# Ronald McDonald House Charities® Published Research: Citations and Summary of Abstracts



#### **Accommodation Benefits and Preferences**

Franck, L. S., Gay, C. L., & Rubin, N. (2013, July 22). Accommodating Families During a Child's Hospital Stay: Implications for Family Experience and Perceptions of Outcomes. *Families, Systems, & Health*. Advance online publication. doi: 10.1037/a0033556.

Family accommodation programs, such as Ronald McDonald House® (RMH), aim to facilitate family proximity and family-centered care during a child's hospitalization, yet little is known about how the programs influence family experience. The aim of this study was to investigate the perspectives of families regarding the impact of the RMH stay on the family and their hospital experience and to explore the influence of demographic and clinical factors on family member views about their experience and outcome of their child's hospitalization. Family members who spent one or more nights at an RMH in Southern California completed a cross-sectional, self-report survey that included descriptive information about the family and the hospital experience. The 2,081 respondents (53% mothers, 24% fathers, 7% other family members, and 15% multiple family members) generally reported positive experiences at RMH. Although effect sizes were small, families who stayed together for at least a portion of their stay believed more strongly that their ability to stay nearby improved their child's recovery and that RMH helped their family to stay together. Cultural differences were also evident, with Hispanic families believing more strongly that RMH shortened their child's hospital stay. A family's ability to stay together and in close proximity during a pediatric hospital stay is facilitated by accommodations such as RMH and provides important benefits in terms of family experience, psychosocial well-being, and perceptions of child recovery. These services also contribute meaningfully to the priority of providing family-centered care.

Daniel, G., Wakefield, C. E., Ryan, B., Fleming, C. A. K., Levett, N., & Cohn, R. J. (2013). Accommodation in pediatric oncology: Parental experiences, preferences and unmet needs. *Rural and Remote Health*, 13, 2005.

**Introduction:** For families of children diagnosed with cancer, proximity to the treatment centre and staying close to immediate family members are essential for proper patient management. Accommodation services are therefore a key consideration in pediatric oncology. This descriptive study explored the accommodation used, and preferred, by parents of pediatric cancer patients at Sydney Children's Hospital, Randwick (SCH), Australia, and investigated their accommodation/practical needs. **Methods:** Forty-two parents from twenty-five families participated in individual semi-structured telephone interviews. Interviews were recorded, transcribed verbatim and coded line-by-line. Coding was facilitated by data analysis software QSR NVivo 8. Emergent themes were numerically assessed to minimize the potential for researcher bias. **Results:** Nine families (36%) lived near SCH and were able to stay at their own residence during treatment (mean distance of

15.4km from SCH). The remaining families were catageorised as 'out-of-area' families, with the average distance between home and hospital for these families being 370.2km. Accommodation provided for out-of-area families was mixed, with several families reporting using multiple accommodation options during their treatment, including Ronald Macdonald House (RMH), private accommodation or a rental property close to the hospital for the duration of the treatment. Five out-of-area families utilized hotel or motel accommodation during treatment as an alternative to RMH due to unavailability of rooms. Three families also used private accommodation, with family, during treatment. The majority of parents (37/42) preferred to stay on the hospital campus, near their child. Twenty parents preferred self-contained accommodation, while 15/42 preferred accommodation shared with other parents, (i.e. communal). Difficulties with booking accommodation were a clear source of stress for out-of-area families, and despite subsidies, accommodation and travel placed a heavy financial burden. The cost of travel to the hospital ranged from \$15 to more than \$600 per person per trip. Seven out-of-area families reported receiving financial aid for travel. Conclusions: With a large percentage of families travelling long distances for treatment at SCH, it is important to assess their accommodation needs and experiences. Although parents positively appraised the accommodation options they utilized, they also provided useful suggestions for enhancing the experiences of future families. There is a clear need for greater access to accommodation specifically tailored to suit the needs/preferences of families from rural and remote locations.

### **Hospital Experience**

Franck LS, Ferguson D, Fryda S and Rubin N. The Child and Family Experience: Is it Influenced by Family Accommodation? *Medical Care Research and Review*, 2015: 1-19. DOI: 10.1177/1077558715579667

Patient and family experiences are important indicators of quality of care and little is known about how family accommodation affects hospital experience. We added questions about accommodation to standardized inpatient pediatric and neonatal intensive care unit family experience surveys at 10 U.S. hospitals to determine the accommodation types used by families, compare characteristics across accommodation types and explore accommodation-type influences on overall hospital experience outcomes. Parents of inpatient children (n = 5,105; 93.4%) most often stayed in the child's room (76.8%). Parents of neonatal intensive care unit infants (n = 362; 6.6%) most often stayed overnight in their own home or with relatives/friends (47.2%). Accommodation varied based on hospital, parent, and child factors. Accommodation type was a significant predictor for most hospital experience outcomes, with families who stayed at a Ronald McDonald House reporting more positive overall hospital experiences (odds ratios: ranging from 1.83 to 4.86 for contrasted accommodation types and three experience outcomes).

Franck LS, Ferguson D, Fryda S, Rubin N. The influence of family accommodation on pediatric hospital experience in Canada. *BMC Health Services Research*, 2017;17:561. https://doi.org/10.1186/s12913-017-2529-0

**Background:** The goals of our study were to describe the types of family accommodation for parents of hospitalized children and to examine their influence on the pediatric hospital experience.

**Methods:** This multi-site cohort survey included 10 hospitals in Ontario Province, Canada. Participants were parents of inpatient children (n = 1240). Main outcome measures included ratings of three parent-reported measures of hospital experience: overall hospital experience; willingness to recommend the hospital to family or friends; and how much the accommodation type helped parent stay involved in their child's hospital care.

**Results:** Parents most often stayed in the child's room (74.7%), their own home (12.3%), hotel (4.0%) or a Ronald McDonald House (3.0%). Accommodation varied based on hospital, parent and child factors. Length of stay and the child's health status were significant predictors for overall hospital experience and recommending the hospital to family or friends, but accommodation type was not. Families who stayed at a Ronald McDonald House reported greater involvement in their child's care compared with other accommodation types (odds ratio: 1.54–20.73 for contrasted accommodation types).

**Conclusion:** Use of different overnight accommodations for families of hospitalized pediatric patients in Canada is similar to a previous report of U.S. family hospital accommodations. In contrast to the previous U.S. findings, Canadian hospital experience scores were lower and accommodation type was not a significant predictor of overall hospital experience or willingness to recommend the hospital. In Canada, as in the U.S., families who stayed at a Ronald McDonald House reported that this accommodation type significantly improved their ability to be involved in their child's care.

#### **Anxiety and Coping**

Franck, L.S., Wray, J. Gay, C., Dearmun, A.K., Lee, K., Cooper, B.A., Predictors of parent post-traumatic stress symptoms after child hospitalization on general pediatric wards: A prospective cohort study. Int. J. Nurs. Stud. (2014), http://dx.doi.org/10.1016/j.ijnurstu.2014.06.011.

**Objective:** The aim of this study was to identify predictors of parental post-traumatic stress symptoms following child hospitalization.

**Methods:** In this prospective cohort study, a sample of 107 parents completed questionnaires during their child's hospitalization on pediatric (non-intensive care) wards and again three months after discharge. Eligible parents had a child expected to be hospitalized for three or more nights. Standardized questionnaires were used to assess parent distress during the child's hospitalization, parent coping strategies and resources, and symptoms of post-traumatic stress after the hospitalization. Correlations and multiple regressions were used to determine whether parent distress during hospitalization and coping strategies and resources predicted post-traumatic stress symptoms three months after the child's discharge, while controlling for relevant covariates.

**Results:** Three months after the child's hospital discharge, 32.7% of parents (n = 35) reported some degree of post-traumatic stress symptoms, and 21.5% (n = 23) had elevated ( $\geq$ 34) scores consistent with a probable diagnosis of post-traumatic stress disorder. In the multivariable model, parent anxiety and uncertainty during hospitalization and use of negative coping strategies, such as denial, venting and self-blame, were associated with higher post-traumatic stress symptoms scores at three months post-discharge, even after controlling for the child's health status. Parental

anxiety and depression during hospitalization moderated the relationship between negative coping strategies and post-traumatic stress symptoms.

**Conclusions:** More than one quarter of parents of children hospitalized on pediatric (non-intensive care) wards experienced significant post-traumatic stress symptoms after their child's discharge. Parents' hospital-related anxiety, uncertainty and use of negative coping strategies are potentially modifiable factors that most strongly influenced post-traumatic stress symptoms. Further research is urgently needed to test the effectiveness of different methods to provide psychological, emotional and instrumental support for parents, focusing on increasing parent coping resources and reducing distress during hospitalization.

Nabors, L.A.; Kichler, J.C.; Brassell, A.; Thakkar, S.; Bartz, J.; Pangallo, J.; Van Wassenhove, B.; Lundy, H. (2013). Factors related to caregiver state anxiety and coping with a child's chronic illness. *Families, Systems, & Health*, Vol 31(2), Jun 2013, 171-180. DOI: 10.1037/a0031240.

The resiliency of families, based on family functioning and family hardiness, may influence caregivers' anxiety while their child is in the hospital undergoing treatment for his or her chronic illness. The current study assessed the relationship among these factors for caregivers of children with various chronic illnesses who were residing at a local Ronald McDonald House (RMH). Caregivers completed paper-based questionnaires to assess family hardiness, functioning, and parent state anxiety and interviews to identify positive and negative strategies and behaviors affecting how they were coping with their child's illness. Findings indicated that family functioning mediated the relationship between family hardiness and caregiver anxiety as a resilience factor that further reduced caregiver anxiety. During interviews, caregivers suggested that support from family members strengthened their coping abilities. Negative interactions with their child's medical team and not knowing how or being equipped to help their child live with his or her illness heightened caregiver stress. Future research should focus on developing, implementing, and measuring the effectiveness of interventions to improve caregiver support, such as by holding caregiver support groups at local RMHs, especially during a child's hospitalization.

Wray, J., Lee, K., Dearmun, N., & Franck, L. (2011). Parental anxiety and stress during children's hospitalisation: The StayClose study. *Journal of Child Health Care*, 15, 163–174. DOI: 10.1177/1367493511408632.

The aims of this pilot study were to assess anxiety and stress in parents of children admitted to hospital and identify influencing factors, and assess the feasibility and acceptability of the methodology to parents and hospital staff. Parents of 28 children hospitalised for at least 3 days completed questionnaires assessing psychological functioning after admission, 16 and 13 of whom completed questionnaires at discharge and 3 months after discharge, respectively. Almost two-thirds of parents scored in the borderline/clinical range for anxiety at baseline and discharge. Higher anxiety scores were associated with the use of self-blame, lower optimism scores, higher levels of illness-related uncertainty and a greater number of previous hospital stays. Three months after discharge, 38% had borderline/clinical levels of anxiety, with scores significantly correlated with those at baseline and discharge. Although parents were willing to participate, and the questionnaires were acceptable, this pilot study identified some practical and logistical difficulties that will be addressed in the next

phase of the study. Parents experience substantial stress and anxiety when their child is hospitalised. Screening for those at high risk for anxiety and implementing interventions to reduce uncertainty and maladaptive coping strategies may be beneficial.

#### **Quality of Sleep**

Franck, LS, Wray, J, Gay, C, Dearmun, AK, Alsberge, I, Lee, KA. Where Do Parents Sleep Best When Children are Hospitalized? A Pilot Comparison Study. *Behavioral Sleep Medicine*, 11:1–10, 2013. DOI: 0.1080/15402002.2013.801347.

This pilot study compared the sleep quality and quantity of parents who slept at their hospitalized child's bedside with parents who slept at the hospital's onsite Ronald McDonald House® (RMH). Wrist actigraphy and questionnaires were used to estimate parent sleep quality and quantity. Parents who slept at their hospitalized child's bedside experienced more sleep disruption (wake after sleep onset) and reported poorer sleep quality and feeling less rested than parents who slept at RMH. Bedside accommodation was associated with poorer parent sleep even when controlling for the covariates of child age and parent gender. Nearby family accommodations, such as RMH, may facilitate parent-child proximity during a child's hospitalization while also providing parents with opportunities for essential sleep.

#### **Hospital Administrator Perspective**

Paula M Lantz Nicole Rubin D Richard Mauery, (2015), "Hospital leadership perspectives on the contributions of Ronald McDonald Houses: results from an international survey," Journal of Health Organization and Management, Vol. 29 Iss 3.

http://dx.doi.org/10.1108/JHOM-09-2013-0194

**Purpose.** An international survey of hospital executives and administrators was conducted to describe their perspectives on the contributions of their affiliation with a Ronald McDonald House--as an example of accommodation in family-centered care--to the hospital's mission, operations and patient experience.

**Design/methodology/approach.** Ronald McDonald Houses worldwide provided the names and e-mail addresses of the people holding key leadership positions in their main hospital partner, who in turn were invited to complete an Internet-based survey (530 participants; response rate of 54.5%).

**Findings.** Hospital leaders reported very positive opinions about the contributions of their Ronald McDonald House affiliation to their ability to serve seriously-ill children and their families. This included such important outcomes as increasing family integrity and family participation in care decisions; and decreasing psychosocial stress and hospital social work resource burdens associated with lodging, food, transportation and sibling support. Hospital CEOs and medical directors reported very strong and positive opinions regarding the value-added of their Ronald McDonald House affiliation in many areas, including enhanced marketing of hospital specialty services and reduced length of stay.

**Research limitations/implications.** Survey response bias is a limitation, although the results are still useful in terms of identifying multiple ways in which Ronald McDonald Houses are perceived as contributing to hospitals' operations and provision of family-centered care.

**Practical implications.** Overall, the results suggest that, internationally, hospital leaders believe that Ronald McDonald Houses play a key and valued role in their provision of family-centered care to seriously-ill children and their families.

**Originality/value.** This international study contributes to the general literature on the role of family accommodation in hospitals' provision of family-centered care and the specific and very sparse literature on Ronald McDonald Houses in particular.

#### The Power of Play

Nabors, Laura PhD, Jennifer Bartz, Jessica Kichler, Rebecca Sievers, Rebecca Elkins, and Jordan Pangallo. Play as a Mechanism of Working Through Medical Trauma for Children with Medical Illnesses and Their Siblings. Issues in Comprehensive Pediatric Nursing, 2013; Early Online: 1–13. DOI: 10.3109/01460862.2013.812692.

Children's reactions to medical trauma have been recorded through play. In this study, participants were 15 children with medical illnesses, 14 siblings of children with a medical illness, and 6 children in the community who did not have any ill family members. Children participated in play groups and their play with medical toys was videotaped and coded for themes that would provide a window on their perspectives. The play of children with medical illnesses and siblings was similar. Medical play was a mechanism for imaginal coping and working through stress related to medical experiences. In contrast, children in the comparison group did not engage in much medical play and when they did, they did not demonstrate a rich play experience with detailed medical stories. Future research should focus on ways to use play therapy techniques to help medically ill children and their siblings cope with their feelings and reactions to medical events related to chronic illness.

## RMH as an Alternative to Hospitalization

Dexter, Scott C. MD, Kristine A. Klein, MD, David A. Clark, MD, Steve L. Ross, MSW, Jean-Claude Veille, MD. (2004) The Ronald McDonald House as an Alternative to Antepartum Hospitalization. *Journal of Perinatology* 24, 623–625. DOI: 10.1038/sj.jp.7211166. Published online 15 July 2004.

**OBJECTIVE**: We sought to evaluate the use of the Ronald McDonald House (RMH) for selected high-risk pregnant women. **METHODS**: Beginning in November of 1999, women on the Maternal Fetal Medicine service at Albany Medical Center Hospital (AMCH) were candidates for antepartum lodging at the Ronald McDonald House (RMH). Women whose only indication for antepartum hospitalization was to maintain proximity to a tertiary care center were offered stays at the RMH. Antenatal and neonatal outcomes were reviewed. **RESULTS**: A total of 41 antepartum subjects stayed at the RMH during the study period. No adverse perinatal outcomes were identified due to utilization of the RMH. Patients stayed at the RMH instead of staying at AMCH as inpatients for a total of 586 days during the study period. **CONCLUSIONS**: Outpatient management at the RMH is a cost-effective alternative for selected high-risk pregnancies. No adverse outcomes in the study population were attributable to the utilization of the RMH.