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Hanna Soumerai
Stuck Kids: A Study Examining
Factors that Contribute to
Hospitalized Children Being
Placed on Administrative Days

ABSTRACT

This study examined factors that contribute to medically complex children getting “stuck” in acute rehabilitation hospital level of care even though they were medically ready for discharge. Of special interest were caretaker and societal-related factors that may have a high potential for change and early intervention. *Sample.* Retrospective, non-comparative case series. *Methods.* The medical records of 20 children discharged between 2010 and 2012 from a specialty acute rehabilitation hospital in New England were surveyed using a protocol designed for the project. The children had been placed on “administrative days” (AD) prior to discharge. Univariate and bivariate analysis examined the impact of patient disease characteristics, parental characteristics, and societal factors on post-AD status length of stay. *Findings.* Although the final sample size (N=20) limited the reliability and types of statistical tests that could be undertaken, analysis suggested that disease factors interact with caretaker and societal factors to create the conditions that delay discharge.

Findings from the study were used to inform the development of screening tools and targeted interventions for use by the Medical Social Work Service at the host hospital. And a recommendation was made to develop a prospective, comparative case series study of all admissions to further explore the factors identified in this pilot study.

**STUCK KIDS: A STUDY EXAMINING
FACTORS THAT CONTRIBUTE TO HOSPITALIZED CHILDREN
BEING PLACED ON ADMINISTRATIVE DAYS**

A project based upon an investigation at a pediatric post-acute rehabilitation hospital, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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2013

ACKNOWLEDGEMENTS

I would like to acknowledge several people whose contributions made this project possible. First, I would like to acknowledge Dr. Elizabeth Irvin for her investment and support as my thesis advisor. Furthermore, I would like to thank the host hospital for allowing me to do research at their agency. In addition, I wish to acknowledge Dr. David Leslie who provided medical consultation during the study. Lastly, I would like to acknowledge research sequence faculty Idene Martin, and Health Policy faculty, Hannah Karpman, for their knowledge and encouragement.

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CHAPTER I

Introduction

This study examines a problem that I observed during my clinical social work internship in a specialty pediatric post acute rehabilitation hospital (PAR-LOC). Some children, who otherwise were medically prepared for discharge, remained in the hospital for extended periods of time, ranging from days to, in one case, several years. This exploratory study was developed with the goal of identifying factors that may have contributed to delaying the discharge of these children. In particular, the study was designed to examine caretaker and societal-related factors affecting timely discharge from PAR-LOC that may have a high potential for change and early intervention.

The study sample, a retrospective, non-comparative case series, was drawn from the records of 20 children discharged from a PAR-LOC hospital in New England between 2010 and 2012.

Children treated in this setting were transferred from Boston-area, and regional, acute medical settings for care ranging from pulmonary rehabilitation to weaning from oxygen or a ventilator and/or for physical rehabilitation while recovering from an acute illness or acquired injury. In addition children with chronic conditions and/or multiple congenital anomalies are admitted for a variety of medical issues that are common among this medically complex population. Lastly, complications due to Neonatal Abstinence Syndrome (NAS) or prematurity

are frequently treated in this setting (O'Brien & Dumas, 2013). Of importance, the host hospital is the only PAR-LOC in New England that admits ventilator dependent children.

After obtaining Institutional Review Board approvals from the sponsoring hospital (Appendix A) and Smith College (Appendix B), the medical records of children who had been placed on “administrative days” (AD) during the target dates were surveyed. An administrative day is identified as “a day of hospitalization on which a child’s [member’s] care needs can be met in a setting other than a . . . rehabilitation hospital and on which a member is clinically ready for discharge” (Commonwealth of Massachusetts: MassHealth: Provider Manual Series: Acute Inpatient Hospital Manual, 2012). For purposes of narrative, in this document, children placed on AD status will be referred to as “stuck kids.”

The survey protocol develop for this study was informed by the work of Cross, Leonard, Rheinberger, and Skay (1998). A copy of the survey tool can be found in Appendix C. Findings from the study were used to inform the development of screening tools at the host hospital, particularly with regard to the identification of caretaker and societal issues that may have a high potential for early intervention.

Most of the studies that examine prolonged medical hospitalization in children focus on ventilator- or technology-dependent children (TDC) being treated in acute care settings. A smaller number have examined TDC in skilled nursing facilities (SNF) level of care. The children in this study “stepped-down” to PAR-LOC settings from an acute medical setting, and were admitted with the goal of eventual reunification with their families. None of the children in this study were discharged to SNF-LOC.

This study is needed because the problem of “stuck kids” in PAR-LOC is significant and far reaching. Unnecessary hospitalization days disadvantage children, burdens families (Gittell

et al., 2000), drains revenue and lowers staff morale unnecessarily (Jansen et al., 1989). We need a better understanding of the factors that contribute to extending hospital stays for children in order to have any meaningful impact on this problem.

Although not the focus of this research, from a policy perspective, in addition to the benefits children and their families derive from shorter hospital stays, reducing hospital utilization also reduces the costs of care, much of which is underwritten by public funding (DeWitt, Jansen, Ward, & Keens, 1993; Gruenberg & Willemain, 1982; Leurer, Be'eri, & Zilbershtein, 2006; Millner, 1991; Noyes, 2002; Sudbery & Noyes, 1999).

The next chapter provides an overview of the research literature that has examined this problem for medically complex and technology dependent children.

CHAPTER II

Literature Review

The literature review is divided in five sections. The first section examines the impact on children of unnecessary hospitalization from the perspective of disrupted attachment. The second section examines the impact of medical technology and patient disease characteristics on length of stay, with particular reference to medically complex children (Gruenberg & Willemain, 1982; Leurer et al., 2006; Ballard, Rosenstein, & Pao., 2007; O'Brien & Dumas, 2013). The third section reviews the literature on caretaker characteristics that have been associated with extending hospitalization (Cross et al., 1998; Leurer et al., 2006; Jansen et al., 1989., 1989; Millner, 1991; Silber, 1989); the fourth examines institutional factors affecting length of stay (Noyes, 2002, Scharer & Dixon, 1989). And, the fifth reviews societal factors related to aftercare and funding issues (DeWitt et al., 1993; Gruenberg & Willemain, 1982; Hamilton & Vessey, 1992); Jardine, O'Toole, Paton, & Wallis, 1999; Millner, 1991; Noyes, 2002; Shipley, 1997; Sudbery & Noyes, 1999).

Disrupted Attachment

Ballard et al argue that prolonged hospitalization disrupts normal development in children and adolescents (2007). Attachment theory provides a useful frame for this review. As described by Berzoff, Flanagan and Hertz (2008), James Bowlby and Joyce Robertson observed toddlers placed in residential nurseries while their mothers were hospitalized. Despite adequate care, these children displayed distress and anger. Researchers in this groundbreaking study concluded that this strong reaction was the result of being separated from their mothers. As the

separation continued, the children became increasingly distressed, leading to signs of depression and eventual detachment. When separated, the children reacted as if their mothers were permanently gone. When reunited with their mother, the children appeared relieved but were easily agitated again during brief separations. These researchers came to understand that the mother-infant attachment is the foundation from which all other relationships are formed. A securely attached child learns that they can trust their surroundings and thus learns to develop autonomy. Therefore the child is able to progress into adolescence, which is a time of identity formation. Theoretically, when there are disruptions in these stages the child usually becomes stuck in a developmental stage (Ballard et al., 2007). Subsequent research has demonstrated that other sensitive adults (fathers, for example) can provide a nurturing context for the development of healthy attachments (Sessions, 2012).

The work of Ballard et al. (2007) reinforces the findings of early attachment theorists. They found that prolonged hospitalization disrupts the child's development; in their study, infants who were frequently exposed to uncomfortable and painful procedures displayed anxiety and struggled to attach to their caregivers. Children with special health care needs (CSHCN) are frequently separated from family, friends, school and the opportunity to become skilled in an activity. Ballard et al. (2007) state, "*Chronically ill children often have difficulty finding something to excel at and thus have trouble feeling confident and competent. (p.2753).*" Noyes has supported these findings (2002). She interviewed 18 ventilator-dependent youth between the ages of 6-18 years with the aim of better understanding their views and experiences. Her participants complained that their basic human needs were unmet during prolonged hospitalization. These included: need for attachment, sense of security, continuity, belonging and ability to freely communicate and makes friendships. Noyes's participants also felt that their

extended hospitalization reinforced a belief that their lives weren't valuable, purposeful, or significant and that they didn't count for something (2002). In short, prolonged hospitalization can have a significant impact on the development of children and thus should be avoided whenever possible.

Medical Technology and Disease Characteristics

Disease characteristics. Disease characteristics that influence extended hospital stays include dependence on medical technology, total dependence on others' for care, and co-morbid medical and behavioral problems (Cross et al., 1998; Gruenberg & Willemain, 1982; Noyes, 2002).

Medical technology. Several authors have written about the influence of advancement of medical technology on CSHCN (Capen & Dedlow, 1998; DeWitt et al., 1993; Ballard et al., 2007). These advances have increased survival rates and profoundly altered the lives of affected children and their families. One possible unintended consequence of these advances is that there is a growing population of children who spend much of their lives in the hospital. Berry et al. (2011) researched the hospital utilization of technology dependent children in a large, multi hospital study. They examined data on 317,643 patients admitted to 37 US children's hospitals in 2003, with follow up through 2008, and found that children dependent on medical technology and children with complex chronic health conditions were at a greater risk of high hospital utilization than children with other medical issues. O'Brien & Dumas (2013) found that ventilator dependent children remained in a PAR- LOC longer as compared with children who were not ventilator dependent. Leurer et al. (2006) also examined this issue in a PAR-LOC and found that children who required mechanical ventilation (MV) post-discharge experienced prolonged hospitalization as compared with the non-MV on discharge group.

Due in part, at least, to the advances in medical technology, there is a growing population of children who spend much of their lives in hospitals. While this population of children is generally sicker than other children in the same LOC and require prolonged hospitalization to stabilize medically, there are other, non-medical issues that delay discharge for these children. In short, children dependent on medical technology for survival are a growing population and are particularly vulnerable to prolonged hospital stays. The last vulnerable group described in the literature includes patients with co-morbid medical and behavioral problems.

Co-morbid medical and behavioral problems. Due to the scant literature, this researcher has included the following study that examines prolonged hospitalization in an adult population. Gruenberg and Willemain examined the utilization of health care facilities by adult patients. Patients in the long-stay group were more likely to be totally dependent on others' for care, their household was more often regarded as unable to cope physically and emotionally with the parent, and the adults in the long-term group were more likely to have behavioral problems (1982). Considering that children are always dependent on adults for care, it is likely that the same dynamics are present in a pediatric population. Thus, children with co-morbid and behavioral problems may be at a greater risk of prolonged hospitalization.

This section has identified several disease characteristics that influence hospital length of stay and may contribute to the problem of “stuck kids.” The next section discusses parental/caretaker characteristics that may contribute this phenomenon.

Parental/Caretaker Characteristics

Parents are expected to assume more responsibility in caring for their CSHCN than previously (Odom & Chandler, 1990). They are required to learn procedures such as suctioning secretions, maintaining indwelling catheters, and to solve issues that arise with ventilators and

other medical equipment (Gill, 1987). Most families are capable of learning care, but other issues often get in the way of caregiver training (Cross et al., 1998).

Caregivers are central to the survival of CSHCN. In many instances, home environments that would be sufficient for healthy children are inadequate for these more vulnerable children. This is complex for social workers who have to think about protective issues when working with parents who would be competent caring for a healthy child but unable to meet the significant needs of their child with special health care needs (Sudbery & Noyes, 1999). Thus, it is important to understand caretaker characteristics that contribute to the problem of “stuck kids.” The literature exploring this issue, can be organized into the following categories: knowledge/competence to learn the child’s care (Cross et al., 1998; Gill, 1987), parental involvement/attachment to the child (Silber, 1989), lack of social and/or financial resources (Schor, 2003), as well as typical protective issues such as child abuse and drug addiction (Millner, 1991).

Knowledge/competence to learn child’s care. Cross et al. (1998) examined a group of 50 technology dependent children in sub-acute care whose discharge was delayed despite being medically stable and ready for discharge and found a significant correlation between number of days the child remained hospitalized after being discharge ready and the capacity of the parent(s) to medically care for their child. While most families were assessed as capable of learning care, there were significant barriers that were interfering with caregiver training. These included being stretched too thin between job commitments, caring for other children at home, and having a limited amount of time to learn care. Many families in their study also had a lengthy commute to the hospital or did not have access to appropriate transportation. Gill (1987) found that

parents avoided or canceled teaching because of some reluctance to learn complicated medical care.

Parental involvement/attachment to child. Scharer and Dixon (1989) are concerned that the focus on caretaking tasks might reduce typical bonding behaviors such as eye contact, smiling and cuddling. Cross et al. (1998) found a lack of bonding between parents of children who endured discharge delays. In addition, they found a significant relationship between the number of unnecessary hospital days and the frequency of parental involvement (visiting and check in phone calls). Specifically, less than three check-in phone calls per week, and infrequent visits (less than two per week), were associated with discharge delays.

Silber (1989) hypothesized that some parents were reluctant to bond with their CSHCN because they were afraid their children would not survive and were protecting themselves from grief. Rapacki (1991) agrees and asserts that bonding problems occur due to the psychological stress of caring for a high-risk child. Reduced involvement and disrupted attachment are confounding variables in most studies. For example, families for whom English is their second language may have difficulty interacting with (calling) the hospital for updates if they are unsure of how to access interpreter services. Most hospitals have a limited number of interpreters and accessing this resource when parents are available to call or visit isn't always feasible.

Research suggests that parents who lack involvement and/or documented bonding with their child are more at risk for having a “stuck kid” (Cross et al., 1998). However, we don't know whether these variables are confounded by other factors; such as poverty, transportation issues, etc. Millner (1991) found that hospital staff believed that care in the parental home was not possible for nearly half of their subjects. Approximately 8% of parents reported that they did not want their children at home, and 16 % of parents indicated that caring for their child at home was

impossible. Other issues identified included protective issues such as: a history of child abuse or drug addiction.

Societal Issues Related to Funding and Aftercare Resources

Unnecessary days in that hospital disadvantages children developmentally and burdens families unnecessarily. Societal factors that influence prolonged hospital stays include a shortage of skilled nursing facilities (Cross et al., 1998; Millner, 1991), delays in home care funding (DeWitt et al., 1993), difficulty recruiting in-home aids (Noyes, 2002), and a lack of common standards across funding and state agencies (Jardine et al., 1999; Noyes, 2002; Shipley, 1997). DeWitt et al (1993) and others have found that public funding agencies took significantly longer to approve home care funding than did privately funded agencies. In several studies, children in need of alternative placements waited significantly longer in the hospital than a comparable group of children who were discharged home (Leurer et al., 2006; Millner, 1991; Noyes, 2002; Sudbery & Noyes, 1999).

Poverty, lack of social support, single parent homes, unemployed fathers, teenage parents, and families with an additional disabled child are other characteristics of families of children who endured prolonged hospitalization (Schor, 1988; Leurer et al., 2006). Social/financial issues associated with “stuck kids” include: families living in poverty, having an additional family member with a disability, teenage parenthood, an unemployed father, single parent families, lack of social support or other social problems that make caring for CSHCN difficult or impossible (Leurer et al., 2006; Millner, 1991; Schor, 1988).

According to Capen and Dedlow (1998), ideals for how and where CSHCN receive care have evolved and created challenges for the health care system. Prior to 1980, children with special healthcare needs were considered too fragile to live outside of intensive care units.

Former Surgeon General C. Everett Koop spearheaded conferences from 1982 to 1987 aimed at developing better ways to meet the needs of ventilator dependent children. Concepts such as family-centered, community-based, and culturally competent care emerged from these conferences. Sending children home into “normal environments” became the new ideal.

Developments in portable technology engineering allowed CSHCN children to attend school and engage in activities that were previously restricted to them. However, community-based health care services and recourses have not caught up with the advancement in medical technology or the growing population needing these recourses (1998).

Institutional Factors: Discharge Planning

Noyes (2002) discusses the institutional factors that contribute to kids getting stuck in inpatient LOC. Her qualitative research focused on the perceptions of families of ventilator-dependent children. Families reported that discharge planning was often poorly managed; comments included: “inexperienced” nurses were managing complex discharges; no single person appeared to be in charge; and there appeared to be a lack of awareness of national standards or discharge policies and guidelines regarding when and how children dependent on ventilators should be discharged. Parents accused doctors of operating from a protectionist attitude, which resulted in many of their children remaining hospitalized well beyond medical need. Noyes (2002) states, “There ‘protectionist’ traditions, however, need to be balanced against the rights of the child and family and known deleterious effects of prolonged hospitalization. (p.6).” Other barriers included perceptions of poor communication between staff with parents, and participants’ perceptions that the attitudes of some professionals delayed discharge (Leurer et al., 2006; Millner, 1991; Schor, 1988). Families reported feeling that

professionals often took a protectionist stance and tolerated months of indecisiveness regarding deposition issues.

Aftercare Funding

Several researchers found that after care resources and funding issues contributed significantly to discharge delays. These issues can be organized into five categories: Shortage of skilled nursing facilities (Millner, 1991), limited and slow approval for in-home services (Cross et al., 1998; DeWitt et al., 1993; Millner, 1991; Noyes, 2002), differences in quality of private versus public insurance (DeWitt et al., 1993), scarcity of discharge options (DeWitt et al., 1993; Leurer et al., 2006; Millner, 1991; Noyes, 2002), and a lack of joint funding of recourses and collaboration across state agencies (Jardine et al., 1999; Noyes, 2002; Shipley, 1997).

Shortage of skilled nursing facilities. There is some disagreement within the literature regarding whether a shortage of skilled nursing facilities has been shown to be a barrier to timely discharge or not (Millner, 1991; Dewitt's, 1993). Millner found that there was a shortage of skilled nursing facilities. However Dewitt's study suggests this is not the case. Instead he found that slow or limited approval delayed timely discharge.

Slow or limited approval for in-home services. Several authors have written about the issue of limited or slow approval for in-home services. These include: difficulty recruiting in-home aids (DeWitt et al., 1993; Leurer et al., 2006; Millner, 1991; Noyes, 2002), shortage of in-home nursing services in local communities (Millner, 1991), and long delays in approval of home care funding (Cross et al., 1998; DeWitt et al., 1993). In Dewitt's study, patients waited more than 3 months on average for approval of home care funding. They also learned that there was a difference in quality of care provided under public vs. private insurance coverage. Publically funding resources in their studies had significantly longer approval timelines for home

care services than did privately insured. Once funding was approved, patients were discharged within two months unless there were issues related to placement (1993).

Lack of discharge options. Based on several studies, children in need of out of home placements remained stuck in the hospital significantly longer than children discharged to home (DeWitt et al., 1993; Leurer et al., 2006; Millner, 1991; Noyes, 2002). In DeWitt's study, three patients needed medical foster care placements because their families were unable or unwilling to care for them. It took an average of one year to place these children (1993). Cross et al. (1998) found that a lack of discharge options was strongly correlated with discharge delays. Similar to the Dewitt study, these three patients waited in the hospital while foster care was arranged.

Lack of collaboration across state agencies. Noyes and several other authors argue that there is a lack of collaboration and funding across various stakeholders. This is especially complex for CSHCN who often rely on several state agencies to fund in-home services. Noyes (2002) found that major discharge delays were experienced because state agencies often could not agree on who was responsible for funding aftercare services. In Noyes's study, conducted in England, parents believed that this problem was exacerbated by an on-going restructuring of the National Health Services (2002). In short, there were many issues related to aftercare and funding that delayed discharge. However, all of these studies target children dependent on mechanical technology and thus cannot be generalized to a broader population of CSHCN. Aftercare services are very different for a child who is a recent amputee and has behavioral issues than they are for a child who is technology dependent.

Summary

The factors that may contribute to a medically complex children becoming “stuck” in acute and/or PAR-LOC are very complex and incompletely understood. Rapid advances in portable life-sustaining technology have created both opportunities and dilemmas for parents and healthcare providers alike, as well as for funding entities and policy makers. Most of the studies reported in this narrowly focused review of the literature were conducted in acute care settings and address this issue with regard to children who are dependent on medical technology. Only a handful of studies describe children in PAR-LOC, and none provide insight into the characteristics of children and families most vulnerable of becoming stuck at this level of care.

Understanding the factors that lengthen hospital stays may improve health outcomes for medically fragile children with CSHCN. Such children can make significant progress at home and experience an increased quality of life as compared with CSHCN who remain institutionalized (Capen & Dedlow, 1998). Caring for a hospitalized child adds to familial care burden, which, in turn, has been associated with poorer health outcomes for children with special health care needs. Families with fewer resources must struggle balancing the demands of daily life with spending time with their hospitalized child. The development of attachment issues is of concern for those infants and children whose parents are unable to visit regularly. Extended hospitalization has also been shown to disrupt normal development due to the restrictive nature of hospital settings (Ballard et al., 2007; Silber, 1989).

The project proposed here looked at the medical records of a small group of children who, using contemporary insurer language, were “stuck” in the hospital in the sense that they no longer met criteria for hospital rehab level of care. They were, by utilization review (UR) criteria, ready to be out of the hospital but were not yet at home. They were placed, for payment

purposes, on “administrative days” (AD status). Medical providers did not disagree with the UR conclusion about readiness for discharge.

The study hoped to further our understanding of caretaker and societal-related factors that may be contributing to continued hospitalization for this unique cohort of children with special health care needs, especially factors with high potential for change and early intervention.

The next chapter outlines the study methods including, research design, sample, inclusion and exclusion criteria, ethics and safeguards, data collection strategies, and data analysis plan.

CHAPTER III

METHODOLOGY

The aim of this exploratory study was to identify factors that contribute to medically complex children getting “stuck” in PAR-LOC. Of special interest are caretaker and societal-related factors that may have a high potential for change and early intervention. As such, the research explores associations between the number of days on AD status and the following major domains of data: 1) patient disease characteristics (5 items), 2) parental/caretaker characteristics (5 items), and 3) societal factors (4 items). In addition, demographic information (18 items) was collected for stratification of sample into groups.

Research Design

This exploratory study utilized a quantitative methods design with the aim to produce generalizable findings.

Sample

The medical records of 20 discharged patients ranging in age from 6 days to 18 years at admission were reviewed.

Inclusion criteria. The study sample was a retrospective, non-comparative case series. The medical records of children who were discharged between 2007 and 2012 on AD-status from a PAR-LOC hospital in New England after insurance utilization review were eligible for inclusion after obtaining IRB approval for record reviews. Operationally, AD status was defined as “a day of hospitalization on which a child’s (member’s) care needs can be met in a setting other than a . . . rehabilitation hospital and on which a member is clinically ready for discharge”

(Commonwealth of Massachusetts: MassHealth: Provider Manual Series: Acute Inpatient Hospital Manual, 2012). The date the reimbursement rate was lowered to an “administrative days” rate was used to operationalize day one of the administrative days status (AD status) for purposes of study inclusion. Since being placed on AD status is associated with a change in reimbursement, hospital billing records were interrogated and identified 54 records meeting criteria for study inclusion.

Exclusion criteria. Discharged patients who were never placed on AD status were excluded from the study. Also, patients older than 18 years of age at admission were not included. Records were excluded if they did not contain sufficient information to address data points in the study protocol. The medical record system was in transition during the index study period. A sample of older record formats suggested that some of the information proposed for collection could not be identified in records generated earlier than 2010. Therefore, the sample was truncated to 20 records, all of which used the same electronic medical record format, and spanning discharge dates between January 2010 to December 2012.

Recruitment Procedures

Access to medical records was through hospital Institutional Review Board (IRB) approval process. Please refer to the Human Subjects / IRB section below for details.

Ethics and Safeguards

Risk of participation. No participants were interviewed for this project. Risk to participants would be associated with allowing unauthorized access to data that were collected, failing to exclude patient names during data collection, or failing to aggregate data free of PMI during data collection or publication phases. These risks were minimized by the procedures for

data collection, management, storage, and publication outlined in the Precautions to Safeguard Confidentiality and Identifiable Information section of this paper.

Benefits of Participation. As the study is a review of medical records of discharged children, participants, as such, did not derive any direct benefit from study participation.

Precautions Taken to Safeguard Confidentiality and Identifiable Information. Approval from host hospital IRB (Appendix A) and Smith College Human Subjects Review Board (Appendix B) were in hand prior to starting data collection. Copies of each institutions approval letter were disseminated to the other institution's committee. Such processes assure that all materials meet federal, institutional, and college standards for protection of human subjects. A unique ID was assigned to each patient record. Only the researcher has access to the code sheet associating patient medical record numbers and names. Completed data collection forms were coded only with the unique ID. No PMI was captured on the protocol.

Data forms were kept in a locked cabinet in the host hospital and were accessible only to the researcher. Electronic medical records were reviewed within the host hospital firewall. Data was logged first on pre-coded forms and then entered into an EXCEL file and stored in a password-protected file within the host hospital firewall. Only the investigator knew the password for accessing the file. The raw data file was reviewed and cleaned by the investigator and checked by the advisor to ensure that no PMI was contained. The cleaned data file was used for analysis.

The researcher conducted data analysis with statistical consultation from a faculty member of Smith College School for Social Work. Smith faculty and staff have signed a confidentiality agreement. Data is not accessible for anyone not mentioned in this list. Data will be kept for three years per Federal guidelines, then destroyed unless needed for a longer

period of time, in which case they will be kept securely as described above and destroyed when no longer needed.

Human Subjects Review Board. The Human Subject Review Board (HSRB) at Smith College, Northampton, MA as well as the Institutional Review Board (IRB) at the host hospital approved the study after assuring that all materials met Federal and institutional standards for protection of human subjects. A copy of the HSRB approval letter is provided in Appendix A. A copy of the IRB approval letter is provided in provided in Appendix B.

Data Collection

Overview. Data were collected using a pre-coded inventory developed for the project (Soumerai, 2013: Appendix C). The inventory was informed by the work of Cross et al. (1998) who examined a group of 50 technology dependent children in sub-acute care whose discharge was delayed despite being medically stable and ready for discharge.

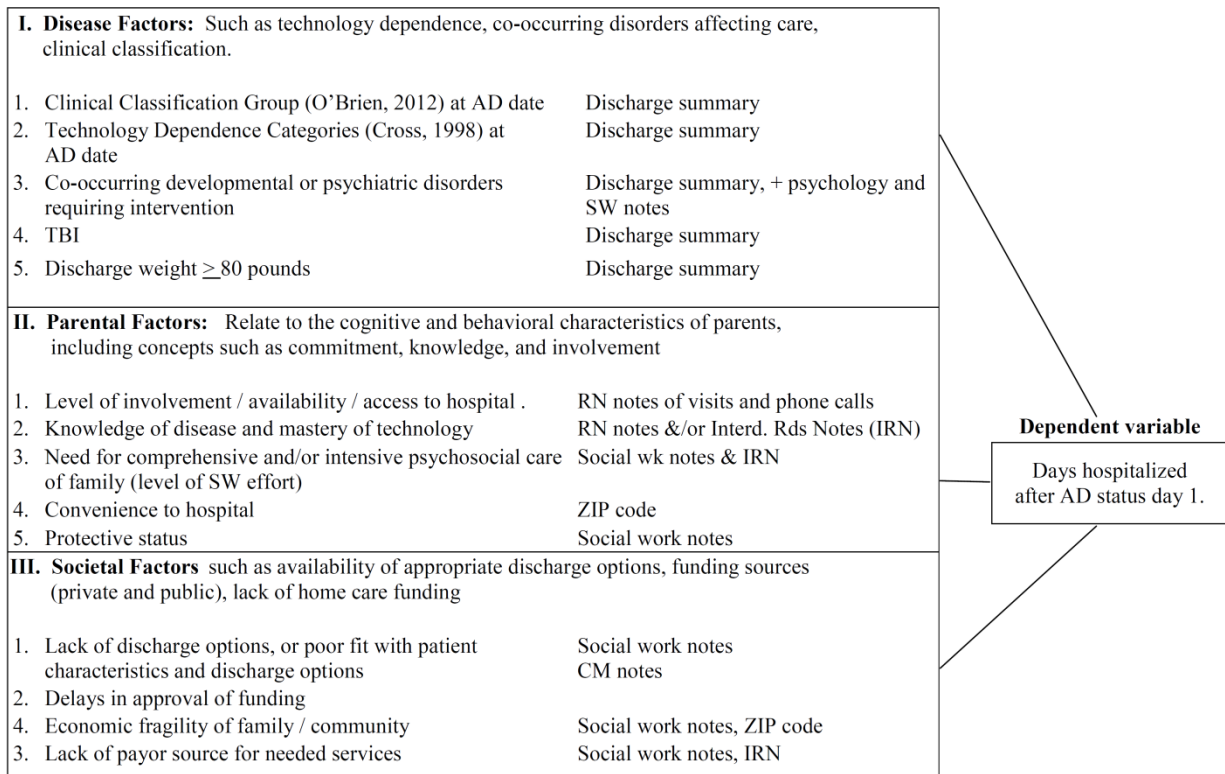
Informed consent procedures. Access to medical records was through the Institutional Review Board (IRB) process at the host hospital.

Data Analysis

The original data analysis plan was designed with a larger sample in mind. Feasibility issues discussed more fully in Chapter V (Discussion), limited the final sample size. However, the original data analysis plan is presented here as a guide for future research, and so the reader can align the original plan with the data collection tool. Univariate and bivariate analyses were used to examine the impact of patient characteristics, parental characteristics, and societal factors on post-AD status length of stay. Disease factors were expected to interact with parental and societal factors to create conditions that delay discharge. Figure 1 describes the domains of interest anticipated sources for data collection.

Quantitative measures. Explanatory (predictor) variables in the study were divided into three groups: 1) Patient disease characteristics (5 items), 2) Parental/Caretaker characteristics (5 items), and 3) Societal factors (4 items). In addition, demographic information (18 items) was collected for stratification of sample into groups, including age, guardianship status, need for Interpreter services, distance from the hospital, length of stay (LOS) in days, race, gender, and insurance type.

Figure 1: Domains of interest and anticipated data sources



Patient Disease Characteristics were used to classify the child's "clinical group" using strategies described by O'Brien and Dumas (2013). The child's "technology dependent status" was determined using strategies described by Cross et al. (1998). Co-occurring disorders, traumatic brain injury (TBI), and discharge weight GT/ET 80 pounds were coded "present" or "absent." Finally, societal factors such as lack of discharge options, delays in funding approval,

economic fragility of the family, problems with payment source, and access to specialty care (rural vs. urban) were coded as “present” or “absent.”

Explanatory (predictor) variable responses were intended to examine correlation between post-AD status length of stay (post-AD LOS) and patient disease characteristics, caretaker characteristics, and societal factors. In addition, we planned to use bivariate analysis strategies to examine the strength of the relationship between each of the explanatory variables and post-AD status LOS. For example, responses were to be examined to explore the relationship (correlation) between length of AD status and such child-centered issues as clinical disease group, co-occurring disorders, and technology dependence. Similarly, Parental/caretaker characteristics and societal factors were planned for examination with regard to an association between these and post-AD LOS.

Demographic characteristics were collected in order to explore within group differences and possible relationships with post-AD LOS. For example, is the guardianship status at admission (or discharge) associated with longer post-AD LOS? Do children with multiple admissions to rehab-LOC vary with regard to the post-AD LOS? Are there differences in post-AD LOS between children from “economically fragile” communities when compared with children from “economically robust” communities? Language at home (English/non-English), insurance type (private/public), and other groups can be formed based on the demographic characteristic.

Finally, we consulted with the statistician at Smith College regarding the possibility of deploying regression analysis to understand which among the 14 independent variables were related to the post-AD LOS, and to explore the forms of these relationships. This was not feasible due to the small sample size that emerged. Finally, disease factors were expected to

interact with parental and societal factors to create the conditions that delay discharge. The next chapter presents findings from the study.

CHAPTER IV

Findings

This was an exploratory study using a quantitative methods design. The purpose of the study was to identify factors that may have contributed to medically complex children becoming “stuck” in PAR-LOC even though they were medically ready for discharge. Of special interest were caretaker and societal-related factors. The goal of the study was to identify factors that may have a high potential for change and early intervention.

The sample consisted of the medical records of 20 children who, before they were discharged, were placed on “administrative days” (AD status) by their insurance carrier. This occurs when the child’s condition no longer meets criteria for the level of care they are receiving. That is, the children in this sample were medically ready for discharge (PAR-LOC) but nonetheless remained hospitalized. Medical providers did not dispute such status. In the study, this group is referred to as “stuck kids.”

This chapter contains a description of the sample and summaries of the quantitative data, including patient disease characteristics, parental/caretaker characteristics, and societal factors. Due to the small sample size, external and internal validity of the findings are not reliable and should not be read as such. However, some observations and inferences can be made for further exploration and are described in the discussion.

Table 1

Demographic characteristics of the children (N=20)

	Frequency	Percent
Gender		
Male	11	55
Female	9	45
Age in years		
Infant (under 2 years)	10	50
Toddler-Pre Latency (2-4 years)	2	10
Latency (5-9 years)	1	5
Early Adolescence (10-13 years)	2	10
Middle Adolescence (14-17 years)	4	20
Late Adolescence (18+ at discharge)	1	6
Race/Ethnicity		
White	8	40
White/Hispanic	4	20
Black	5	25
Black/Hispanic	1	5
Black/Haitian	2	10
Language, Family of Origin (FOO)		
English	14	70
Spanish	4	20
Haitian/Creole	2	10

Almost two-thirds of the children placed on AD status were younger than 5 years of age (n=12). 60% identified as white, 30% were not native English speakers.

Patient Disease Characteristics

The patient disease characteristics included O'Brien and Dumas clinical classification (2013), technology dependence (Cross et al., 1998), and whether the child had an acquired a brain injury, the need for handicap accessible housing at discharge, presence of a co-occurring behavioral disorders affecting care, and discharge weight.

Table 2

Patient Disease Characteristics, (N=20)

	# Cases	Percent
Clinical Classification		
Active Rehab	4	20
Medically Complex	13	65
Neonate	3	15
Ventilator Dependent	0	0
Technology Dependence		
None	9	45
Nutrition or drugs,	8	40
Other nutrition or respiratory support	2	10
Trach/Suctioning	0	0
Prolonged Dependence on mechanical supports	0	0
Missing	1	5
Traumatic Brain Injury		
None	17	85
Acquired, non-traumatic	1	5
Acquired, traumatic	2	10
Requires handicapped assessable housing		
Yes	9	45
No	10	50
Missing	1	5
Developmental delay or psychiatric disorders complicating treatment		
Yes	3	15
No	17	85
Discharge Weight > 80 lbs.		
Yes	6	30
No	14	70

None of the children in this sample of “stuck kids” were ventilator-dependent. This is contrast to the population described by Cross, et al. (1998) in which most of children were ventilator dependent.

This contrasts with the O'Brien and Dumas (2013) study which examined all admissions for calendar year 2010 and 2011 in the same hospital and service that this study was conducted. They found that 24 % (93 of 262) patients were ventilator-dependent children. Furthermore, in their study, ventilator dependent children had significantly longer hospital stays than any other clinical group, with a mean of 57.78 days. It is noteworthy that no ventilator dependent children met enrollment criteria for this “stuck kids” study. In addition, this study had a higher percent of children in the medically complex group (n=13, 65 %) vs. 42% (n=161) in the O'Brien and Dumas (2013) cohort.

The active rehabilitation group (n=4) was congruent with O'Brien and Dumas (2013) sample (n=77, 20%). In addition, the neonate group was almost congruent with their findings (n=3, 15%) and O'Brien and Dumas (n=51, 13%).

Weight at discharge was included in this study because children weighing more than 80 pounds are a “two person carry” for purposes of safety planning and would potentially require handicapped accessible housing for safe discharge.

Parental/Caretaker Characteristics

Parents and caretakers exhibited a wide range characteristics, including level of involvement, bonding, capacity to care for child, family of origin language and whether Interpreter services were need to interact with parents, particularly with regard to caretaker training.

Table 3

Caretaker involvement: Number of caretaker calls 30 days prior to AD status (N=20)

	# Cases	Percent
3 or fewer calls per week	6	40
More than 3 calls per week	9	60

Four children were visited less than 1 day per week. One child had no visits during the 30-day period prior to initiation of AD status. The records of children visited less than 3 days per week were examined to learn if they caretakers called the hospital to check in with nursing staff during the same period. This was not the case. In addition to minimal visits, this group called less than 3 times per week.

Narrative data. Nursing notes were examined searching for descriptors of parental bonding. The text was organized into five categories, involvement, bonding, capacity, minimal involvement and capacity issues using the following criteria: 1) *Involvement* included any text that referred to engagement in a literal sense, and/or when parents were described as “engaged,” “involved,” or “always at child’s bedside.” 2) *Bonding* included documentation of the child responding positively to a parent or caregiver such as “smiling and laughing,” or parental expressions of happiness when talking about child’s progress, or described as “loving,” “tender,” “bonded,” or having strong attachment. Other examples were parents providing “support,” or “nurturance,” by “consoling,” “holding,” or “rocking” the child, and/or parent expressions of concern when the child experienced pain. 3) *Capacity* includes describing the parent in any of the following ways, “good advocate,” “competent,” “capable,” “proficient,” “appropriate,” “attentive,” “responsive with care,” or described as having learned care and having a good

understanding of child’s needs. 4) Minimal *Involvement* includes any documentation expressing that the parent rarely visits (or does not visit) or words that describe a lack of engagement in a physical sense (not at bedside, etc.). 5) Capacity *issues* include any mention of DCF involvement, issues in capacity, significant knowledge gaps essential for child’s care and/or protective concerns. The check mark (☐) signifies that involvement, bonding, capacity, etc. were present in the data.

Table 4

Narrative data: Evidence of involvement, bonding and capacity (N=20)

Case Number	Involvement	Bonding	Capacity	Minimal Involvement	Capacity Issues
1	☐	☐	☐		
2				☐	☐
3	☐		☐		
4		☐			☐
5				☐	☐
6					☐
7				☐	☐
8					☐
9	☐	☐			
10					☐
11	☐	☐	☐		
12		☐		☐	☐
13					☐
14		☐	☐		
15	☐	☐	☐		
16		☐	☐		
17		☐	☐		
18		☐	☐		
19		☐			
20				☐	☐
Totals Down	5 (25%)	11 (55%)	8 (40%)	5 (25%)	10 (50%)

80% of caretakers were described as either involved or bonded. One patient turned 18 during admission. Despite his age, he required a caretaker but his family was not involved in care (abandoned patient in hospital). Two parents had anxiety surrounding whether their

children would return to “normal.” One parent was quoted as follows: “She was a normal child before her illness. Now she is in a vegetative state.”

Table 5

Caretaker convenience to the hospital

	# Cases	Percent
Owns a car		
Yes	6	30
No	6	30
UTD	3	15
NA	4	20
# of miles from home to hospital (Range, 6-60)		
0-20	7	35
21-40	1	5
41-60	3	15
NA or Missing	9	45
Route to hospital assessable by public transportation		
Yes	7	35
No	8	40
NA	5	25
Requires financial assistance for public transportation		
Yes	4	20
No	9	45
UTD	3	15
NA	4	20
Requires \$ for fuel assistance		
Yes	1	5
No	12	60
UTD	3	15
NA	4	20

Access to public transportation was endorsed if the commute was less than 90 minutes long. Much of this data for this item were difficult to find. For example, it was determined that a family required money for fuel assistance if they were provided the assistance by a hospital program. However, it is possible that some of these families needed financial assistance for their

commute but did not seek out social work services and therefore did not receive this benefit, or a benefit may have been received but not recorded as part of the medical record.

Table 6

Caretaker, guardianship, and protective issues

	# Cases	Percent
Did caretaker change during admission?		
Yes	7	35
No	13	65
What was the DCF status at admission? (highest level)		
None	12	60
51A filed just prior to or during admission.	3	15
Open case	1	5
Custody	4	20
What was the DCF status at discharge (highest level)		
None	10	50
Open case	4	20
Custody	6	30
DCF disposition		
Foster care	2	33
Medical foster care	3	50
Pre-adoptive home	1	16

Two children were placed in the custody of the Department of Children and Families (DCF) during their admission. Caregiver changes included: DCF to permanent caregiver, DCF to foster or kinship placement, Mother to Father, and caregiver to DCF.

Table 7

<i>Language</i>	# Cases	Percent
<hr/>		
Family of Origin Language		
English	14	70
Spanish	4	20
Haitian/Creole	2	10
<hr/>		
Requires an Interpreter		
No	16	80
Yes	3	15
Sometimes	1	5
<hr/>		

One parent struggled with a language barrier when trying to learn care. A nurse stated, “Mom is primarily Spanish speaking, which tends to hinder communication with staff.”

Parent/caretaker characteristics were captured in a number of domains: these included: parental involvement and capacity, level of convenience getting to the hospital, guardianship and protective issues and primary language. Many different conditions, or combination of conditions, were documented. Some parents were very involved and competent while others were minimally involved and struggled with capacity issues. In addition, some caregivers had long commutes and/or needed financial assistance for transportation to and from the hospital. One family had to travel 60 miles to visit their child. 20% of those on AD status needed financial aid for public transportation, and only 40% of caretakers had access to the hospital by public transportation. Most striking, 50% of the children were either in the custody of the Department of Children and Families (DCF), or were involved in an ongoing protective investigation by the Department. Lastly, 30% of patient caretakers at admission were not native English speakers.

Societal Factors

Societal factors examined include economic fragility, housing status, private versus public insurance and the question of whether a family has an additional family member with a disability.

Table 8: *Economic fragility*

	# Cases	Percent
Poverty at admission (SW estimate)		
Yes	16	80
No	2	10
Missing	2	10
Homeless at admission		
Yes	4	20
No	14	70
NA	2	10
Housing status at admission		
Homeless, rooming in	2	10
Homeless, shelter	1	5
Homeless with relatives	1	5
Sub standard housing	2	10
Housed	12	60
NA	2	10
Housing status at discharge		
Homeless, rooming in	1	5
Homeless/shelter	1	5
Housed	11	55
NA	7	35
Private Insurance		
Yes	1	4
No	19	95
Secondary Insurance		
None	20	100
Additional family members (s) ill or disabled		
Yes	7	45
No	9	35
UTD	2	10
NA	2	10

The majority of families were living in poverty and 20% were also homeless at admission. This number of homeless families drops to 5% (n=1) at discharge. This is probably because many of these children were placed in DCF custody and therefore labeled “NA” to some data points in the data set. Lastly, almost 50% of the families identified an additional family with a disability.

Length of Stay

Hospital length of stay (H-LOS) was explored from three perspectives: 1) total number of days in the hospital, 2) total number of days on “AD status,” and 3) the percent of all hospital days that the child was on AD status.

Table 9

Hospital length of stay

	# Cases	Percent
<hr/>		
Total days on AD status (Range, 1-138)		
1-30	11	55
31-60	5	25
61 to 90	2	10
91 or greater	2	10
<hr/>		
Total days in the hospital (Range, 23 to 396)		
0 to 100	9	45
101 to 200	4	20
201 to 300	3	15
301 to 400	4	20
<hr/>		
% days on AD status (Range, 2% to 89%)		
Under 5 %	4	20
Under 35 %	10	50
Under 65 %	3	15
Under 95 %	3	15
<hr/>		

One patient remained on AD status for 138 days. 9 children (45 %) were on AD status for 31 days and 4 children remained in the hospital between 301 and 400 days. When just looking at the total number of days in the hospital, the mean is 163 hospital days. In O'Brien and Dumas' study conducted in the same research setting (2013), they compared the length of stay by clinical group and found that the ventilator dependent group had the longest mean LOS (57.78 days). Thus, this sample remained in the hospital almost 3 times longer than the ventilator dependent group described in O'Brien and Dumas' study.

Results

Ten hypotheses were evaluated based on features identified in the review of the literature. Of the 10 explored, 2 were found to be significant and one approached significance.

Table 10

Hypothesized direction of effect of case characteristics on length of time on spent on AD status

HR	Characteristic	Hypothesized direction of correlation or effect on AD-LOS	
H1:	Caregiver change during hospitalization	+	
H2:	Unstable housing at admission	+	*
		-	
H3:	Higher number of caretaker phone calls and visits	-	
H4:	DCF-involved during admission	+	
H5:	Require handicapped accessible housing	+	
H6:	Discharge to "out of home" placement	+	
H7:	Caretaker does not own car	+	*
H8:	Longer distance from hospital	+	
H9:	Higher degree of medical complexity	+	
H10:	English is not primary language	+	

* p.<.05

A two-tailed t-test was used to explore possible differences in the total number of days on AD status for patients whose families had unstable housing at admission as compared with those families in stable housing and a significant difference was found. An “out of home” placement includes kinship, foster care, medical foster care, medical group home, and other residential facility.

Table 11
Unstable versus stable housing at admission

Groups	N	M	T	df	P
Unstable	5	67.8	2.479	18	.023
Stable	15	26.27			

Those in stable housing had a lower mean total number of days in AD status (M=26.27) than those with unstable housing (M=67.8).

Table 12
Parents who own a car compared with parents who don't

Groups	N	M	T	df	P
No car	6	64.83	3.020	5.521	.026
Car	6	11.83			

A two-tailed t-test was also used to examine possible differences in mean number of total days on AD status by whether the child’s family at admission owned a car and a significant difference was found. Those who owned a car had fewer days on AD status (m=11.83) as compared with families without a car (m=64.83).

Table 13

Family of origin English vs. non-English speakers

Groups	N	M	T	df	P
English	14	26.57	2.032	18	.057
Non-English	6	60.17			

A t-test was used to examine if there was a difference in the total number of days on AD status by family of origin language and the result *approached* significance ($p=.057$, two-tailed). Those whose primary language was not English had a mean AD status days of 60.17 compared to a mean AD status of 26.57 for those whose primary language was English. Patients whose language is not English are at a greater risk of spending more days on AD status than patients whose language is English.

Summary

In short, three factors were identified as possible contributors to the problem of “stuck kids” in this setting. These included families with unstable housing, caretakers where English is not the primary language, and caretakers who do not own a car.

CHAPTER V

Discussion

Summary of Previous Findings

The literature reveals that, although there has been some research examining the problem of prolonged hospitalization in children who are dependent on technology, there is a dearth in research addressing this issue with children with other medical diagnoses. Although some work has been done to investigate societal and parental factors that contribute to kids becoming stuck in medical levels of care, there is much to be gained by examining this problem further.

Previous Work

The O'Brien and Dumas (2013) study, “hospital length of stay, disposition, and reimbursement by clinical group in pediatric post-acute rehabilitation,” was conducted in the same pediatric rehabilitation hospital, examining discharged cases during the same index period that the sample for this “stuck kids” study was drawn. For narrative convenience, O'Brien and Dumas work will be referred to as Study1, and the “stuck kids” project will be referred to as Study2.

Ventilator dependent children. Obrien and Dumas (Study 1) collected data on all discharges from their pediatric post-acute rehabilitation hospital occurring between 2010 and 2011 (N=382). The “stuck kids” study (Study 2) examined a small subset of these same discharged patients, 20 children who were medically ready for discharge (using insurance utilization review criteria) but remained hospitalized on “administrative days.”

It is interesting to compare the clinical groups for the AD status children with the sample of all admissions to the facility as described in study1.

Table 14

Comparison between Study1 and Study 2

Clinical Group Classification	O'Brien & Dumas (2013) Study1: All discharges (N=382)		Soumerai (2013) Study2: "Stuck Kids" (N=20)	
	n	%	n	%
Active Rehab	77	20	4	20
Medically Complex	161	42	13	65
Neonate	51	13	3	15
Ventilator Dependent	93	24	0	0

As the table demonstrates, ventilator dependent children were under represented in the "stuck kids" study as compared with all admissions. In fact, none of the children in the "stuck kids" study were ventilator dependent, whereas ventilator dependent children made up 24% of all admissions to this facility in the index period. And, few in the "stuck" group were dependent on other forms of technology (such as G-tubes for feeding).

These findings are incongruent with the research literature which suggests that children dependent on technology for survival are at a higher risk of becoming "stuck" than those who are not technology dependent (Cross et al., 1998; DeWitt et al., 1993; Leurer et al., 2006; Millner, 1991). However, this study differs from other studies in that it uses administrative days (AD status) to operationalize the concept of unnecessary hospital days, and by adopting this definition, may have excluded "stuck" kids who were not placed on AD status. That is, insurance reviewers may be more reluctant to place a medically fragile child on AD status than children in other clinical groups.

Psychosocial factors. The literature does not address language issues when discussing LOS and disposition issues. We learned in this study that the children of non-English speaking families had longer LOS on AD status, and that these differences are very close to approaching significance, even in this small sample, suggesting that language may be a contributing condition. This could be the result of many issues, including: language barriers resulting in a delay in learning the child's care, and difficulty advocating for meetings that speed up discharge processes. Sometimes, professional medical interpreters are not available at hours that working families may be more likely to visit. This host hospital has full time Spanish interpreters but there is significant need and they cannot always meet the needs of all families at any given time. Unlike other parents, non-English speakers need to schedule an interpreter for caregiver training; English-speaking families can learn their child's care in smaller chunks at the bedside when there is no language barrier. This may also contribute to delayed discharges if caregiver teaching is prolonged.

It is also possible that families who do not speak English have a harder time navigating the larger healthcare system. There is a vast public health literature addressing this issue. In this cohort, English speaking families often complain that paperwork required for food stamps, subsidized housing, and other entitlements and resources were complicated and difficult to understand. Even trained social workers sometimes struggle with the amount and complexity of the documentation required to apply for such services. Families who do not speak English have even greater barriers when attempting to access these resources, and this challenges not only family but also hospital resources to assist them.

It is also important that, of the family characteristics reaching significance or near-significance, all could potentially be interpreted as placeholders for poverty, and future studies

should keep this in mind, controlling for the potential significant impact of poverty when examining other factors such as attachment disruption.

Limitations and Strengths of the Study

Limitations. There are limitations to this study. Initially, this project proposed looking back for 5 years at the records of an estimated 50 children placed on AD status during that period. Clearly, a larger sample size would be helpful for improving our understanding of these complex, multi-factorial problems. However, the medical record system was in transition during that period and a sample of older record formats suggested that some of the information proposed for collection could not be identified in the records older than 2010. Therefore, the sample was truncated to 20 records with the recommendation that a prospective study be developed going forward.

The final sample size (N=20) limited the types of statistical tests that could be undertaken. Therefore, the data collected provides descriptive information about the AD group as a whole but does not yield findings that can be generalized. Also, by exploring this complex issue with a quantitative approach, one runs the risk of missing important, more subtle indicators that families or staff may be able to describe using more narrative approaches.

The concept of unnecessary hospital days, or “stuck kids”, is also complex to define, and the approach taken for this study, while easier to operationalize, may exclude cases that staff or families would otherwise classify as “stuck.”

And, although there was no significant disagreement between medical providers and the insurance utilization opinion that the children examined in this study were, indeed, stuck, in practice disagreements are common. For example, the hospital discharge planner may state the patient needs medical care while the insurance company argues that care is unnecessary. Both

parties are biased because they have financial incentive to describe the patient in a particular way. While the insurance utilization definition was selected for study inclusion, attempts were made to mitigate potential bias by examining discharge planner's notes as a secondary source for study inclusion.

There were several methodological issues posed by reviewing medical records as primary sources for this type of study. For example, some data were difficult to find. Specifically, immigration status was excluded from the study because only a small number of patient charts comment on family immigration status. There are several reasons why this information is not included in the records. Parents tend to maintain privacy about these issues due a fear of possible repercussions. When immigration was mentioned in the chart, it was under circumstances where a family's discharge was impacted. For example, in one instance, Federal housing was denied due to family immigration status, but the same family was eventually eligible for state-funded options.

This was an issue in much of the data. Many of the factors examined were only found in the record if they were significant enough of an issue to require a social workers' assistance. For example, the poverty estimate is based on the social work director's knowledge of the cases. Again, there are some cases that are more known to social workers than other cases. Thus it is likely that the social work poverty estimation is skewed towards families being poorer because these families will more likely need social work services and thus are more known by the social worker. In addition, there were two separate social work directors during this period and several social work interns, all of whom documented in the records. It is likely that the documentation varied across providers and, therefore, the quality of the data (for purposes of this study criteria) had limitations. This is a common problem when using medical records for study, especially

when trying to examine such concepts as “bonding” and other interactions. In short, this was a very ambitious project involving many uncontrolled factors that posed methodological issues.

Strengths. Although this study has limitations, it also has strengths. Most important, it yielded information that will be important for future research. In addition, this study helped bring awareness to the problem of “stuck kids” and helped the social work department generate ideas of factors that contribute to the problem. It also was an exploratory study which allowed for a very comprehensive examining of this important problem. Clearly, a prospective study, containing the elements identified in the literature review and through this study, would yield important, generalizable findings.

Implications for Social Work

This study has direct implications for social work. Specifically, it may help the social work department create interventions to reduce the number of “stuck kids” as well as number of unnecessary days. If this is possible, it will have important benefits to the development of children and decrease family burden.

In addition to the impact on the child and family, this problem is costly. O’Brien and Dumas (2013) examined reimbursement rates from private and public agencies and compared these rates across clinical groups. The ventilator dependent group received the lowest mean reimbursement rate per day (\$1,163) and the medically complex group received the highest reimbursement rate per day (\$1,199). Public payers paid a mean of \$1,155 per day compared to private payers that paid a mean of \$1,088 per day. In this study sample, 19 of the 20 patients (95%) had Medicaid as their primary health insurance. One patient had Medicaid as a secondary insurance. When a child is placed on AD status the hospital receives a lower reimbursement rate; this adjusted rate is unknown to this researcher. However, the hospital is usually burdened

with whatever the insurance company does not pay for care. Without including the lower reimbursement rate for AD status, the mean rate per day would be \$1,155 or higher because this study sample does not include children who are ventilator dependent (the population with the lowest reimbursement rate) and there was a higher percentage of medically complex children (the population with the highest reimbursement rate) in this sample than in the O'Brien or Dumas' sample. This cost associated with AD status is unclear to this researcher. However, considering the reimbursement rates quoted in O'Brien and in Dumas, it is evident that "stuck kids" and their families are not the only parties with a stake in resolving this problem. The financial cost is significant for the hospital as well as state and federal agencies.

Recommendations for Future Research

First and foremost, a more accurate definition of medical readiness for discharge is needed in order to study the problem of stuck kids. Due to a variety of factors, discharge readiness is not always identified in the medical records. These factors include: a lack of clarity among providers regarding whether the child is medically ready for discharge or not, and inconsistent documentation of these perspectives. In cases where there are significant social barriers to discharge, it is important to distinguish medical readiness for discharge from the barriers to discharge. Failure to do so would, in my view, potentially actually contribute to the child remaining "stuck" because all parties are not likely to be focused on the focal problem (solving the psychosocial issue).

Given that the records currently do not consistently document when a child is medically ready for discharge, in order to study this issue, it would be useful to operationalize the concept of medical discharge readiness and create and implement a protocol for documenting when a child is determined medically ready.

Secondly, I recommend that the social work department develop a screening tool for all admissions, with the goal of early identification of potential barriers or factors that may interfere with optimal participation during hospitalization and social barriers affecting safe discharge. Such tool should include questions regarding disease factors, societal, parental and demographic information. Such data, in addition to being clinical useful, could provide information valuable for conducting a retrospective study of all admissions, comparing “stuck kids” with the general population of admissions on variables of interest. This would provide the hospital and social work department information that could be used to create interventions designed to reduce unnecessary hospital days. It would also be important to work with other hospitals to produce findings that are generalizable.

These findings could also be used to advocate for policy changes in the state and national level. For example, if housing issues are shown to be the greatest contributors to the problem of “stuck kids”, this information can be used to advocate increased funding for subsidized handicap assessable housing. In short, this problem is significant and thus needs to be researched further. A prospective study that eventually includes other hospitals would yield meaningful data that could be used to create interventions to reduce unnecessary hospitalization.

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Appendix A

Sponsoring Hospital's IRB Approval Letter

Date: February 20, 2013
To: Hanna Soumerai, B.A., Clinical Social Work Research Intern
From: Dr. Jeffrey Forman Institutional Review Board

X hospital (xxx) xxx-xxxx, ext. xxxx

Re: Research Project- Exploring the factors contributing to children getting placed on AD status

Dear Ms. Soumerai,

This letter is to notify you that the Institutional Review Board (IRB) at x hospital has reviewed the revisions to the above-named proposal submitted in January, 2013 and provisionally approved in February, 2013. It has been determined that your proposal now meets the requirements set forth by the x IRB (in keeping with federal regulations), and hence has approved your request to conduct this research at FHC.

Federal regulations require that you report to the IRB at FHC on the progress of your research. For this project, you are required to file a report detailing your progress at its completion or in twelve calendar months from the date of this letter, whichever comes first. Should your research still be ongoing at that time, the IRB will then determine the interval when your next update will be due. You are also required to immediately report to the IRB any situations or outcomes which have adversely affected one or more of your research subjects. Failure to comply with these measures will necessitate the IRB's revocation of approval for your research involving our patients and resources. These steps are critical for protecting both our subjects and our hospital.

We wish you the best of luck in your research! Sincerely,

Jeffrey L. Forman, MD Chair, x Institutional Review Board

Institutional Review Board

Jeffrey L. Forman, MD, Chair



Appendix B

Smith College Human Subject's Committee Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

February 26, 2013

Hanna Soumerai

Dear Hanna,

Thank you for making all the requested changes to your Human Subjects Review application. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

A handwritten signature in cursive that reads 'Marsha Kline Pruett' followed by a stylized initial 'MK'.

Marsha Kline Pruett, M.S., Ph.D., M.S.L.
Acting Chair, Human Subjects Review Committee

CC: Elizabeth Irvin, Research Advisor

Appendix C

Pre-coded Inventory

Study Data Collection Tool (Soumerai, 2013)

Appendix C

“Stuck Kids” Data Sheet (Soumerai, 2013)

DEMOGRAPHIC INFORMATION

Subject ID	(001-999)	
Age at Adm (in days)	→	
Date of Admission	→	
Total # admissions	→ ___ ___	
Date of Discharge	→	
TOT # days in hosp	→	
Date start AD	→	
TOT # days on AD status	→	
% days on AD status	→	
Race/Ethnicity	<input type="checkbox"/> White <input type="checkbox"/> White/Hispanic	<input type="checkbox"/> Black <input type="checkbox"/> Black/Hispanic <input type="checkbox"/> UTD
Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> UTD	
A: Legal Guardian	<input type="checkbox"/> Father <input type="checkbox"/> DCF <input type="checkbox"/> Mother <input type="checkbox"/> Court appointed	<input type="checkbox"/> Parents <input type="checkbox"/> UTD <input type="checkbox"/> Kinship
D: Legal Guardian	<input type="checkbox"/> Father <input type="checkbox"/> DCF <input type="checkbox"/> Mother <input type="checkbox"/> Court appointed	<input type="checkbox"/> Parents <input type="checkbox"/> Kinship <input type="checkbox"/> UTD
A: FOO Lang	<input type="checkbox"/> English <input type="checkbox"/> UTD	<input type="checkbox"/> Spanish <input type="checkbox"/> Haitian/Creole
A: Needs Interpreter	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> As Needed <input type="checkbox"/> UTD
A: Zip Code	→	
A: Family SES	<input type="checkbox"/> Lowest SES <input type="checkbox"/> Low <input type="checkbox"/> Mid <input type="checkbox"/> Mod <input type="checkbox"/> Highest SES <input type="checkbox"/> UTD	

A: Private Insurance	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD		
A: Secondary Insurance	<input type="checkbox"/> None <input type="checkbox"/> MassHealth <input type="checkbox"/> Private Insurance <input type="checkbox"/> UTD		
A: MassHealth only	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD		
D: Medicaid	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD		
Weight at discharge	00.00 → #	<input type="checkbox"/> KG <input type="checkbox"/> Pounds	<input type="checkbox"/> UTD (8)

DISEASE FACTORS

ADM: Clinical Group (O'Brien, 2012)	<input type="checkbox"/> Active Rehab <input type="checkbox"/> Medically complex <input type="checkbox"/> Vent dependent <input type="checkbox"/> Neonate <input type="checkbox"/> UTD
DIS: Clinical Group (O'Brien, 2012)	<input type="checkbox"/> Active Rehab <input type="checkbox"/> Medically complex <input type="checkbox"/> Vent dependent <input type="checkbox"/> Neonate <input type="checkbox"/> UTD
DIS: Technology Dependence Categories (Cross, 1998)	<input type="checkbox"/> Not applicable <input type="checkbox"/> Ventilator <input type="checkbox"/> Nutrition or drugs <input type="checkbox"/> Other nutritional or respiratory support <input type="checkbox"/> Trach/Suctioning <input type="checkbox"/> Prolonged dependence on mechanical devices, apnea monitors, catheters <input type="checkbox"/> UTD

AMD: Brain Injury	<input type="checkbox"/> None <input type="checkbox"/> Acquired, non-traumatic <input type="checkbox"/> Acquired, traumatic <input type="checkbox"/> UTD	
AMD: Co-occurring psychiatric or developmental issues	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD	
Did caregiver change during admission?	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD	
Date of change in caregiver (CG)		<input type="checkbox"/> UTD
# days admitting CG involved		<input type="checkbox"/> UTD

DEFINITIONS	
Active rehab:	Children exhibit neurological or musculoskeletal impairment that is of recent onset, regression or progression, are medically stable, and demonstrate a prognosis for improvement in the areas of self-care, mobility, safety, cognition, communication, and behavior (p.4). See Table 2 for examples (Jane O’Brien, 2012).
Vent dependent:	Admitted to post-acute care to be weaned from mechanical ventilation and/or to provide the least restrictive and least invasive form of respiratory support necessary for an active and productive childhood.
Neonates:	Primarily infants with neonatal abstinence syndrome who require an extended hospitalization to wean from maternal and treatment drugs to promote development, improve feeding skills, enhance tolerance to external stimuli, and to treat unresolved medical issues. (see table 2 for examples). (Jane O’Brien, 2012).
Medically complex:	Children with complex chronic conditions (example, multiple congenital anomalies) with a medical need that requires extended hospitalization (p 5). See table 2 for examples. (Jane O’Brien, 2012).
Traumatic Brain Injury (TBI)	Is typically the result of an external blow to the head like a fall or accident.
Acquired Non-Traumatic Brain Injury (ABI)	Usually results from internal brain damage from conditions like a stroke.
Co-occurring Psychiatric or developmental issues	A psychiatric or developmental disorder independent of the medical condition that impacts care of the child's illness and requires additional hospital-based or post-hospital services (for example, psychology treatment to support care, DSM V Dx, MR, autism, suicidality, severe behavioral disorders).

GUARDIAN / CAREGIVER CHARACTERISTICS

CAREGIVER BONDING (*First 3 months*)

Caregiver Bonding	Subjective words used in nursing/SW notes to describe parental bonding (e.g., loving caring, attentive, interactive.) → Check SW notes + assessment, 2) Nursing narrative <i>first 90 days of admission</i>
Words used to describe parental bonding during first 3 months of admission. Sources: (RN, SW notes to verify → MD daily notes)	

Comments:

CAREGIVER INVOLVMENT (30 day prior to AD status)

Caregiver Involvement	Lit: “A subjective judgment of more than three visits to the hospital per week and daily phone calls to the hospital was used to determine parental involvement.” (Cross, Leonard, Skay, & Rheinberger, 1998). → Check nursing notes <i>30 days prior to AD status</i>	
# caretaker visits 30 days prior to AD status (Total all visit)	Visits: ___ ___	<input type="checkbox"/> UTD
# caretaker calls 30 days prior to AD status (Total count)	Calls: ___ ___ ___	<input type="checkbox"/> UTD

CAREGIVER CAPACITY (30 day prior to AD status)

Caregiver capacity	Label: Capacity to provide technology care Definition: Subjective words, or objective accomplishments, which indicate the capacity to provide medical / technology care of child’s needs → Word examples (capacity, independent, competent), (Cross et al., 1998) → Interdisciplinary Teaching Record → SW / Case Management Notes	
Subjective words, or objective accomplishments, which indicate the capacity to provide medical / technology care of child’s needs)		

CONVENIENCE TO HOSPITAL (within 30 days of admission)

ADM: # miles from home to FHC on ADS day1	This will be a computed variable (ZIP-ZIP)
ADM: Owns a car	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ADM: Provided \$ fuel assistance / or identified need in notes.	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ADM: Route to hospital accessible via public transportation	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ADM: Requires \$ for public transportation	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD (8)

SOCIETAL FACTORS

ECONOMIC FRAGILITY OF FAMILY/CAREGIVER

ACG: Food Stamps	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: Cash Assistance (DTA)	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: Text: SES status (SW Notes)	
ACG: Immigration status of HOH	<input type="checkbox"/> Undocumented <input type="checkbox"/> Documented <input type="checkbox"/> U.S. citizen <input type="checkbox"/> UTD
ACG: Subsidized housing	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: Female Headed household	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: Single parent household	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: Unemployed father	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: # of caregivers	<input type="checkbox"/> State <input type="checkbox"/> 1 Parent <input type="checkbox"/> 2 parents <input type="checkbox"/> UTD
ACG: # of siblings in home	Number sibs in home: ___ ___ <input type="checkbox"/> UTD
ACG: Family members(s) ill or disabled	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ACG: Rural, city or suburb	<input type="checkbox"/> Rural <input type="checkbox"/> City <input type="checkbox"/> Suburb <input type="checkbox"/> NA <input type="checkbox"/> UTD

HOUSING STATUS

ADM: Housing Status	<input type="checkbox"/> Homeless, unhoused (rooming in?) <input type="checkbox"/> Homeless / shelter <input type="checkbox"/> Homeless, with relatives <input type="checkbox"/> Sub-standard housing <input type="checkbox"/> Housed <input type="checkbox"/> DCF custody <input type="checkbox"/> UTD
DIS: Housing Status	<input type="checkbox"/> Homeless, unhoused (rooming in?) <input type="checkbox"/> Homeless / shelter <input type="checkbox"/> Homeless, with relatives <input type="checkbox"/> Sub-standard housing <input type="checkbox"/> Housed <input type="checkbox"/> DCF custody <input type="checkbox"/> UTD
DIS: Child requires handicapped accessible housing	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
Is d/c housing handicapped accessible?	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD

DCF DISCHARGE

Discharged home with parents?	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> UTD
ADM: What was the DCF status at admission? (highest level)	<input type="checkbox"/> None <input type="checkbox"/> 51-A filed just prior to or during admission <input type="checkbox"/> 15-day Investigation <input type="checkbox"/> Open case <input type="checkbox"/> DCF Custody <input type="checkbox"/> UTD
DIS: What was DCF status at discharge? (highest level)	<input type="checkbox"/> None <input type="checkbox"/> 51-A filed just prior to or during admission <input type="checkbox"/> 15-day Investigation <input type="checkbox"/> Open case <input type="checkbox"/> DCF Custody <input type="checkbox"/> UTD
DIS: If DCF Guardian at discharge, state disposition	<input type="checkbox"/> Not applicable <input type="checkbox"/> Kinship <input type="checkbox"/> Foster care <input type="checkbox"/> Medical Foster Care <input type="checkbox"/> Med Group Home <input type="checkbox"/> New program <input type="checkbox"/> Pre-adoptive home <input type="checkbox"/> Other, describe: _____ <input type="checkbox"/> UTD

ALTERNATIVE PLACEMENT NEEDS

Date alternative to home placement need Identified	→
Date Alternative Placement Found	→