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The Experience of Children with Disabilities and their Families during Hospital Admission - Literature Review

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Abstract

Purpose: This review aimed to look for the findings from different qualitative studies that addressed the experience of children with disabilities and their families during hospital admission.

Methodology: Using a descriptive qualitative design, semi-structured interviews were conducted. Criteria for selecting the studies were: peer-reviewed, qualitative studies focused on the experience of disabled children younger than 18 years old and their caregivers. A systematic search found 13 relevant papers based on titles, then selected studies were reviewed and data were extracted. Three common themes were highlighted: communication between the disabled children and medical staff, quality of care provided during the inpatient stay and involvement in decision-making.

Results: Communication issues were the papers' most repeated and highlighted theme. This review reveals that the experience of children with disabilities during hospital admission is not ideal.

Unique Contribution to Theory, Practice and Policy: Enhancing the medical staff's communication skills and supporting disabled children and their families during admission would make a difference. Two models of change will be explored at the end in view of these themes.

Keywords: *Children with Disabilities, Families, Hospital Admission*

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INTRODUCTION

Disabled children are prone to get frequent hospital admissions compared to other children (Mahon & Kibirige, 2004). Therefore, as a paediatrician dealing with a such vulnerable group, it is essential to highlight their perspectives with their caregivers while they receive medical services. Their views should be taken into consideration as stated in The UN Conventions on the Rights of Child (United Nations, 1989) and supported by the Rights of Persons with Disabilities (United Nations 2006). Of note, children with disabilities have been exposed to more different forms of neglect and abuse compared to other children (Eric, 2013). In light of this statement, I decided to address this point in my literature review as it is more relevant to my work. Furthermore, it would minimize the gaps in a health system to provide better care and quality of services for disabled children.

In this review, 13 papers were collected by using three different databases. A thematic analysis approach was used from different qualitative data (Braun and Clarke, 2008) searching for the perspectives of children with disabilities and their families during hospital admission. Initially, the process of the literature search will be elaborated. Then, three themes that emerged will be analyzed including communication, quality of care provided, and involvement in decision-making. Likewise, two theories of change will be discussed in light of these themes: the COM-B Model by Mitchie. et al and the Transition Model by Schlossberg. Eventually, I will end with a conclusion summarizing the literature review.

LITERATURE REVIEW

A broad search was conducted initially looking for the most relevant papers answering the literature review question (Pautasso, 2013). A systemic search was performed using different databases including ProQuest, MEDLINE, and Nursing and Allied Health Literature (CINAHL). Different keywords were used like ‘disabled children’, ‘families’, ‘perspectives’, ‘experiences’, ‘hospitals’, ‘inpatient’, and ‘qualitative study’. Using a Boolean operator to link between the words ‘AND’ and ‘OR’ gave a broad search result starting with 2235 papers among three databases. However, after considering my inclusion and exclusion criteria, and removing the duplicated articles and unrelated topics the final retrieved articles were significantly reduced. Two studies were added by hand-searching for further additional search. The details of the literature search illustrating the number of articles included with reasons for exclusion are displayed as a flow chart (Figure 1).

In regard to inclusion and exclusion criteria, papers were considered to be included if they were peer-reviewed, published since 1995 to the present, English language, and looked at the experience of children younger than 18 years with disabilities or chronic illnesses admitted at the hospital. Moreover, caregivers’ or parents’ views were considered because of difficulties to get perspectives of some disabled children among different forms of neuro-disabilities or chronic diseases. Although the focus of views was on the children themselves rather than including their caregivers, I believed adding their experience is very valuable as long as they were the one who was taking care of them during admission. In my literature review, I preferred to use qualitative studies for all the papers to explore the detailed views of children with disabilities and their families during hospital admission particularly when behavioural issues needed to be investigated (Hammamberg, et al. 2016). Most of the studies were done in the UK except 4 (2 in Australia, 1 in Ireland, and 1 in the USA) (Table 1).

Data were extracted from the articles by highlighting the themes with different colours. The CASP Qualitative Studies Checklist was used to assess their reliability and validity and

evaluated the literature quality (CASP, 2018). Despite some limitations noticed like small sample size in some papers, and overlap between the themes, overall, the average score for the papers was 8 out of 10 points reflecting good quality of research. Lastly, the three most relevant themes were nominated as mentioned above (Table 2).

Theme 1: Communication

Communication was the most highlighted issue among the articles (Table 3). Indeed, I believe communication is the cornerstone for expressing the children's and their families' satisfaction with the medical services provided. This fact was supported by (Garth, B, and Aroni, 2003) when they assessed the impact of effective communication in relation to doctor-patient interaction.

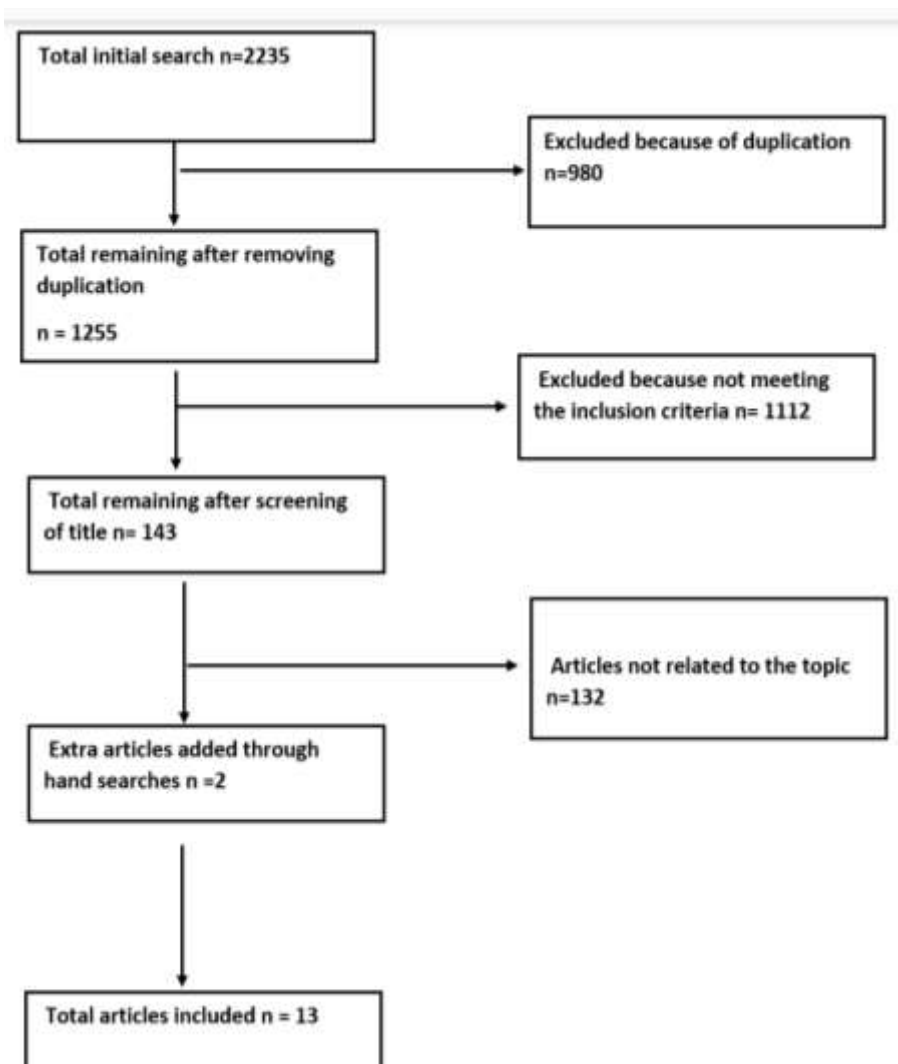


Figure 1: Identification of Articles for Inclusion in the Review

Similarly, It was found that effective communication has been linked to better health outcomes in areas such as symptom resolution, pain management, and improvement in anxiety and blood pressure (Roter and Hall, 1993). Most of the papers addressed the nurses' communication when dealing with disabled children rather than physicians assuming they were the most staff engaged

with the patients during admission. This finding indicates that educational strategies for improving communication among nurses, families, and children are highly recommended as concluded by (Avis and Reardon, 2008).

Communication was viewed from different angles in most of the papers. For instance, the family-centred approach was discussed extensively by Siobhan, et al. (2016). They considered it one of the barriers that directly affects communication between medical staff and disabled children or their families. In the same way, the parent-professional relationship was highlighted by (Graham, Table 2: _CASP Checklist Results for Included Studies

Article number: →	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Was there a clear statement of the aims of the research?	+	+	+	+	+	+	+	+	+	+	+	+	+
2. Is a qualitative methodology appropriate?	+	-	+	-	+	+	+	+	-	+	+	+	+
3. Was the research design appropriate to address the aims of the research?	+	+	+	+	-	+	-	+	+	+	-	-	+
4. Was the recruitment strategy appropriate to the aims of the research?	+	+	+	+	+	+	+	-	+	+	+	+	+
5. Was the data collected in a way that addressed the research issue?	+	-	+	+	+	+	+	+	+	+	-	-	+
6. Has the relationship between researcher and participants been adequately considered?	-	+	-	+	-	+	-	-	-	+	+	+	-
7. Have ethical issues been taken into consideration?	+	+	+	-	+	-	+	+	+	-	+	+	+
8. Was the data analysis sufficiently rigorous?	-	-	+	-	+	+	-	+	+	+	+	-	+
9. Is there a clear statement of findings?	+	+	+	+	+	+	+	+	+	+	+	+	+
10. How valuable is the research?	+	+	+	+	+	+	+	+	+	+	+	+	+
Total	8	7	9	7	8	9	7	8	8	9	8	7	9

Pemstein and Curley, 2009) who clearly found that nurses taking care of children with disabilities in PICU with a high level of empathy, collaboration, and expert advice exchange resulted in less parental stress and more satisfaction. In addition, nurse- parent relationship was elaborated further by Avis and Reardon who found that nurses failed to recognize parents' needs for communication and reassurance (Avis and Reardon, 2008). Although it was a small sample study, it was reasonable to be concerned about nurses' attitudes toward children with disabilities.

On the other hand, the study showed some examples that reveal nurses' competency to communicate effectively with disabled children and their families. Likewise, changing staff care during admission makes it difficult to maintain a good rapport with the children and their caregivers, thereby losing trust and dissatisfaction (Siobhan et al. 2016). The idea of keeping the same nurses taking care of the same disabled children every changing shift should be taken into consideration, thus will ease the continuity of care and facilitating the relationship with parents and their children.

In regard to physicians, several studies have revealed that children have a great relationship with their long-term paediatricians (Tates & Meeuwesen, 2001), whilst this fact was not consistent when (Garth and Aroni, 2003) who assessed this relationship with disabled children and their parents. Although their study was among cerebral palsy children, most of the parental frustration contributed to the ambiguity of information given and inappropriate counselling. In contrast, most of the articles found that paediatricians were approachable and well-communicative with families and disabled children with either verbal or non-verbal skills. In addition, communication might be conflicted with parents' attitudes and other barriers. For example, time pressure is one of the challenges facing medical staff despite disabled children needing more supervision in contrast to abled children. However, the literature recommends that giving more time to the medical staff alone will not improve communication while other communication skills were not taken into consideration (Siobhan et al. 2016). Overall, communication was the most concern cited by the family and their disabled children during the hospital, therefore more efforts are needed to improve in this aspect like conducting workshops in communicating with this group of children and their families.

Theme 2: Quality of Care Provided

According to the NHS Executive (1998), children and people with disabilities have more health demands than the general population therefore, the quality of care needed is different. About half of the papers addressed this issue and some explore it extensively (Table 3). A number of barriers directly affect the quality of care provided to disabled children at hospitals varying from attending the emergency room to discharge. For instance, physical space and environment during admission were raised by parents of both physical and intellectual disabilities children. Wharton and his friends found that families of children with complex needs felt that their children should have calm and spatial rooms to prevent getting agitated and disturbing others by noise-induced (Wharton, Hames and Milner, 2005). In addition, they highlighted the frustration of families and their children when they wait for a long time in the emergency room, particularly in excessive noise areas. Indeed, it is very difficult for parents to manage such a group of children with their complex needs thereby, special considerations and facilitations should be taken into consideration and minimize their stress. An example of this recommendation is the study carried out by (Brown and Guvenir, 2009) who elaborated on findings about the significance of proper facilities for a great hospital stay experience.

Theme 3: Involvement in Decision-Making

Although this theme is less explored in the literature, previous studies showed that children and young people are keen to participate in decisions and care during hospital admission (Coyne, 2006). Furthermore, it was found that parents realized the value of involving disabled children in the decisions that are made to promote their autonomy and also as they were aware of their illness and treatment. As stated by the UN Conventions on the Rights of Child (United Nations 1989), children with disabilities should be consulted in view of their medical care and treatment hence, their decision is valuable and should be taken seriously. However, the ability of children with disabilities in decision-making is variable, this might be affected by previous experiences in healthcare-related decisions and a sense of independence (Coyne & Gallagher, 2011).

Despite the fact that it is claimed that the doctor-patient relationship has altered recently, with the doctor being less controlling and the patient more independent (Lagerlov et al., 1998), research showed that it is often still deficient in children with disabilities as found by (Garth and Aroni, 2003). However, Children with learning disabilities felt there were ignored and left

with disempowered feelings when medical staff spoke to their parents instead of them during the medical assessment (Scott et al. 2005). Moreover, as pointed out by (Coyne, 2006) parents argued that their children were capable to understand and participate in their care actively. Overall, these studies highlighted the importance of involving such group of children and their families in their care plan and treatment.

Table 1: Details of Articles Included in the Review

Number	Reference	Aims/Research Questions	Type of Paper	Context of Study	Findings/Conclusions	Country	Age	Type of the study
1	Brown, F. and Guvenir, J. (2009) 'The experiences of children with learning disabilities, their carers and staff during a hospital admission'. <i>British Journal of Learning Disabilities</i> , 37 (2), pp.110-115	To find out the children with disabilities, their families and staff experience during hospital admission	Qualitative	Interviewed the carers of 13 children with learning disabilities admitted to the hospital for a period longer than 24 h Five themes : (i) child, carer and staff anxiety, (ii) preparedness for the admission, (iii) difficulties managing the child's behaviour, (iv) carer presence during the admission and (v) ward environment.	Hospital admission can be an anxious and challenging time for children, carers, and nursing staff lack of preparation to support disabled children in hospital can have a negative impact on the quality of the care received	UK	2-19 years	Interview
2	Siobhan, S., Claire, L., Richard, T., Eleanor, T., Alice, M., Stuart, L. and Christopher, M. (2016) 'Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study' <i>Health Expectations</i> , 9 (3), pp.738-751	To explore experiences of ward staff and families to identify barriers and facilitators to effective communication with disabled children whilst inpatients	Qualitative	15 parents and 25 staff working in paediatric wards. Communication mostly explored	Communication with disabled children on the ward was perceived as less than optimal	UK	5-16 years	Interview
3	Graham, R.J., Pemstein D.M. and Curley, M.A. (2009) 'Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities' <i>Critical Care Medicine</i> , 37 (6), pp.2064-2071	To describe the experience of paediatric intensive care hospitalization from the perspective of a parents of children with severe, antecedent disability	Qualitative	Eight parents were interviewed during, or just after, PICU admission until data saturation was achieved. Seven major themes emerged from analysis: 1) know my child's baseline; 2) integrate and bridge multiple services; 3) disconnect between role of parent at home versus parent in the PICU; 4) a PICU admission does not equate with respite; 5) high stakes learning environment; 6) heterogeneity within group; and 7) lack of fit within the acute care model.	Children with severe antecedent disabilities and their parents are inextricably linked with critical care services	USA	5-18 years	Interview

4	Garth, B and <u>Aroni</u> , R. (2003) 'I Value What You have to Say'. Seeking the Perspective of Children with a Disability. Not Just their Parents. <i>Disability & Society</i> , 18 (5), pp. 561-576	To explore children with disabilities perspectives in general including health services	Qualitative	interviewed parents and their children who have cerebral palsy about their perceptions and experiences of communication in the medical consultation	The views of children and parents were different, further retesting the need to seek the perceptions of children as well as their parents	Australian	6-16 years	Interview
5	Phau, V., Reid, S.M, Walstab, J.E. and Reddihough, D.S. (2005) 'Inpatient care of children with cerebral palsy as perceived by their parents' <i>Journal of Paediatrics & Child Health</i> , 41 (8), pp.432-437	To evaluate the inpatient care of children with CP, as perceived by their parents	Qualitative	Forty parents of children with CP and 90 parents of able-bodied children completed a questionnaire designed to evaluate their perception of their child's hospital admission, including the care provided.	Parents of children with CP were, as a group, less satisfied than parents of able-bodied children with their inpatient experience.	Australia	1-18 years	Interview
6	Avis, M. and Reardon, R. (2008) 'Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study' <i>Journal of Child Health Care</i> , 12 (1), pp.7-18	To explore parents' views on how their child with additional needs had been cared for by hospital nursing staff, focusing on how well their own and their child's needs had been identified and met	Qualitative	Twelve interviews with parents of children with additional needs Four themes including communication with staff, nurse-parent relationships, and perceptions of nurses and nursing care	Parents experience some difficulties in developing a trusting relationship with the nurses caring for their child with additional needs	UK	Not mentioned	interview
7	Whetton, S., Hames, A. and Milner, H. (2005) 'The accessibility of general NHS services for children with disabilities' <i>Child: Care, Health & Development</i> , 31 (3), pp.275-283	To investigate the accessibility of general NHS services for children with disabilities, particularly for children with learning disabilities	Qualitative	25 parents of children with disabilities (mainly learning disabilities). Eight themes were reported 'preparation', 'flexibility', 'parking', 'physical space', 'waiting areas and consultation rooms', 'health professionals' understanding and knowledge of disabilities, particularly around communication', 'on the wards' and 'overseeing care	This preliminary and small-scale investigation identified some of the main issues related to the accessibility of general NHS services. However, the experiences of parents of children with disabilities are often magnified, as they are likely to have to attend hospitals more often	UK	3-18 years	Interview
8	Boyd, R. ; and Mabel, H. (1998) 'Chronically Ill Children Coping With Repeated Hospitalizations: Their Perceptions and Suggested Interventions' <i>Journal of pediatric nursing</i> , 13 (6), pp. 330-342	To learn from chronically ill children who are repeatedly hospitalized how they cope and how they feel others can assist them to cope with their recurrent hospital experiences	Qualitative	Six hospitalized children, with various chronic conditions participated	Their coping is enhanced by familiarity and knowledge and by the respect and patience of gentle, supportive, and competent health care professionals. These findings indicate that pediatric health care professionals should (1) become cognizant of their patients' perceived use of specific coping strategies and support and encourage their use; (2) assess and support child and parent patterns of coping; (3) exhibit respect, patience, gentleness, and competence at all times; and (4) provide information to hospitalized children in a developmentally appropriate manner.	UK	10-13 years	Interview & drawing
9	Mahon, M. Kibirige, M.S., Mahon, M. and Kibirige, M. S. (2004) 'Patterns of admissions for children with special needs to the paediatric assessment unit' <i>Archives of Disease in Childhood</i> , 89 (2), pp. 165-170	To determine the role of the acute assessment unit for these children.	Qualitative	86 children registered for special needs. The study covered five years between January 1997 and December 2001	Of the 86 children, 48 (58%) were boys; 62 children had cerebral palsy and 52 learning disability. Children with special needs tend to have a predictable pattern of conditions requiring inpatient care. One third of the inpatients episodes did not need a prolonged stay in hospital. This latter group of children could be managed at home with support of community nurses. Integrated care pathways need to be developed to minimise disruption to their lives	UK	1-20 years	Case notes and other records

10	Artin, S.A., Clarke, C.L. and Heyman, R. (2000) 'Hearing the voices of children with chronic illness' <i>Journal of Advanced Nursing</i> , 32 (4), pp. 913-922	To explore children's, parents' and health professionals' experience of childhood chronic illness	Qualitative	Seven families and their professional carers participated in semistructured interviews. The children's interviews were augmented with a 'drawing' technique	Children can communicate competently their experiences of all health and health care. There also exists the possibility of adopting these methods of data collection to other populations of vulnerable health service users.	UK	8-14 years	Interview & drawing
11	Coyne, I. (2006) 'Consultation with children in hospital: children, parents' and nurses' perspectives' <i>Journal of clinical nursing</i> , 15 (1), pp. 61-71	To explore children's, parents' and nurses' views on participation in care in the healthcare setting	Qualitative	11 children, 10 parents and 12 nurses from four paediatric wards in two hospitals	Parents felt that children should be involved in the decision-making process. Health professionals' communication behaviour may reflect recognition of children's cognitive abilities rather than their competence to understand. Hospital services should be child-centred and that all children should be consulted and involved in all aspects of their care	UK	9-15 years	Interviews, questionnaires and observation
12	Coyne, I. and Gallagher, P. (2011) 'Participation in communication and decision-making: children and young people's experiences in a hospital setting' <i>Journal of clinical nursing</i> , 20 (15-16), pp. 2334-2343	To explore hospitalised children and young people's experiences of participation in communication and decision-making	Qualitative	Data were obtained through a combination of focus groups and single interviews with 55 participants	Some prefer to leave the more 'serious' decisions to parents and health professionals, whilst others prefer to share the decision. Children's preferences can vary, therefore, decision-making should be seen as being on a continuum rather than an 'all or nothing' basis.	Ireland	7-18 years	Interview
13	Brady, M. (2009) 'Hospitalized Children's Views of the Good Nurse' <i>Nursing Ethics</i> , 16 (5), pp. 543-561	To identify characteristics of the good nurse from the perspective of children in hospital; and to inform children's nursing practice	Qualitative	Twenty-two children were interviewed using an adapted 'draw and write' technique. Five themes relating to children's views of the good nurse emerged from the analysis: communication; professional competence; safety; professional appearance; and virtues	Children appeared to appreciate being valued positively, as demonstrated by the nurse being attentive, spending time with them, and using praise and endearing terms when communicating with them.	UK	7-12 years	Interview using the 'draw and write' technique

Table 3: Common Themes among the Articles

Themes	Study Number
Communication	1,2,3,4,5,8,9,11,12,13
Quality of care	1,3,5,7,9,10
Involvement in decision-making	1,3,4,11,12
Staff confidence	1,4,5,7,8,9,13
Anxiety	1,2,3,7,8,12

The COM-B Model by Mitchie et al.

This model is one of the widely used theories to change behaviors which was designed by Mitchie, Stralen, and West. Capability, opportunity, and motivation are the three important components that need to be involved in any behavioral changes (West and Mitchie, 2020). Furthermore, Because of the way these variables interact over time, behavior can be viewed as a component of a dynamic system with both positive and negative feedback loops (Figure 2). According to the model, one or more of its components must be changed to allow effective and

long-lasting behavior change. Different researches showed that the COM-B model has been applied in different clinical fields including behavioral interventions during hospital admission (Heneghan, et al 2020). Therefore, I think it would be useful to explore how it relates to the challenges that encounter disabled children and their families.

Initially, as it was highlighted by the model, the targeted people should be capable of behavioral changes. Therefore, in view of the themes mentioned above I feel “involvement in decision making” seems more correlated to this component. Furthermore, children with disabilities felt there are disempowered in the community and at the hospital as well (Scott et al, 2005). Consequently, they occasionally were not involved in their health plan and felt they could not make decisions. Medical professionals should enhance the autonomy of such vulnerable groups of children hence there are able to take decisions and changes. In addition, as discussed in the second theme, because of their physical and intellectual disabilities they need to be enabled and supported by special rehabilitation programs to become more independent and capable to face difficulties.

Additionally, disabled children need to be motivated in order to cope with the hospital environment during admission. Great communication from medical professionals to the children and their parents will positively enhance their motivation and encourage them for further satisfaction during their hospital stay (Roter and Hall, 1993). Conducting communication skills workshops among nurses and physicians who are dealing with disabled children is a crucial step (Avis and Reardon, 2008). Thus, establishing a robust bridge of rapport between medical staff and disabled children so all get motivated.

Moreover, I feel it is interesting to explore the “opportunity” component in the COM-B model in relation to the quality of care provided for children with disabilities during admission. Mitchie and his colleagues defined the opportunity as ‘opportunities include events outside the individuals that make behavior change (Mitchie, Stralen, and West, 2011), so environmental factors are the main players that might either help to assist or discourage the behavior. Physical and intellectual disabilities are considered barriers that influence disabled children’s opportunity to get the best care. Therefore, they need to overcome these barriers by providing good quality medical services and a friendly environment. Despite this component of the model being challenging when it is linked to disabled children but still can be achieved with collaboration from the health system and medical staff.

Although motivation is influenced by opportunity and capability, all three elements eventually affect behavior. Consequently, facilitating any of these components will help eventually in changing behavior. (Mitchie, Stralen, and West, 2011).

The Transition Model by Schlossberg

Nancy Schlossberg who developed this model defined a transition as “any event or non-event that results in changed relationships, routines, assumptions, and roles” (Schlossberg, 2011). Situation, Self, Support, and Strategies (also known as the 4 S's) are the four main factors that

Schlossberg found as having a significant impact on a person's ability to cope with a transition.

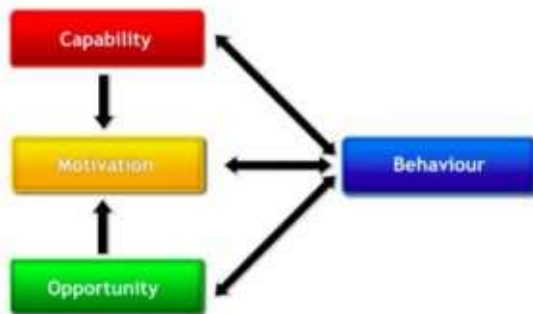


Figure 2: COM-B Behaviour Change Model (Mitchie et al. 2011)

Although her model was established specifically for helping adults, the framework has been extensively used in different aspects for transition support. However, it would be great to explore this model in relation to children with disabilities during hospital admission as long as the four factors are correlated to disabled children and the themes mentioned above.

The transition of disabled children to a hospital environment is a challenge in most cases particularly if it is an unanticipated form (Schlossberg, 2011). First of all, the situation could be addressed when the quality of care provided for such children is emphasized. Although it is a temporary situation, coping with this stress requires further efforts from medical staff through promoting professional communication. Secondly, as stated by Coyne, disabled children commonly experienced self-confidence issues because they feel there are ignored. (Coyne, 2006). Thereby, they perceived there were disempowered in taking decisions related to their illness. Nevertheless, I think this relationship is due to communication barriers assumed by medical professionals toward a such group of children although this is not an excuse for them not sharing their views. Eventually, Social support from caregivers toward disabled children is one of the essential factors helping with coping strategies they got during hospital admission (Garth, and Aroni, 2003). Moreover, (Boyd and Mabel, 1998) extensively explored variable behavioral and cognitive coping strategies for such children as distraction, emotional expression, avoidance, and endurance.

Conclusion

According to this review, children with disabilities and their families who were inpatients may not necessarily have the best experience and satisfaction. Communication with this group of children and their parents was the main repeated theme in this synthesis that reflects whether the inpatient stay was perceived as a positive or negative experience. Additionally, the quality of care provided and involvement in decision-making were highlighted.

However, these findings were handled by two models of change. The COM-B Model by (Mitchie et al. 2011) contributed to a better comprehension of the fundamental issue that disabled children expressed by enhancing capability, opportunity, and motivation. Furthermore, the four factors prompting coping with the change including situation, self, support, and strategies were emphasized by Schlossberg's Transition Model. Overall, change is a complex stress that might face disabled children with different barriers, therefore, it is crucial to select the appropriate theory of change that fit the targeted people's circumstances to enhance the likelihood of success.

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