

Assessing communication between health professionals, children and families

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INTRODUCTION

Much attention has been given recently to hospitals providing an efficient, quality service of the highest standards. To meet these standards, effective communication within an organisation is essential. However, how well we as health professionals communicate with children and families in decision-making processes and with one another is often difficult to quantify. Rather than waiting for adverse events to occur before communication is scrutinised, an organisation may develop better ways of ensuring patients are placed to receive the best of care through an understanding of existing communication strategies.

The literature provides considerable evidence that families expect clear information on diagnosis, treatment, prognosis as well as support from health professionals (Jensen, 1995; Claassen, 2000; Hummelinck and Pollock, 2006). Despite this knowledge and the numerous efforts to promote participation of parents and children in children's health care which is supported by research and international policy (Flatman, 2002; Australian Association for the Wellbeing of Children in Healthcare (AWCH)-National survey report, 2005; Association for the Welfare of Child Health, Revised 2002)

there is still strong evidence which demonstrates that parents and children feel excluded from decision making processes (Hummelinck and Pollock, 2006).

In 2001 the Child Friendly Healthcare Initiative (CFHI) (Clarke and Nicholson, 2001) programme was developed which aims to promote the active involvement of children and parents through the implementation of 12 child and family friendly standards. These 12 standards focus on the emotional and psychological needs in conjunction with the physical and medical needs of the child, and include criteria that assess all aspects of health care provision for children and their families. The standards were developed as a joint effort of Child Advocacy International; Royal College of Paediatrics and Child Health, UK; United Nation's Children's Fund and the Royal College of Nursing, UK and are supported by the World Health Organisation. The initiative is designed so that it may be implemented globally in a variety of health care settings (Ronald and Southall, 2002), using the CHF Toolkit to identify where care could be improved and the change measured (Clarke and Nicholson, 2007).

Feedback from a variety of sources such as staff, families, and analysis of complaints combined with a commitment to promoting family centred care, led a research group at Sydney Children's Hospital to select and pilot Standard 5. From this baseline information we developed recommendations, which would aim to improve performance in relation to communication with children and their families. This paper presents the findings from the project.

METHODS USED AT SYDNEY CHILDREN'S HOSPITAL

The CFHI Standard 5 toolkit -*Parents and children will be kept fully informed and involved in all decisions affecting their care* was used to provide baseline information of communication systems and models in place within the organisation and how parents, children and staff perceived the level of effectiveness.

Participants:

The participants were children (over 7 years of age) and parents /carers attending the hospital as inpatients or outpatients and nursing, allied health and medical staff working within the Hospital Campus and staff from external agencies working within the hospital.

Materials:

The CFHI Toolkit (Nicholson and Clarke, 2007)

The three-part tool kit as described in the CFHI pilot projects in relation to Standard 5 had been tested for reliability and validity and deemed appropriate for this context.

- Part 1- Organisational Assessment

This is a checklist of the organisation, the shared services and those external organisations operating within the hospital existing clinical and operational policies, procedures and systems in relation to communication.

- Part 2 - Health professionals' perspectives.

This survey addresses the perspective from health care professionals on how well staff communicate with each other, and with children and families. The information gathered was about their awareness of current written policies and guidelines, how information is delivered to children and their families, and what type of training, if any staff had received in relation to communication.

- Part 3- School aged children and parents or carer's perspectives

The survey relates to patients (seven-16 yrs) and parents or carers experiences as either inpatients or outpatients and their perspective on how information is shared, the ease or difficulty of finding their way around the facility, information on consent processes prior to procedures or operations, consistency and accuracy of information received, participation in decision making, awareness of the names of staff working with them and their knowledge of how easy it is to make suggestions and /or complaints.

Procedure:

Approval for the project was obtained from the relevant Area Human Research Ethics Committee and the subsequent steps were taken.

Step 1: Raise awareness of the CFHI throughout the hospital.

- A marketing exercise involving a standardised presentation was initiated to raise awareness of the CFHI in relation to Standard 5 throughout the hospital. The project team comprising members of nursing, allied health, consumer representation of a parent and adolescent, and a senior medical manager conducted several sessions throughout the hospital. This proved to be a pivotal step in the implementation process to encourage “buy in” from staff, community teams and consumers.

- The *Patient Friend* (a social worker employed by the hospital) played a vital role in communicating with, and enlisting the assistance of the Parent and Consumer Council. Her role also included talking with parents and young people about the initiative.

- Major relevant government and professional organisations including the Commission for Children and Young People and Association for the Welfare of Child Health were provided with articles and newsletters concerning the initiative.

Step 2:

- Organisational Assessment.

The project officer assessed what policies and procedures existed within the organisation. Using the checklist from the toolkit the project officer interviewed randomly chosen staff from different hospital departments as well as some services shared within the campus (e.g: Theatre and Medical Imaging) and external services operating within the hospital (e.g: Starlight Foundation).

Step 3:

- Health professionals' perspectives.

a) Written surveys were distributed over a 4 week period to all nursing staff, medical, allied health, Patient Services Assistants, and external recreational services such as the Starlight Foundation. Surveys were returned to the project officer through the internal mail or collected from the ward by the Project Officer. The surveys were anonymous with identification of discipline only.

b) Two multidisciplinary focus groups, of approximately one-hour duration were held in the hospital. These comprised six to eight staff and used open-ended questions based on the written survey. Written consent was obtained, responses were audio taped, and transcribed by an administration officer.

Step 4:

- School aged children and parents or carer's perspectives

a) Written surveys were distributed to children and families in the wards by the project officer over a 4-week period. Selection of the participants was by bed numbers which were randomly chosen to ensure children with chronic and acute conditions were represented in the sample. Surveys were distributed to families in the Outpatients Department by Clinical Nurse Consultants. The project officer distributed surveys to patients in the Emergency and Medical Imaging Departments. Surveys were either collected by the project officer, returned to the Clinical Nurse Consultant or returned in a supplied reply-paid envelope to the project officer. Respondents were offered the choice of completing the survey themselves or have the project officer conduct a structured interview using the survey questions. The surveys were anonymous with information only collected on the relationship of the respondent to the patient and whether the patient was admitted for chronic or acute reasons.

b) One structured focus group of approximately one-hour duration was conducted in the timeslot of the regular Parent and Consumer Council meeting held in the hospital. This group comprised of eight parents from the Parent and Consumer Council and two parents who had a child as an inpatient

and used open-ended questions based on the written survey. Written consent was obtained, responses were audio taped, and transcribed by an administration officer.

DATA ANALYSIS

Data collected from the three parts of the toolkit were analysed to measure the degree of involvement parents and children have in decisions affecting their care. The toolkit provides a scoring system for the surveys and the organisational assessment. To help assist with giving meaning to the scoring system a four step benchmarking process was used to measure the current status of the organisation or practice. That is, the total possible score for each part was calculated and presented as a percentage of the total score possible and graded (see Table 1).

Insert Table 1.

Transcriptions of focus group discussions were analysed for themes using the systematic approach outlined by Pope et al (2000) (Pope et al., 2000).

RESULTS

Organisational Assessment:

Staff from a broad cross section of the hospital (nine Departments) participated in interviews to assess the efficacy of existing policies, procedures and systems in place to address communication (See Table 2). This included written information, standardised guidelines, and resources available to staff and families. For example staff in 7 out of 9 areas, stated yes to knowing about guidelines addressing “telling parents/carers about their rights to receive information about the investigations, procedures, and other treatments”, conversely 7/11 areas stated no when asked whether there were “standardised guidelines for health workers about ‘How to give bad news’”. When the scoring system was applied Part 1 scored 75%, which is Level 2/Silver (see Table 1).

Insert Table 2.

Health professional's perspectives:

The responses from the questionnaire from nursing, allied health and medical staff gave insight into their perspective of the quality of communication with patients and their families. This questionnaire extended on information collected in Part 1 of the survey. The response rate of the written survey was 37% (56/151), representing 23 nursing, 15 medical and 15 allied health staff, 3 did not state their profession. The average length of employment at the hospital was 3.2 years. The following are examples of types of questions and answers - 37/56 staff stated yes to "do you give general information to new children and their families about the healthcare environment (such as about ward facilities/routines)" whereas only 12/56 staff stated yes to "ask them to explain back to you what is going to happen" in relation to explaining a medical procedure to a patient and family. As with Part 1 of the toolkit respondents were scored for each response using the guidelines described in the CFHI. The final score (60%) is an overall percentage of each demographic in regards to their total score possible, hence equates to Level 2/Silver (see Table 1).

Insert Table 3

School aged children and parents or carer's perspectives:

The purpose of this survey was to ascertain how the consumers view communication at the hospital. Fifty-two surveys were distributed to patients and carers in general wards, Outpatients Department, Emergency Department and in Medical Imaging over a four-week period. The return rate was 96% (50/52). Four respondents were interviewed by the project officer while the remaining completed the survey independently. A further five parents requested a survey as a result of advertising on consumer notice boards throughout the hospital. Four were returned. Eight children aged between 7-16 years returned completed surveys. This survey addressed such questions as "do you know the name of the nurse looking after you". 50/62 replied yes, or 33/62 responding yes to "has anyone asked what you think and feel about how you/your child is being treated and cared for?"

As with Part 1 and 2 of the toolkit respondents were scored for each response using the guidelines described in the CFHI. The final score of 83% (Level 1/Gold) is an overall percentage of each demographic in regards to their total score possible.

Insert Table 4

The scores from Parts 1-3 of the assessment of Standard 5 were then averaged to give an overall assessment score of 73% (Level 2/Silver) for the hospital. This framework has enabled the project group to identify from the data, five main areas in relation to meaningful inclusion and communication with children and their families receiving treatment and care at the hospital. The following section describes these areas and subsequent key recommendations for implementation of improved communication strategies within the hospital.

DISCUSSION AND RECOMMENDATIONS

1. Communication with families and multidisciplinary teams.

With the growing complexity of care it is rare to find that any one individual clinician is the decision-maker. Invariably, multiple teams may care for the patient, whereby effective communication within and between those teams and with the family and child is paramount in facilitating continuity of care. Parents and carers were positive regarding communication. Of the 54 responders, 91% felt that they had been adequately informed about their child's health problem, 84% understood everything they had been told and 98% reported that they had been given the chance to ask questions. In the case of when more than one team was involved in the care of a child and family the likelihood of poor communication increased and provision of adequate information decreased. Conversely, parents reported good communication and improvement in the understanding of treatment options when their child was under the care of a single team. Clearly staff felt that there was room for improvement in the way they communicated with each other and children and their families. Only 43% of workers believed

that communication within their professional group was as good as it could be and not surprisingly 25% believed that multidisciplinary communication was optimal.

Recommendation

- a) The management of children with chronic and complex care, requiring the input of multiple teams, be coordinated by one key person from within one the lead team.
- b) The general area of team functioning be examined within the hospital and strategies found for enhancing teamwork.

2. Meaningful involvement of children and parents in decision-making.

The parents were very positive (91%) regarding their ability to be involved in the decisions about their child's care. Eighty eight per cent of parents reported that they understood everything and were provided with the opportunity to ask questions, however only 21% of staff asked parents to repeat their understanding of the information back to them. A similar response from health professionals (95.5%) believed that parents and children should be provided with all information pertinent to the treatment. Interestingly only one third of staff was aware of existing hospital policies and guidelines relating to the meaningful involvement of children and parents in decision-making. Half of the staff (50%) felt there was a lack of consistency in the information provided.

Recommendation

That opportunity be developed for the participation of children and parents in decision making and care planning undertaken.

3. Delivering bad news to children and their families.

In daily clinical practice a health care professional may have to deliver bad news to parents and their children. How parents respond to this is dependent on the manner in which the clinician conveys the news (Phipps and Cuthill, 2002). Research from a number of clinical specialties, report considerable

levels of parental distress in the ways bad news is broken. Studies have shown that informing parents that their child has a serious disability is often poorly handled (Farrell et al., 2001) In our project only one third of health care professionals surveyed in relation to this believed that they had received adequate training for the delivery of “bad news”. Farrell et al (2001) argue that poor educational preparation in relation to breaking bad news is a major reason for clinicians’ failures in relation to this challenging task (Kai, 1996).

Recommendation

Written guidelines are developed to support clinicians in conveying potentially distressing news, and those educational processes are introduced into the organisation to improve the clinicians’ competence and confidence in this area.

4. Printed resources for communicating with children and families who have English As a Second Language (EASL).

Communicating effectively with children and families with English as a second language presents a challenge to many health professionals. The provision of adequate information must be balanced with the complexities of cultural factors, awareness of the need for information, economic and time restrictions.

One third of the areas taking part in the survey had guidelines and standards for providing information in the child and family’s main language. The survey indicated that there are some resources that are available to families in their main language, however the extent of the material available and its method of distribution was difficult to gauge. Concurrently 82% of health care worker respondents felt that children and families with EASL did not receive as much useful information as those that spoke English as their first language.

This low level of access to appropriate information is of particular importance as it is well known cultural and ethnic factors play a large role in the way that children and families respond to and cope with childhood illnesses, injuries and disabilities (McCubbin et al., 1993). Health care professionals must be able to recognise, respect and engage cultural and ethnic diversity in a way that leads to mutually desirable outcomes.

The provision of written information is an adjunct to verbal information, therefore for many of the families cared for in the hospital access to interpreter services is essential. Health professionals anecdotally reported that they felt they were able to use interpreter services for 'serious' conversations, mostly pertaining to important medical decisions and consent. Many felt that it was the day-to-day things that were difficult such as orientation to the ward and administering medication to children.

In a focus group a comment was made that long-term families feel that communication is often inadequate with people from Non English Speaking Background. The parent commented that it was often parents of other patients that provided support and information to these families.

Patients who face language barriers are entitled to interpreter services and this requires a concerted effort from administrators and health care staff (Tang, 1999). To this end most facilities have an organised interpreter service and policies mandating this right for patients and families (Multicultural Health Unit of South Eastern Sydney Area Health Service and Health Care Interpreter Service of Central Sydney Area Health, 2001). Some of the issues in providing this service to all who require it are that it is left up to staff to determine if an interpreter is needed. Many individuals who do not understand English well are reluctant to admit this and may nod yes and smile to be polite, but have little understanding of what is being said (Wood, 2002). In fact, research has demonstrated an increased risk of adverse health outcomes among patients with limited English (Foss et al., 2004; Ku and Flores, 2005). Not only are health outcomes affected, but also satisfaction with health care is

lower among limited English speaking persons when an interpreter is not used (Baker et al., 1998; Garcia et al., 2004).

Recommendation

- a) The profile of the cultural diversity officer is increased in order to improve communication with children and families with EASL.
- b) Representation of EASL consumers on committees is increased to ensure appropriate input into decision-making
- c) The availability of materials in a range of languages is increased for children and parents with EASL.

5. Making suggestions and complaints

Most of the staff from the various areas within the hospital believed that they had systems and policies in place for making complaints, however only 18% (2 out of 11) of areas had guidelines that encouraged people to make suggestions or share ideas.

Of the 58 patients and families that responded to the questionnaire, 70% (41) felt that it was easy to make a suggestion and 52% (32) felt it was easy to make a complaint. Just over half of the respondents felt that it was easy or knew of the system to make a complaint, however it was noted in the comments that in some cases this was due to the absence of need to look into making complaints. The comment did arise in a focus group that some families did not feel comfortable making a complaint in front of staff that would be looking after their child. Ideally a feedback management process at a local level ensures that feedback from patients and a family is accepted in a non-punitive, transparent fashion (New South Wales Health Care Complaints Commission, 2001; Sydney Children's Hospital, 2005; Health Care Complaints Commission, 2000). There is evidence to suggest that following an adverse event; patients who are promptly and fully informed are less likely to litigate as

the result of the event (Niselle, 2000). There are also Commonwealth and State Departments to act as central complaint handling bodies.

Recommendation:

Improvements are made to the feedback and complaints processes through the provision of a communal suggestion box and appropriate mechanisms on the hospital web site.

CONCLUSION

We will continue on our work to enhance communication channels for children and their families' by implementing the above recommendations for change. In particular the coordination of the management of children with chronic and complex care under multiple teams and the general area of teamwork functioning needs further investigation, to develop strategies for improving the capacity of individuals to contribute to their teams work. In addition we would advocate further research to assist in assessing the current situation after implementing the changes in practice.

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0-25%	26-50%	51-75%	76-100%
Basic care- Level 4	Bronze Care- Level 3	Silver Care- Level 2	Gold care Level 1 best possible practice

Table 1- Overall scoring system CFHI toolkit (Nicholson and Clarke, 2007).

Department	Score (%) *
Physiotherapy	84
Recreation and Play Therapy	74
Clinical Services	85
Nursing (Medical, Surgical and Day Only wards)	83
Medical imaging (shared service with an adjoining adult facility)	68
Operating Theatres	71
Pain unit	75
Practice and Education Development Unit	70
<i>Starlight</i> Foundation room	63
Total average score	75

Table 2 – Percentage score related to organisational assessment of communication policies, procedures and systems.

* Percentages rounded

Role	Average length of employment at SCH	Survey return rate	Average CFHI score (%)*
Allied Health	3.7 years	15/40 (37.5%)	59
Medical	2.9 years	15/25 (60%)	62
Nursing	3 years	23/85 (27%)	60
Role not identified		3	
Total		56/150 (37%)	60

Table 3- Demographics and percentage score of health professionals' knowledge of standards and communication within the hospital.

*Percentage rounded

	Parent	Carer	Child 7-16 yrs	Unknown respondent	Survey return rate	Average CFHI score %*
Inpatient	27	0	6	1	34/55 (62%) Chronic – 21 Acute - 13	85
Outpatient	12	1	1	3	17/37 (46%) Chronic – 15 Acute - 2	83
ED	6	0	1	0	7/8 (87.5%) Chronic – 1 Acute - 6	75
Total					58/100 (58%)	83

Table 4- Demographic information and the overall percentages scored in line with the CFHI scoring system.

* Percentage rounded