Following severe childhood stroke, specialised residential rehabilitation improves self-care independence but there are ongoing needs at discharge

Short title

Self-care outcomes for childhood stroke

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Abstract

Introduction

Stroke is a major cause of mortality and disability in childhood. There is a false belief that children will recover better than adults and recent research confirms that younger age at injury can have a negative impact on rehabilitation outcomes, resulting in lifelong disability. Self-care is a key rehabilitation outcome for children and young people.

Methods

This service evaluation reviews routinely collected clinical self-care data from one specialised residential rehabilitation centre in the UK. Admission and discharge scores from UK Functional Independence Measure + Functional Assessment Measure, Rehabilitation Complexity Scale-E and Northwick Park Nursing Dependency Scale were analysed

Results

Twenty-six children and young people age 8yrs and over with severe stroke were included. Mean scores of independence increased and mean scores of complexity and dependency decreased. A proportion of the sample had ongoing self-care needs in relation to support needed in washing, dressing and bathing. A small number remained highly dependent, requiring assistance from 2 carers.

Conclusion

Children and young people make significant gains in self-care independence during specialised rehabilitation. However, a proportion return to the community with high

self-care needs. Occupational therapists and the wider care team should address ongoing self-care needs in this population.

Keywords

Rehabilitation

Stroke

Self-care

Childhood

Health occupations

Introduction

Childhood stroke is a rare but important cause of neurodisability. Recognition of adult stroke as a medical emergency has had a significant impact on outcomes but childhood stroke faces challenges related to recognition at the hyperacute stage (Royal College of Paediatrics and Child Health, 2017). This study examines the outcomes of UK specialised rehabilitation on self-care independence for children and young people following severe childhood stroke within the context of international occupational therapy research to raise awareness of ongoing needs at discharge.

Literature review

Childhood stroke is defined as an acquired brain injury (ABI) due to a disturbance of blood supply to the brain occurring from 29 days after birth to 18 years (Mallick and O'Callaghan, 2010); Royal College of Paediatrics and Child Health, 2017).   Stroke affects several hundred children in the UK alone each year with 75% occurring in children aged under 10 years (Mallick and O'Callaghan, 2010). Childhood stroke is among the top 10 causes of childhood death and the incidence is comparable to the number of children affected by brain cancer (Greenham et al., 2016; Mallick et al., 2014). There is a false belief that children with stroke will recover better than adults, but recent research confirms that younger age at injury leads to poorer cognitive, behavioural and self-care outcomes (Gordon, 2014; Jacomb et al., 2018; Fuentes et al., 2016). It is estimated that of the children who survive a stroke, half will face long-term neurological disability and functional limitations (Mackay and Steinlin, 2019). As a result full participation in everyday social, educational and family life may be severely compromised with the effects becoming more apparent over time (Greenham et al., 2018; McKevitt et al., 2019; Yvon et al., 2018; Ganesan, 2013; Shepherd, 2012).

Acute and long term rehabilitation for children with stroke differs from adult rehabilitation. Not only does it include the recovery of previously acquired skills but also must address the challenge of supporting CYP to acquire new skills and functional independence throughout childhood with the impact of stroke (Gordon, 2014). Targeted rehabilitation is recommended for all children and young people (CYP) who present with neurological deficits following stroke (Royal College of

Paediatrics and Child Health, 2017). Best practice for rehabilitation comprises the enabling of functional independence following childhood stroke. It employs a multi-disciplinary team approach that involves working in collaborative partnership with the child and family to set goals, agree an intervention plan and set priorities (Royal College of Paediatrics and Child Health, 2017). In the UK, CYP with the most severe rehabilitation needs following stroke are eligible for a period of specialised rehabilitation, typically three to four months, funded by NHS England (NHS England, 2013).

Self-care includes personal care (eating, drinking, toileting, bathing, dressing, oral hygiene, nose, nail and hair care, personal device care, health maintenance safety procedures, emergency response, sexual expression rest and sleep); functional mobility (transfers, open/closing doors, stairs, carrying object, level, rough or uneven surfaces, slopes/ramps, curbs, escalators) and community management (public transport, shopping, money management). Independence develops over time with age and is typically fully achieved for personal care by the age of eight years excluding activities that start post puberty (Law et al., 2014). In the context of neurorehabilitation this is conceptualised in relation to the International Classification of Function (World Health Organisation, 2012) in which professionals must measure mastery of basic self-care skills eating/drinking, wash/dress, toileting, transfers, communication, behaviour and safety awareness. These skills are represented at the activity level of the International Classification of Function – Children and Youth version (World Health Organisation, 2007) and are typically measured in UK rehabilitation centres using the UK Functional Independence Measure and Functional Independence Measure (Turner-Stokes and Siegert, 2013) .

Self-care independence is a common priority for many CYP with neurodisability and their families (McAnuff et al., 2017; Allard et al., 2014) and unsurprisingly features as a common rehabilitation goal for CYP with stroke (Galvin et al., 2011; Kelly et al., 2018). At this sub-acute stage of rehabilitation, mobility and self-care goals are often prioritised by children and their families above cognitive skills. Perhaps this is because the full range of cognitive deficits are yet to be fully appreciated at this stage in the recovery trajectory and within the supportive environment of residential rehabilitation (Kelly et al., 2018).

Rehabilitation professionals including occupational therapists and nurses can target self-care independence and occupational participation through both a restorative approach, which aims to teach the child the skills they need to complete a task independently, or a compensatory approach by which strategies are put into place to compensate for the cognitive or physical deficits (Fisher and Bray Jones, 2017). A key review paper has recently published evidence supporting functional skills training for children and young people with neurodisability (Novak and Honan, 2019). Among the recommendations are the importance of partnering with parents and taking a top-down activity focus to occupational therapy interventions when working with children and young people.

Following inpatient rehabilitation CYP are discharged to their local community teams for ongoing and long term rehabilitation into and throughout adulthood. Studies

reporting the outcomes of rehabilitation show positive progress, in particular greater rates of change in physical function outcomes compared to cognitive or social skill outcomes (Wales 2018; Yvon et al 2016; Galvin et al 2010; (Bedell, 2008). In order to support planning of local services it is important to establish the impact of rehabilitation on functional independence. This study examines the outcomes of UK specialised rehabilitation on self-care independence for children and young people following severe childhood stroke to raise awareness of ongoing needs at discharge.

Method

Data were examined as a service evaluation assessing the extent to which the service is achieving its rehabilitation aims of functional independence. A retrospective analysis of standardised outcome data collected from 2012-2016 was conducted. Ethical approval was not required as a service evaluation of anonymised data. Approval for the study was gained from The Children's Trust Research committee, reference TCT043, 13 December 2016.

Population

A cohort of 26 CYP with diagnosis of stroke aged 8 years or over were selected from a larger cohort of CYP with mixed ABI aetiology receiving specialised rehabilitation in one national residential centre for with brain injury in the UK. CYP routinely admitted directly from acute hospital setting or directly from home for a NHS England commissioned placement of approximately 3-4 months, as appropriate. By the nature of this setting, this cohort of CYP do not typically receive additional services from those provided in the centre. Their needs are assessed prior to admission and mostly meet the NHS England Category A criteria requiring "Intensive, co-ordinated interdisciplinary intervention from 4 or more therapy disciplines, in addition to specialist rehabilitation medicine/nursing care in a rehabilitative environment" (NHS England, 2013 p14).

Intervention

Specialised rehabilitation intervention for CYP with severe acquired brain injury, including stroke, is primarily goal directed and led by a multi-disciplinary team. The team includes specialist therapy, nursing, medical and psychosocial professionals.

In this service review the individual goals for rehabilitation intervention were determined in collaboration with the CYP (where possible) and family using the Goal Attainment Scale described in Kelly at al (2018). These goals were shared by the multi-disciplinary team around the child and reviewed regularly at team meetings. Each goal had an action plan with the key professionals identified for each of the goals. Occupational therapists, nurses and healthcare assistants typically focussed on self-care goals in response to the desire for functional independence highlighted by CYP and their families. CYP also receive motor, communication, emotional and behavioural interventions from the wider rehabilitation team. Intervention approaches included restorative (e.g. daily wash and dress programmes), acquisitional (e.g. modified constraint induced movement therapy bimanual therapy), compensatory (e.g. splints, equipment, strategy use), parent and child education and training.

Outcome measures

The measures reported in this paper are part of the mandated routine data collection set from NHS England as art of National Specialist Commissioning (UK Rehabilitation Outcome Collaborative – UKROC).

1. The UK Functional Independence Measure + Functional Assessment Measure (UKFIM+FAM) is the required outcome measure for children from eight years of age. Functional independence is defined by the UKFIM+FAM as activities required for independence: basic self-care function (eating, swallowing, grooming, bathing, dressing, toileting); motor function: transfers, locomotion and community mobility; communication; cognitive and psychosocial functions (Turner-Stokes and Siegert, 2013). The UKFIM+FAM has a 7 point ordinal scoring system for 30 items. Each item is scored from 1 (complete dependence) to 7 (full independence) and derives total motor, total cognitive and total overall scores. The UKFIM+FAM has concurrent validity (Callen, 2017) and has been shown to detect clinically meaningful change in functional ability in children and young people with ABI over 8 years with a range of aetiologies including childhood stroke (Austin et al., 2018).
2. The Rehabilitation Complexity Scale-E (RCS-E) is a 22-point, summed measure designed to evaluate complexity of rehabilitation needs/intervention (Turner-Stokes et al., 2012). It comprises five subscales; C= basic care and support needs (range 0–4), N =skilled nursing needs (range 0–4), T= therapy needs (range 0–8), Equipment (0-2) and M= medical needs (range 0–4). The RCS-E has moderate internal consistency (Turner-Stokes et al., 2012)
3. The Northwick Park Nursing Dependency Scale (NPDS) is a measure that captures the need for nursing care and support, particularly for highly dependent patients (Siegert and Turner-Stokes, 2010). An ordinal scaling system is used capture the nursing dependency data and directly relates to a range of activities associated with daily living, safety awareness, behavioural management and communication. Raw scores equate to four levels of dependency – low, medium, high and very high. The NPDS has good internal consistency, is responsive to change and is able to discriminate between people with different levels of dependency in adult with complex neurological disabilities (Siegert and Turner-Stokes, 2010).

Data analysis

Analysis of the data included descriptive statistics to summarise the sample characteristics and admission and discharge scores on the UKFIM+FAM, RCS-E and NPNDS. These data were imported into a software statistical analysis platform namely IBM Statistical Package for Social Sciences (SPSS), Version 25.0 for analysis. It was our assumption that due to the heterogeneity of the group and the small sample size that non-parametric tests should be used in the analysis of these ordinal data. Wilcoxon tests were used to identify changes in scores between admission and discharge. Scores at discharge were reviewed to identify any ongoing issues with functional independence. It was hypothesised that during rehabilitation

there would be a reduced score on RCS and NPNDS and an increased score on UKFIM+FAM.

Results

Twenty six CYP (mean age 12.5 years, range 8-17) with a stroke accessed residential rehabilitation services from 2012 - 2016. Of these, 12 were girls and 14 boys. More children has Haemorrhagic Stroke (HS) than Arterial Ischaemic Stroke (AIS) with the main cause being Arteriovenous Malformation (AVM). The UKROC system was used to categorise and classify the children and young people. The mean length of stay was 22.1 weeks (range 8-66 weeks). Four categories of stroke location were identified and included right and left hemspheric, global, cerebellar (Table 1).

The total UKFIM+FAM median was105; mean 97.4 (range 30-175) at admission and; median 157; mean 135.8 (range 32-197) at discharge. A Wilcoxon Signed-Ranks Test indicated that post-test ranks for the overall total UKFIM + FAM scores, motor and cognition subsections (max score 210) was statistically significantly higher than the pre-test rank ($z=3.48$, $4.37,4.46$, respectively, $p<0.05$).

The change in the self-care items (1-12) is greater than the change on the psychosocial items as illustrated in the 'FIMFAM splat' (See Figure 1).

Further interrogation of these data revealed that CYP who had a specific hemispheric stroke (n=14) had a UKFIM+FAM mean score of 106.6 on admission improving to 147.6 on discharge, whereas in those with cerebellar strokes (n=5) scores increased from 70.8 to 111.9. In CYP diagnosed with diffuse/global stroke (n=6) the mean score on admission was 85.3 increasing to 126.2 on discharge. All groups regardless of stroke location however, did show improvement following intensive rehabilitation care with a mean change scores of 41, 41, and 35 respectively. Statistical analysis was not carried out due to the small numbers in these subgroups.

The median Rehabilitation Complexity Scale-E score (max score 22) at admission was 14; mean 13.9 (range 10-18) and on discharge median12; mean 12 (range 7-18) ($z=2$, $p<0.05$) and overall demonstrated a reduction in rehabilitation needs. While this change in scores does not appear clinically substantial, the change in RCS-E levels indicates a shift in the dependency profile of this group and gives more clinical information that the children and young people were easier to care for (Figure 2). The change in complexity from admission to discharge varied greatly at an individual level. Some children and young people made positive changes, in one case changing from 'very heavy' to 'low'. In eight cases there was no change between admission and discharge, while two young people had an increase in their level of complexity. This variability demonstrates the heterogeneity of childhood stroke, even within the more severe group.

The Northwick Park Nursing Dependency data revealed that the majority of CYP had self-care difficulties on admission requiring the assistance and support of 1 or 2 members of the nursing and care team. The total NPDS was 27(median) and 38.42 (mean) range 5-63 (with a score >25 indicative of greater care needs and higher

nursing dependency). Eight CYP were able to use the toilet independently to pass urine/have their bowels open, only two were able to dress themselves without assistance and just one was able to complete washing/ grooming, showering or bathing activities independently. Again a Wilcoxon Signed-Ranks Test indicated that post-test ranks for the overall total scores was statistically significantly higher than the pre-test rank ($z=-4.46$, $p<0.001$) and reflected a reduction in nursing dependency (Figure 3). While some CYP regained independence at discharge in many aspects of self-care (including bladder and bowel function n=11 & n=12 respectively, washing (n=7), dressing (n =6) and bathing (n =4). Over 60% had ongoing care needs in relation to support needed in washing, dressing and bathing activities. Similarly, 34.6% and 50.0% respectively required care support to manage bladder and bowel function. A small number remained highly dependent which was reflected by the need for two carers to assist with self-care including with bladder function (n=6), washing (n=4) dressing (n=4) and bathing (n=6) each activity taking over ½ hour to complete.

Discussion and implications

The results of this study are encouraging and provide support that children and young people who have a severe stroke can make significant progress in self-care during a period of intensive residential rehabilitation.   As in previous studies the analysis of these routinely collected clinical data demonstrate a heterogeneity, even within this more severe group. Overall, we present a reduction in the complexity of care needs and an increase functional independence which concurs with previous findings ((Yvon et al., 2018; Galvin et al., 2011). While analysis of the data has shown that those with a hemispheric stroke had a higher level of independence than those with a global stroke, the numbers in these subgroups are small and further collaborative research is necessary across rehabilitation centres using commonly agreed measures to understand more about the outcomes in this group.

The range of admission UKFIM+FAM scores indicate that there was a wide clinical presentation even within this severe cohort. During the rehabilitation programme the children and young people would have received a self-care intervention as directed by their goals – see Kelly et al 2018 further details. The self-care intervention would have varied on an individual basis between a restorative and an adaptive approach with elements of active practice, explicit learning of strategies and equipment provision. Knowing that both cognitive and motor skills have an impact on the development of self-care independence, a programme of rehabilitation must provide sufficient opportunity for nurses and therapists to work together with children and young people to help them develop/relearn skills in a graded manner leading to a decreasing level of support and supervision. A number of the team around the child would have been involved (parents, carers, nurses and occupational therapists). However, identification of the type of intervention provided for each individual child was not available through the measures used in the routine data collection in this study. New approaches to the capture of rehabilitation input, such as Paediatric Rehabilitation Ingredients Measure – PRISM (Forsyth et al., 2018) have potential to help evaluate child outcomes against intervention approaches in the future.

At the point of discharge, it is of note that a considerable number of the CYP have ongoing rehabilitation needs in basic areas of self-care that will have an impact on their occupational participation at home, school and the community. While a level of ongoing difficulty may be expected in this cohort (Greenham et al., 2016; Hurvitz et al., 2004), this study revealed that some of the young people remain reliant on the help of two adults for basic self-care tasks. This level of dependency will impact the daily life of their whole family, meaning either that both parents are helping or that there is a reliance on external carers.

Local therapy services typically receive referrals for children and young people when the leave specialist rehabilitation services. The chronic, persistent and lifelong nature of childhood stroke needs to be balanced with the concept that children and young people continue to make progress with their skills for many years after stroke. Recent Stroke in Childhood Guideline promotes long term rehabilitation through access to the appropriate level of support (Royal College of Paediatrics and Child Health, 2017). The results of this study demonstrate the need for this group to access ongoing self-care interventions (Bee P et al., 2018).

It is important that interventions initially reflect the CYP age at injury. All of the children in this study were aged 8 years or over. It is expected that the majority of these young people would have been independent in these basic self-care skills prior to their stroke, in the absence of co-existing conditions. Not only do they now have a reduced ability in basic self-care but moving into puberty brings new challenges in managing areas such as menstruation, shaving and grooming. Furthermore, with increasing age the expectations for independence in more complex activities such as meal preparation, laundry, housework and shopping increases. As seen in the UKFIM+FAM data this group of young people have ongoing cognitive, communication and psychosocial challenges that persist and have a long term impact on function and psychosocial development. Ongoing care and therapy should focus on the need to address yet to be acquired skills in the light of newly acquired deficits, while being mindful that a different approach may be required when relearning previously mastered skills.

There are limitations to this study in relation to the measures used. The measures in the UKROC dataset do not have a developmental perspective. While there has been some encouraging psychometric examination of the UKFIM+FAM for CYP with acquired brain injury, it remains an adult measure with the scoring criterion related to an adult norm. Other developmental or ABI specific measures of self-care may be appropriate for future studies. The Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) has the advantage of being familiar to rehabilitation and community paediatric neurodisability services in the UK (Dumas et al., 2017). As such, it is a common measure that can be used to monitor functional ability and participation into adulthood (up to 25yrs). The Paediatric Care and Needs Scale (PCANS) has a different advantage (Soo et al., 2008). As well as being constructed with developmental norms, it has been developed for an ABI population and is being used in other specialist rehabilitation units internationally. Common measures provide an opportunity to pool data across services. Further examination of these measures is warranted.

While these results are encouraging and add to our understanding of childhood stroke, further research is indicated. First, greater collaboration is required between rehabilitation centres to confirm the findings of this small study. Second, there is a need to conduct further research to define and understand the self-care interventions used in the rehabilitation settings. The role of the rehabilitation nurse is clear in adult rehabilitation settings but poorly articulated and understood in paediatric neurorehabilitation. In particular, the interplay between occupational therapy, nursing and care alongside the role of parents should be further examined. Furthermore, this service evaluation did not capture the full rehabilitation input of the wider team in the full recovery trajectory of the CYP that could have influenced self-care performance. New tools such as PRISM have the potential to address this gap in future research studies (Forsyth et al, 2018).

The clinical implication of this paper is that children and young people with severe stroke leave the specialist rehabilitation with ongoing and in some cases substantial self-care needs that may change over. A long term, developmental perspective is required.

Conclusion

Despite the limitations of the outcome measures used in this UK study, it is demonstrated that children who sustain a severe stroke make progress with self-care independence during a period of intensive residential rehabilitation. Improvements have been identified across physical and cognitive domains that parallels reductions in the complexity of needs. As in adult stroke survivor's, children tend to make greater improvement in functional skills but are likely to have ongoing cognitive deficits. A proportion of young people return to the community with ongoing self-care difficulties that require the assistance of 1 or 2 carers. This level of care is greater than expected for age matched peers and should be a priority for ongoing intervention in the community. Without the opportunity for continued, longer term intervention based on a restorative or compensatory approach to encourage self-care independence, CYP face lifelong difficulties that could lead to increased social isolation, reduced health and emotional well-being. Further research is needed to determine the support that needs to be made available to ensure CYP surviving a severe stroke can transition into adulthood with optimal independence and receive ongoing intervention.

Key findings

- Multi-disciplinary inpatient rehabilitation results in increased self-care independence with the potential to reduce the complexity of rehabilitation needs and level of nursing dependency.
- At discharge many CYP have ongoing care needs which will need addressing by neurodisability professionals.

What the study has added

Raised awareness of what rehabilitation can add to improve self-care independence among childhood stroke survivors and, challenged the need for further ongoing rehabilitation beyond the specialised neurorehabilitation setting in the community.

Research ethics

Ethics approval was not required for this study

Conflict of Interest

The Author(s) confirm that there is no conflict of interest

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Contributorship

All authors contributed to the methodology, analysis and writing of this manuscript.

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Table 1: Demographic data for cohort (n=26)

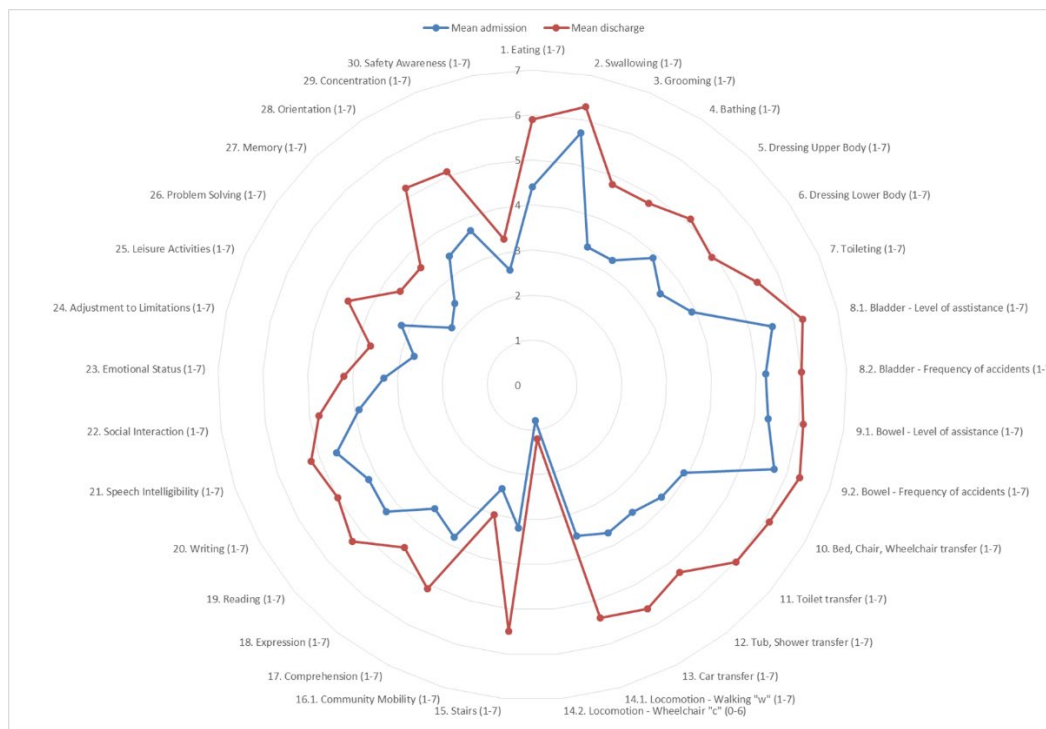| Demographic	
Gender	Female 12 Male14
Age at stroke	Mean 12.5 yrs; range 7-17 yrs
Stroke type	Haemorrhagic=22 Arterial Ischaemic=4
Stroke location	Right hemisphere=8 Left hemisphere=6 Cerebellar=5 Diffuse = 6
Length of stay	Mean 22.1; range 8-66 weeks

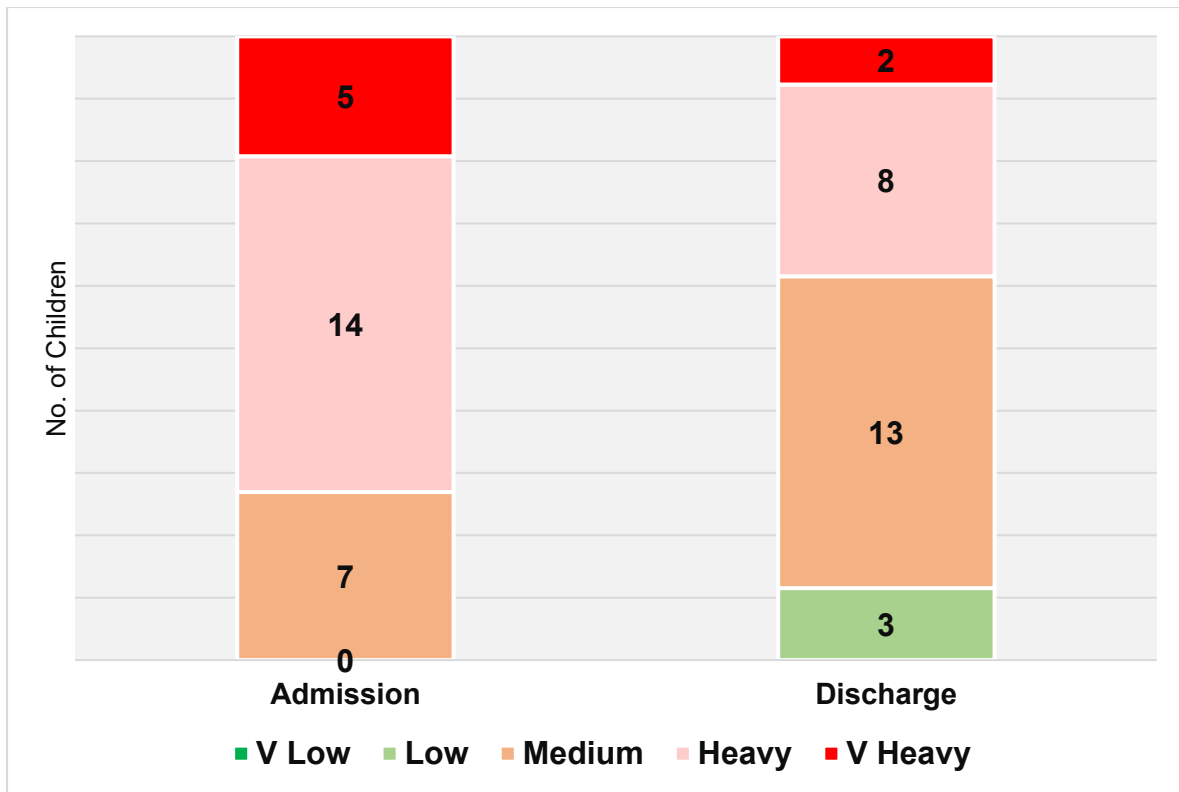*Figure 1: Change in UKFIM+FAM by item (n=26): personal care items 1-12*
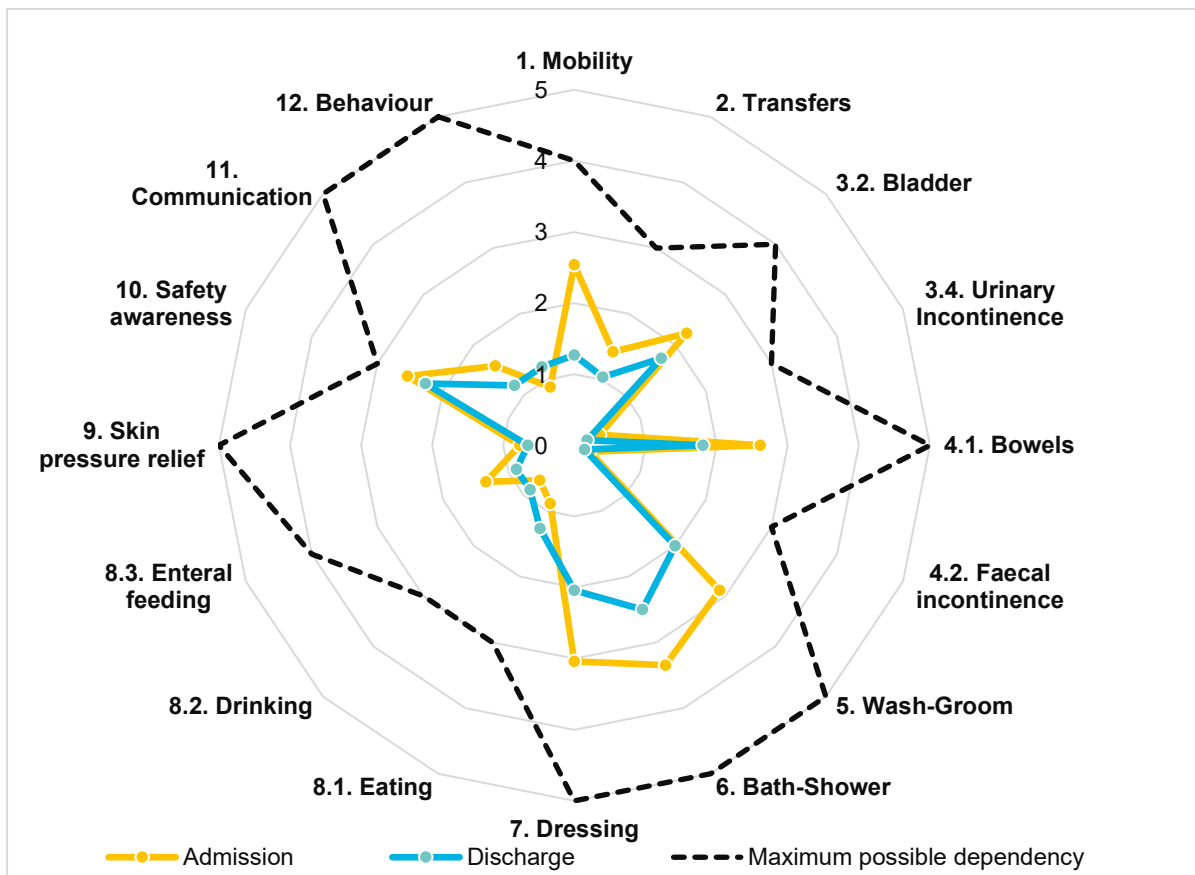
Figure 2: Change in RCS complexity category (n=26)

Figure 3 Change in NPDS scores (n=26):