</td>
<td>Fulfilment</td>
<td>Independence</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Important</td>
<td>Not important</td>
<td>p</td>
<td>Met</td>
<td>Not met</td>
<td>p</td>
<td>Need help</td>
<td>Does not need help</td>
<td>p</td>
<td></td>
</tr>
<tr>
<td>Have meals with their child on the ward/unit</td>
<td>P</td>
<td>90 (114)</td>
<td>10 (13)</td>
<td>NS</td>
<td>70 (77)</td>
<td>31 (34)</td>
<td>NS</td>
<td>72 (68)</td>
<td>28 (27)</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td>92 (72)</td>
<td>8 (6)</td>
<td>NS</td>
<td>81 (62)</td>
<td>19 (15)</td>
<td>NS</td>
<td>79 (59)</td>
<td>21 (16)</td>
<td></td>
</tr>
<tr>
<td>Have bath and shower facilities for themselves</td>
<td>P</td>
<td>94 (118)</td>
<td>6 (8)</td>
<td>NS</td>
<td>84 (93)</td>
<td>16 (18)</td>
<td>.05</td>
<td>75 (69)</td>
<td>25 (23)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td>100 (78)</td>
<td>0</td>
<td></td>
<td>93 (68)</td>
<td>7 (5)</td>
<td></td>
<td>97 (71)</td>
<td>3 (2)</td>
<td></td>
</tr>
<tr>
<td>Be able to ‘room in’ with their child</td>
<td>P</td>
<td>97 (121)</td>
<td>3 (4)</td>
<td>NS</td>
<td>97 (106)</td>
<td>3 (3)</td>
<td>NS</td>
<td>80 (77)</td>
<td>20 (19)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>S</td>
<td>99 (79)</td>
<td>1 (1)</td>
<td></td>
<td>100 (77)</td>
<td>0</td>
<td></td>
<td>99 (73)</td>
<td>1 (1)</td>
<td></td>
</tr>
<tr>
<td>Be encouraged by staff to come and stay with the child</td>
<td>P</td>
<td>97 (123)</td>
<td>3 (4)</td>
<td>NS</td>
<td>96 (110)</td>
<td>4 (5)</td>
<td>.003</td>
<td>80 (81)</td>
<td>20 (20)</td>
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<td>Know that their child will get proper schooling so they will not fall behind in development</td>
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Note: Frequencies in parenthesis underneath the percentages. NS = Non significant