Study Protocol

‘*Investigating the effect of an Admission Support Plan on improving the hospital admission experience of children and young people with developmental disabilities, communication difficulties and challenging behaviours.*’

Supervisors: Dr Hiran Thabrew[1,2]
Dr Jin Russell[1,2]
Dr Colette Muir[1],

1. Starship Children’s Hospital 2. University of Auckland

Research Summary

Children and young people with developmental disability, who need support with communication, language and behaviour, can find hospital admissions particularly challenging. There is limited research regarding effective interventions to improve hospital experiences for this patient group, however caregiver-completed tools appear promising. In this research study, I aim to investigate whether the introduction of a caregiver-completed Admission Support Plan (ASP), describing child-specific needs, at the start of admission, can improve the hospital admission experience for these children and their families. A pre-intervention study of hospital admission experience will be conducted with families, using an online or telephone assisted survey. An Admission Support Plan (ASP) will be created through a co-design process with patient and staff representatives. The ASP aims to improve staff understanding and awareness of the child’s developmental, communication and behavioural needs, to enable staff to more compassionately and effectively meet those needs during a hospital admission. The ASP will be piloted on an inpatient ward at Starship Children’s Hospital and tested for acceptability, feasibility and preliminary evidence of efficacy to both families and staff members using it. The results of this study will have broad relevance for children with communication and behavioural difficulties, who access health care services within Starship Children’s Hospital and across New Zealand.

Background

Children and young people with developmental disability can find hospital admissions particularly difficult. This patient group includes those with communication difficulties such as Autism Spectrum Disorder (ASD), cerebral palsy or language delay, behavioural challenges such as Attention Deficit Hyperactivity Disorder (ADHD), and intellectual disability or global developmental delay. These patients are sometimes unable to effectively interact with their care team and often lack the ability to express pain or discomfort. Unfamiliar people and environments, along with unusual sensory stimuli from hospital equipment, can cause stress and anxiety which can manifest in disruptive or self- injurious behaviours (Oliver & Richards, 2010). These patients may require more intensive nursing care and in some circumstances, medication to mitigate these behaviours. The New Zealand Autism Spectrum Disorder Guideline emphasises that familiarity is critical to reducing stress during hospitalisation for children with Autism Spectrum Disorder (Ministries of Health and Education, 2016).

There is limited previous research which investigates the resources and adaptations required to improve the hospital admission experience of children and young people with communication and behavioural difficulties. The majority of the literature focuses specifically on Autism Spectrum Disorder with a lack of studies which include children with other developmental disabilities such as ADHD and intellectual disability.

Gupta et al, 2019 trialled a comprehensive, four part pathway for children with sensory sensitivities in an emergency department, with positive feedback on parent survey. However, the response rate was low and it is not clear whether the pathway would be applicable to other clinical areas. Clark et al, 2019 implemented a pre-admission checklist and communication 'passport' in a pilot study of children with Autism Spectrum Disorder in the perioperative period. Feedback given by families was encouraging, however, the study did not assess the efficacy or feasibility of the intervention and staff feedback was not sought.

Broder-Fingert et al, 2016 designed a pilot study to assess the feasibility of an 'Autism Care Plan' (ACP) at MassGeneral Hospital in Boston, USA. Caregivers were recruited to complete the ACP which was subsequently loaded onto the electronic medical record to inform future admissions. Caregivers who utilised the ACP reported a better overall hospital experience when compared to those who had not. However, the generalisability of this study was limited as only children with Autism Spectrum Disorder were included. Similarly Pratt et al, 2012 implemented a child-specific, structured pre-admission check list as part of a quality improvement programme at a tertiary level hospital in London, UK. Caregivers and staff felt that the checklist was beneficial but the intervention was time consuming and required a specific member of staff to complete.

The limited data available does suggest that interventions are feasible and receive positive feedback from patients, their families and staff members alike. However, it is not known whether the findings from these studies are applicable to New Zealand. The pre-existing inequities in New Zealand make importing tools that have been developed overseas problematic. Māori children are at increased risk of parent- reported social, emotional and behavioural difficulties relative to non-Māori children (Ministry of Health, 2018). Similarly, Māori and Pacific Island populations have a 50% and 30% increased risk respectively of being diagnosed with Autism Spectrum Disorder when compared to other ethnic groups (Ministry of Health, 2019). Any interventions to improve hospital experiences for this patient group need to be tailored to New Zealand needs. Co-design with patients, families and staff members, including representation from Māori and Pacific Island groups, is an essential element in the development of a successful intervention for our population.

This study aims to answer some of the current gaps in knowledge by broadening the patient group studied, using an inpatient setting and evaluating the acceptability, feasibility and preliminary evidence of efficacy of an intervention within the New Zealand context.

Aims & Objectives

The overall goal of this research is to develop a caregiver-completed Admission Support Plan (ASP) describing child-specific developmental, communication and behavioural needs; and investigate whether the introduction of the ASP at the start of an admission improves the hospital experience for children and young people with developmental disability and their families.

Research objectives:

1. To investigate the experience of care that children and young people with developmental disability receive in the inpatient setting, as described by their caregivers after the hospital admission has concluded.
2. To develop an Admission Support Plan (ASP) describing child-specific developmental, communication and behavioural needs, for completion by caregivers at the start of the hospital admission.
3. To investigate the acceptability, feasibility and preliminary evidence of efficacy of the ASP, and identify any issues that may be barriers to successful implementation.

Methods

Part 1 (Pre-intervention):

Senior medical officers (SMOs) working within the Neuroservices department at Starship Children's Hospital will contact the parents/caregivers of their patients with developmental disability by email or in person (for example during a clinic appointment) to invite them to participate in the study. These will include children and young people with communication difficulties such as Autism Spectrum Disorder (ASD), cerebral palsy or language delay, behavioural challenges such as Attention Deficit Hyperactivity Disorder (ADHD) and intellectual disability or global developmental delay, including children with genetic conditions such as Down syndrome.

Families whose child has been admitted to Starship Children's Hospital within the last 6 months will be invited to complete an online or telephone assisted survey, regarding their experience of their child's most recent admission. Survey questions will include (1) challenges encountered during the admission (for example communication between patient and staff, sensory or environmental stressors and behavioural events); (2) overall satisfaction with the quality of experience in hospital; and (3) opportunity to make suggestions for how the hospital can better meet the child's developmental, communication and behavioural needs during future admissions. The online survey will be delivered using 'Survey Monkey' technology that is compatible with computer, tablet and mobile devices. In order to collect a breadth of responses, the study aims to recruit approximately 20 participants of which 50% Māori representation will be sought where possible.

Part 2 (Admission Support Plan design):
A written Admission Support Plan that caregivers complete at the start of a hospital admission or ahead of time (such as during an outpatient appointment) will be created. Previously described tools from the literature (Pratt et al, 2012, see Appendix 1), will be used to guide a New Zealand specific design, paying particular attention to the needs of Māori and Pacific Island patient groups. The specific content of ASP will be developed using a 3-step iterative co-design process including representation from a number of groups: patient/caregivers with Māori and Pacific Island participants, advocates from within the developmental disability sector, and staff members (both clinical and non-clinical). Principles for development include (1) ease of completion, (2) specificity for the child, (3) succinctness and (4) acceptability, particularly to the Māori and Pacific Island communities. Group design sessions will be conducted in person and/or via Zoom and recorded with consent for design and editing purposes.

The ASP aims to improve staff understanding and awareness of the child's developmental, communication and behavioural needs, and enable staff to more effectively and compassionately meet those needs. It will empower caregivers to directly communicate their specific knowledge of their child's behaviours, motivators, and emotional landscape with staff, at the start of an hospital admission.

The Admission Support Plan will allow caregivers to describe their child's specific developmental and behavioural needs such as:

- communication difficulties and preferred communication aids,
- key sensory sensitivities,
- behavioural warning signs, and
- practical strategies to reduce child stress.

Part 3 (Implementation and review):
Once developed, the ASP will be administered to patients at the start of an admission to an inpatient ward at Starship Children's Hospital, over a period of 2 months. After the caregiver has completed the ASP, it will be inserted into the clinical notes for staff to access, with a copy in the child's bedspace to increase visibility. Ward staff will be reminded to use the Admission Support Plan where indicated, at the start and middle of the implementation period.

A further online or telephone assisted survey, using the same outcome measures to evaluate satisfaction as in Part 1 of the study, will be conducted. Families will be contacted using details they submitted when completing the ASP during the implementation period. Similarly to Part 1, the online survey will be delivered using 'Survey Monkey' technology that is compatible with computer, tablet and mobile devices. Part 3 of the study aims to recruit approximately 20 participants of which 50% Māori representation will be sought where possible.

Alongside the survey completed by families, a short online survey of staff members who have used the ASP will be conducted to determine the acceptability, feasibility and preliminary evidence of efficacy. Similarly to the family survey, the online staff survey will be delivered using ‘Survey Monkey’ technology that is compatible with computer, tablet and mobile devices. A range of staff members will be approached to include both clinical (for example, nursing and medical staff) and non clinical roles (for example, play specialists).

Measures

As a mixed methods study, both quantitative and qualitative data will be collected during Part 1 and Part 3.

Quantitative data:

- Part 1+3
    - Family survey: patient characteristics such as age, gender, ethnicity, specific diagnoses and measures of satisfaction with the quality of hospital admission experience (using validated Likert scales)

- Part 3
    - Staff survey: staff characteristics such as age, gender, ethnicity and role within Starship Children’s Hospital and overall measure of satisfaction with the Admission Support Plan (using validated Likert scales).

Qualitative data:

- Part 1+3
    - Family survey: challenges encountered during the admission (for example staff/patient interaction, sensory or environmental stressors and behavioural events); caregiver suggestions for child-centred improvement of the hospital admission experience.

- Part 3
    - Staff survey: self-reported levels of knowledge and confidence in providing care for children with developmental disability, the feelings of staff when caring for children with communication and behaviour difficulties, and staff suggestions for further support in caring for patients with these challenges.

Analysis

Descriptive statistics of quantitative data will be carried out in Stata 16 and provided in descriptive tables. All analysis of qualitative information will be carried out as thematic analyses to identify common challenges, as described by Braun, Clarke and Terry (2014). This information will be summarised into key themes from caregivers and staff, with quotations provided as examples of these themes. Input from researchers with expertise in qualitative analysis from the School of Population Health at The University of Auckland will help inform this step.

Commitment to Māori

I have informally discussed the research protocol with a Māori academic, Dr Sarah Herbert, at the University of Auckland. I have contacted Helen Wihongi from the Auckland Research office to review the proposal and the study will be reviewed by the Māori research advisor at ADHB to ensure that it meets the needs of Māori where possible, as part of the local approval process.

I will seek review of the online and telephone assisted survey questions by the ADHB Developmental Coordinator and Māori and Pacific Community Health Workers at Starship Community to ensure cultural acceptability in the development phase. Face to face meetings to enable completion the survey will be offered to those participants who feel this is more culturally appropriate. Efforts will be made to achieve ethnic diversity within the sample of study participants.

The co-design phase will include input from patient representatives and staff with understanding or personal experience of Te Ao Māori and Māori health needs. Co-design groups are to be conducted in a culturally appropriate manner (beginning and ending with a karakia, allowing time for introductions/pepeha, providing kai and allowing for whānau support). Additional cultural support will be made available where requested to address any other concerns.

Results will be interpreted respectfully and free of unduly negative cultural biases and Māori data will be analysed in conjunction with Māori research advisors at ADHB.

Ethics

Ethical approval will be sought from ADHB Research Office and the Auckland Health Research Ethics Committee (AHREC) in advance of approaching participants in the initial stages of data collection.

Timeline & Key Milestones

- *March 2021:* Application to Ethics Committee.
- *May-June 2021:* Identification of patient group to contact by SMOs. Start of online or telephone survey distribution/collection.
- *June 2021:* Co-design of Admission Support Plan (ASP) via Zoom with aid of patient representatives and staff members.
- *August- October 2021:* Implementation of the ASP on admission. Prospective identification of post intervention cohort and administration of post admission online or telephone assisted surveys.
- *November 2021*: Distribution of post intervention online staff survey.
- *December 2021:* Data analysis.
- *January- February 2022:* Initial results are ready for dissemination via seminars/publication.

Outcomes

This research project aims to address the significant gap in the care provided for children and young people with developmental, communication and behavioural difficulties who are admitted to hospital in New Zealand. The implementation of an acceptable, feasible and effective Admission Support Plan has the potential to improve the experiences of children and families who access hospital care within Starship Children's Hospital, and more broadly across New Zealand.

The results of the study will be shared with participants and whānau via email if they have requested this during the consent process. A hui will be arranged if sufficient parties (including interested groups such as Altogether Autism) have requested dissemination of the results in this way. The research will be shared more widely with the paediatric and research community through seminars, conferences and via submission of a manuscript for publication by a peer-reviewed scientific journal.

Career Benefit

I am a dual advanced trainee in Community Child Health and General Paediatrics and my long-term career goal is to become a Developmental Paediatrician within the Auckland region. This research project will enable me to gain experience in quality improvement and data analysis; an area of clinical research that I hope to continue throughout my career.

References

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Appendix 1

Intended admission of a child or young person with a learning disability including an autism spectrum disorder and autism information sheet

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The key to a successful admission is planning and involvement of the parent or caregiver and young person themselves in that planning.

When considering admission of a child or young person, please ask: Does the child have a learning disability?

*If the answer to the question is **Yes** please complete this checklist with the help of the child's carers and school, identify and contact the ward key co-ordinator, and file this in the notes.*

Child's name:
Likes to be called:
Age Ht Wt

Parent contact tel. no:

School contact details:

Identify the key co-ordinator for the admission of a child with learning disability and co-occurring conditions – usually the play specialist for the relevant ward.

____________ contact details:

Others

The key co-ordinator contacts the family to complete the checklist.

1. Information about the child
1a. Functioning age equivalent. At what age do you think ____________ is functioning? – e.g. a parent might estimate their 10-year-old child to have learning abilities at a 4-year-old level.

1b. Method of communication. How does ____________communicate?

If verbal, does ____________ use signs/picture exchange system or an augmentative communication device? Does the child have a communication passport?

1c. What makes ____________ **comfortable**/what do they need with them to be comfortable?

1d. What rewards does ____________ work for? How do you get co-operation? (**motivators/reinforcers)**.

2. Challenging behaviour
2a. Does ____________ display **challenging behaviours**, e.g. running away, throwing things, verbally abusive, aggression towards others? To whom would that be – anyone in the vicinity or a targeted person?

2b. If ____________ has challenging behaviours, what are the likely **trigger points**? e.g. giving medicines, noise, etc.

2c. What tactics can **defuse** challenging behaviours?

2d. Does ____________ display **self-injurious behaviour**?

2e. Should you as parent/carer be with ____________ all the time? **Will a single room be needed**?

2f. Has ____________ **had an anaesthetic before**? Were there particular problems or strategies that worked? ____________

2g. Are there any other **particular problems that are likely to arise during admission** to hospital? e.g. needle phobia.

For the key co-ordinator. Aim: Admission and procedures to be personalized

3a. Make a list of what procedures need to be done and their timing.

3b. Is a cubicle needed?

3c. Decide in advance and discuss with anaesthetist in order to discuss with parents what sort of admission observations are necessary and whether they are likely to cause distress. Discuss what **medications** the child is on. What about pre-admission sedation?

3d. Is 1:1 nursing required?

3e. List the **basic measurements** (e.g. BP) and any **tests that could be done while child or young person is anaesthetized**.

3f. Plan the timing: **minimize waiting** by putting first on the list and **minimize the length of admission** by admitting on the morning of the procedure.

3g. Prepare appropriate **communication strategies**, e.g. visual (*pictures/card/symbols*) if these are needed.

3h. Suggest **appropriate clothing**, e.g. track suit/shorts to minimize undressing if this is a problem. Also **bring own food/snacks** if a particularly fussy eater.

4. Day of admission

4a. Key worker to ensure that the team and designated health team are fully briefed. Again discuss everything about process with parent or carer.

4b. Do not do **observations**, or even give premed if it is going to distress the child or young person. Take samples if possible under anaesthetic. Ensure there are no delays; be 100% ready. Minimize the personnel present (*ketamine i.m. as anaesthetic has been very successful; it may lengthen recovery period*). Ideally allow recovery to take place in the cubicle from which the child has come which will be left completely unchanged and therefore familiar.

4c. Discharge home as soon as practicable. Remember that on any subsequent visits some children with autism will expect the routine to be completely unchanged.

4d. Document **what worked well** on that particular child and **what did not**, so that it can be used/omitted on another occasion. **Who else is available to advise**?

Paediatric Clinical Psychologist
Name:
Contact details:

Liaison Child & Adolescent Psychiatry if there are severe behaviour difficulties and mental health problems Name:
Contact details:

The neurodisability team:

AUTHOR: Karen Pratt Clinical Nurse Specialist
Review date: 24 January 2011