

Developing a nursing dependency scoring tool for children's palliative care: the impact on hospice care

Abstract

Background: Occupancy is commonly used to measure bed management in hospices, however increasing complexity of children and young people, and technology dependence mean this is no longer effective. **Aim:** to develop a dependency tool that enables the hospice to safely and effectively manage the use of beds for planned short breaks (*respite*), preserving capacity for children requiring symptom management and end of life care. **Methods:** a comprehensive literature review and existing tools were used to inform the development of the Martin House Dependency Tool Framework. Training was provided to staff and the tool piloted before applying it across the hospice caseload. **Findings:** The Tool has been used on 431 children (=93.1% of caseload). The Tool enabled consistency of assessment and more effective management of resources, owing to a contemporaneous understanding of the clinical needs of those on the caseload. **Conclusion:** The tool has enabled consistent and transparent assessment of children, improving safety, effectiveness and responsiveness, and the management of the workforce and resources.

Key words

allocation; nursing; technology dependence; leadership; service design; management

Key points

- Children with life limiting conditions are living for longer and with more technology dependence than ever before.
- Bed occupancy is frequently used as a measure of resource management, but due to the increased needs of children who use hospices, nursing dependency is a more effective measure.
- The clinical areas that mean children require greater than 1:1 staffing can be divided into three themes: medication, respiratory conditions and challenging behaviour/communication difficulties.
- The Martin House Dependency Framework enables the safe and effective use of planned beds, ensuring capacity to respond to those requiring symptom control and end of life care in the children's hospice setting.

Reflective questions

- How do you ensure your knowledge about the contemporary needs of those in your care is up to date?
- What measures or tools could be used to help you demonstrate the management of resources in your workplace?
- How do you ensure that your service can meet both planned and unplanned demands from those who require palliative care?
- How do you know that the care you deliver is safe, responsive and effective?

Introduction

The needs of children and young people (hereafter 'children') who access care from children's hospice services are changing. Advances in medical technologies, medicines, therapies and scientific research mean that children with life limiting and life-threatening conditions (LLTTCs) are living longer, with more children than ever being reliant on these technologies to live (Price et al. 2018), dependent on complex medicine regimes (García-López et al. 2020) or living with increasing morbidity or complex health and social care needs (Constantinou et al. 2019). In some cases, the needs of these children mean they require a higher level of nursing or care support in order to meet their needs (Weaver et al. 2018). This is described as having a higher care dependency (Hatzmann et al. 2009).

There are 54 children's hospices across the UK - charitable organisations that provide a range of care services for children with a range of LLTTCs, together with their families in hospice buildings or community settings, such as family homes (Widdas et al. 2013). Anecdotally, it is acknowledged by children's hospices across the UK that there needs to be a shift in the way resources are considered and managed. Bed occupancy is commonly used by hospices as a measure of effective resource management (Cochrane et al. 2007). Whilst this has some benefits, it does not capture episodes of care where beds are essentially closed to ensure the safe and responsive care of children with increased dependency, due to their condition, or the technologies required to meet their needs.

Whilst developing a dependency score for children, it became clear that a '*one size fits all*' approach could not be applied to all hospices, as each organisation sets the roles and expectations of staff at different grades, in addition to significant variation in the number of

beds and how these are managed. We hope that sharing the process we have been through in developing the tool, as well as the tool itself, will help services providing hospice and palliative care to children to develop tools that enable them to measure the effective use and management of their resources.

Context

Martin House is a 15 bed children's hospice, providing care across Yorkshire and the Humber region of England, both in the hospice and at home. 12 of the hospice beds are used for planned care (or 'respite'), with the remaining three reserved for emergency use, including symptom control and end of life care. In addition, there are three cool bedrooms, used to care for children after their death (Tatterton et al. 2019). Children are routinely cared for on a 1:1 basis during the day, with six staff working overnight. The Care Team comprises around 60% registered nurses, with the remaining 40% of the Team including allied health professionals, nursery nurses and care support workers.

For some time, we have debated the benefits and challenges of introducing a dependency score to manage planned bed allocation. Informal arrangements were in place to ensure that we are able to balance the needs of children in the hospice at any given time. They included casual arrangements about the number of children with tracheostomies and those requiring parenteral nutrition that can be admitted for planned care at any time, however these were not always applied consistently. On occasion, the high level of dependency of resident children on planned stays sometimes meant it was difficult to meet the needs of those requiring unplanned care.

The project started in 2019 and was completed in spring 2020 by members of the hospice's Clinical Leadership Team. The group was tasked with developing a more meaningful way of measuring bed use and allowing us to more effectively match the needs of the children against the skills and levels of staff.

Aim

The aim of the project was to develop a nursing dependency tool that enabled the hospice to safely and effectively manage the use of beds for planned short breaks. We sought to develop a tool that:

- is easy to use;
- reflects the needs of the children and young people who use Martin House;
- enables the safe allocation of beds;
- can be used consistently;
- allows transparent decision making.

Method

To ensure that we achieved our aims, the dependency scoring tool was developed in three stages: an initial evidence search and literature review to ascertain current practices, the development of the model, ensuring that it reflected the specific needs of the hospice, and finally, piloting the tool to acquire feedback on the impact to children and families, staff and the organisation as a whole.

Literature review

A literature review was undertaken using six databases (psycINFO, PubMed, Web of Science, Academic Search Complete, CINHAL and Embase) in September 2019. The search terms used are shown in table 1. Additionally, we looked at the children's continuing care decision support tool (Department of Health 2016) and were informed by work currently being undertaken with the national long-term ventilation forum. A total of 97 papers were identified, reduced to 11; the reasons for exclusion are shown in the PRISMA diagram (figure 1). All papers were assessed to assure quality, transparency and that they were relevant to our enquiry. We used the Critical Appraisal Skills Programme (CASP) (CASP, 2018), exploring validity, results and clinical relevance, led by one reviewer (CM).

Due to the scant availability of published literature, an international call for grey literature was made via PaedPalCare, an email-based forum facilitating the sharing of information relating to children's palliative care, used worldwide. Through PaedPalCare, we identified tools used by four other children's hospices: Children's Hospices Across Scotland (CHAS), Donna Louise Hospice for Children and Young People, Haven House Children's Hospice and Rainbows Hospice for Children and Young People. The hospice tools were reviewed, each taking a different approach to scoring and using the scores in a variety of ways to manage their resources. Scoring frequency varied from numerous times daily, to annually; some services used them to vary staffing levels in response to the needs of resident children, where others used the tool retrospectively. It was clear from reviewing the tools that none could be

applied to Martin House that would enable us to meet all of our objectives without making significant changes.

Problem or patient or population	Children Complex needs Complexity Dependency Hospice Life limiting condition Nursing Palliative
Intervention or indicator	Bed management Dependency score Measurement
Comparison	Bed occupancy Occupancy
Outcome of interest	Patient safety Safe staffing Safety Skill mix

Table 1: search terms

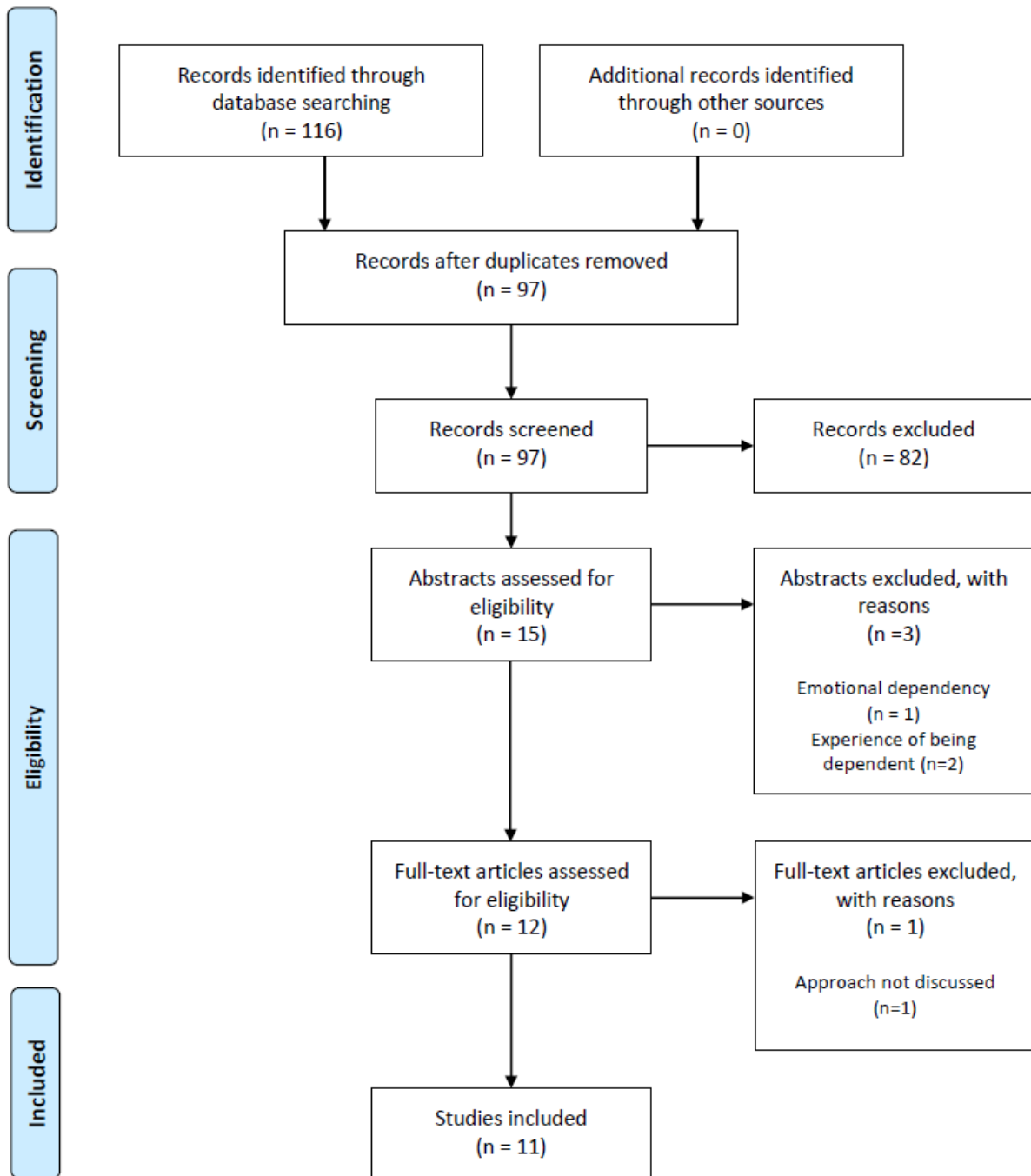


Figure 1: PRISMA diagram

None of the papers identified related to children; all were based on dependency scoring in adult settings, including hospice (Roberts and Hurst 2013) and community-based palliative care (Bracken et al. 2011), rehabilitation (Plantinga et al. 2006; Kosakowska et al. 2018) and intensive care (Garfield et al. 2000). Bracken *et al.* (2011:600) suggest that an effective

dependency score can provide '*efficient and effective workforce planning [...] crucial for ensuring adequate, timely service provision for patients and their families while also helping to alleviate the potentially onerous workloads.*' Turner-Stokes *et al.* (1998), Post, Visser-Meily and Gispen (2002), Hatfield, Hunt and Wade (2003), Svensson, Sonn and Stibrant Sunnerhagen (2005), Plantinga *et al.* (2006) and Kosakowska *et al.* (2018) explored the use of the Northwick Park Dependency Score (NPDS), designed for neurorehabilitation, using a numerical scale to measure the dependency/independence of patients, tracking progress in four areas, including basic care needs, such as washing, dressing and mobility. It can also be used as a measure of nursing care workload (Kosakowska *et al.* 2018). Bracken *et al.* (2011) compares the use of dependency scores by Graves and Payne (2007), Birch *et al.* (1997) and the unpublished '*Vale Prioritisation Tool*'. These are used in the community setting, identifying the amount of nursing time required by patients considering factors such as travel time, length of visit and phone calls. Garfield, Jeffrey and Ridley (2000) explored the relationship between using a therapeutic intervention scoring system (Moreno and Morais 1997) and a nursing dependency score in intensive care and high dependency units with the aim of establishing standardised nurse-patient ratios. These approaches have limited application to the children's hospice setting as the tool we are endeavouring to create is to identify staffing levels within an inpatient unit, with flexibility to adapt the nurse-child ratio in response to individual needs.

Bracken *et al.* (2011) discussed a dependency tool used in three adult hospices. In addition to capturing dependency to determine nursing workload, rather than the number of patients, the tool sought to plan short- and long-term staff planning, increase the hospices' ability to

respond to fluctuations in demand and as a means to evaluate the impact of services. Quinn, Allan and Bryan (2004) used qualitative interviews to gather staff opinions on the use of a tool used for older people, modified for use in an adult hospice. Staff were dissatisfied with the approach taken, perceiving no link between patient scores and subsequent management of resources and an omission of the emotional component of care, taken by some as devaluing this aspect of hospice care by the organisation. Some staff reported that the scores awarded did not reflect patient need and that some aspects of care, including the inability to score the technical care of patients on pumps and other medical devices. Staff also highlighted difficulties on shifts where staffing had been reduced due to low patient dependency, particularly when the condition of patients increased, requiring more care.

Roberts and Hurst (2013) considered occupancy and dependency, nursing activity, quality and staff skill mix, recognising that *'recent years have witnessed changing inpatient specialist palliative care (also known as hospice and end-of-life) services, with an increasingly interventionist approach to care for patients and carers presenting with complex needs* (Roberts and Hurst, 2013: 123). Using daily scoring, the study found that occupancy and dependency scoring ranged widely between organisations, and that between a quarter and half of patients fell into the highest dependency category, suggesting that the tool was applied ambiguously across organisations. The findings of this research demonstrate the need for clear descriptors relating to the scores, facilitating consistency between practitioners.

Although the findings from the literature review did not yield evidence that could support the development of a dependency model for children directly, there were lessons learned from published studies. These included the need to enable staff to undertake scoring consistently

through clear score descriptors; training, education and support; and the need to review scores regularly to ensure that contemporary needs were reflected.

Developing our model

As the usual model of nursing in the hospice is to care for children on a 1:1 basis; we considered elements of need that result in a child requiring more intervention from staff due to clinical needs, technology dependence or behaviour. Care requirements relating to meeting the comfort, hygiene and enteral feeding needs were therefore not included in the model.

We identified three key domains, shown in figure 2: respiratory, medication and challenging behaviour and communication difficulties. As this tool focused on planned care, we did not consider the needs of children at end of life or those requiring sporadic symptom management, as this care is delivered responsively, based on acute needs and using our emergency bed provision. However, children with LLLTCs may require long term, dynamic symptom management (for example, children with Batten's or Huntington's Disease), reflected in the medication domain.

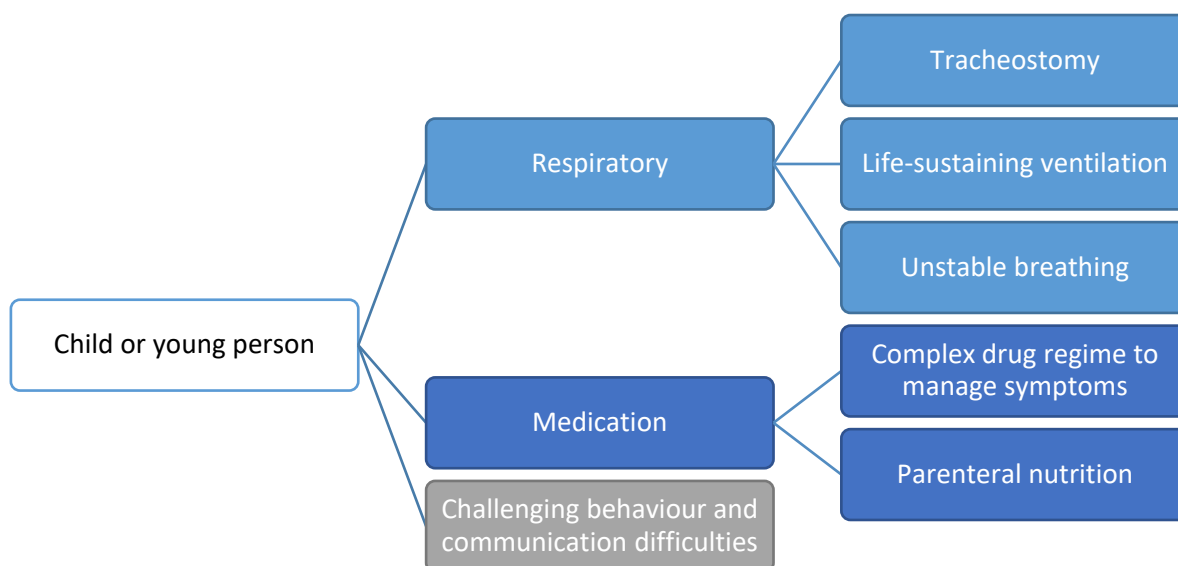


Figure 2: nursing dependency domains

All children on our caseload are scored against the same criteria; nursing dependency scores are only used to allocate planned care and do not influence decisions around emergency or unplanned care. Staff were used to talking about our ‘bookable beds’; for familiarity, we opted to have a maximum planned care nursing dependency of 12. The default score for all children and young people is 1. Children can receive a higher score, reflecting their increased nursing dependency (table 2), based on the descriptors shown in table 3. The score awarded to each child will represent the highest score in any one domain. The highest score available to a child is 2, indicating they require a daytime staffing level of 2 staff to one child. ‘Staff’ refers to any member of the interdisciplinary care team, including registered children’s and learning disability nurses, allied health professionals and support workers.

Level of need	Standard	Moderate	High
Dependency score	1	1.5	2
Staff:child ratio	1:1	3:2	2:1

Table 2: proposed dependency scores

	Moderate need (score: 1.5)	High need (score: 2)
Tracheostomy	Stable tracheostomy requiring routine predictable management.	Tracheostomy management requires frequent essential interventions e.g. high risk of tube blocking, difficult tube changes. Has a cuffed tube for high risk aspiration , requires frequent cuff deflation needing a two person technique.
Life sustaining ventilation	Unable to breathe independently and requires 24 hour mechanical ventilation. Has no respiratory drive when asleep requiring mechanical ventilation, disconnection of which would be fatal (e.g. CCHS).	
Unstable breathing	High risk and hard to predict apnoeas. Difficult to manage OPA/NPA (including frequent suction)	Frequent and severe uncontrolled seizures that do not respond to treatment and previously have resulted in life threatening breathing difficulties or respiratory arrest.
Complex drug management to manage symptoms	Uncomplicated symptom management: using established doses of medicines to manage anticipated symptoms	Rapidly changing/deteriorating condition where continual monitoring and dynamic symptom management is essential to maintain comfort
Parenteral nutrition / IV fluid replacement	Routine PN IV fluid replacement Complex parenteral therapies and/or complex plan for replacement losses (for example, where varying doses or fluids are used to manage needs.)	Risk of life threatening episodes requiring acute IV management e.g. hypoglycaemia, hypotension.
Challenging behaviour	Challenging behaviour but responds well to a behaviour plan. Incidents of upset but these do not pose a risk to self or others. Unpredictable behaviour that means the child is unable to maintain their own safety.	Regular challenging behaviour that puts others at risk of harm. Disruptive behaviour that poses a risk to themselves e.g. decannulates tracheostomy. Behaviour management plan identifies the need for 2:1 staffing.
Communication difficulties	Shows severe frustration about their inability to communicate e.g. significant distress to the child. This distress may present through physiological symptoms e.g. sweating, spasms.	

Table 3: nursing dependency score descriptors

Piloting the model

Following theoretical development of the nursing dependency, the working party tested the model on 30 children from the caseload, purposefully selected to reflect children with a range of technological and care dependencies. After this testing, the scoring tool was modified to make the descriptors clearer, before being piloted on the whole caseload, applied by the Care Team, under the leadership of the working party. The steps taken are outlined below.

Training and education

The application and use of a dependency score represented a significant change to practice within the hospice, therefore we were keen to ensure that it was implemented in a robust and supportive manner. Quinn, Allan and Bryan (2004) highlighted staff concerns regarding the implementation of a dependency tool within adult hospices, particularly the perceived link between scores and the allocation of resources, as well as valuing and preserving the biopsychosocial and family-centred approach to care offered by the hospice. We wanted staff to understand the reasons behind the change, as well as ensuring that gathering the data was as clear and simple as possible, which we hoped would increase staff willingness and consistency in application. Training, including the rationale for the initiative, the reasons behind the chosen model and how to complete the documentation, was provided to all members of the care team, including nurses, allied health professionals and care support staff. This included the provision of both face to face and written information.

In practice, the data collection tool is completed by the child's named practitioner, who keep in regular contact with families on their caseload, so have a robust understanding of the needs of the child. Staff were supported in the review of the first few children, with ongoing support

offered regularly. Scores are internally validated using a system of peer review. Children scoring more than 1 are moderated through the referral and eligibility panel – an interdisciplinary panel of staff comprising clinical leaders.

Applying the model

As illustrated in figure 3, following initial acceptance, children are scored by a clinical nurse specialist during an initial home visit, with input from the family. Children are then rescored, usually by their named practitioner, annually, or when we become aware of a change in need. For those already on the caseload (431 children), children were scored over a period of three months. These were overseen by one of the authors (CW), with support from the Clinical Leadership Team. Once scored, scores are added to the bookings system and checked at the time of booking planned stays.

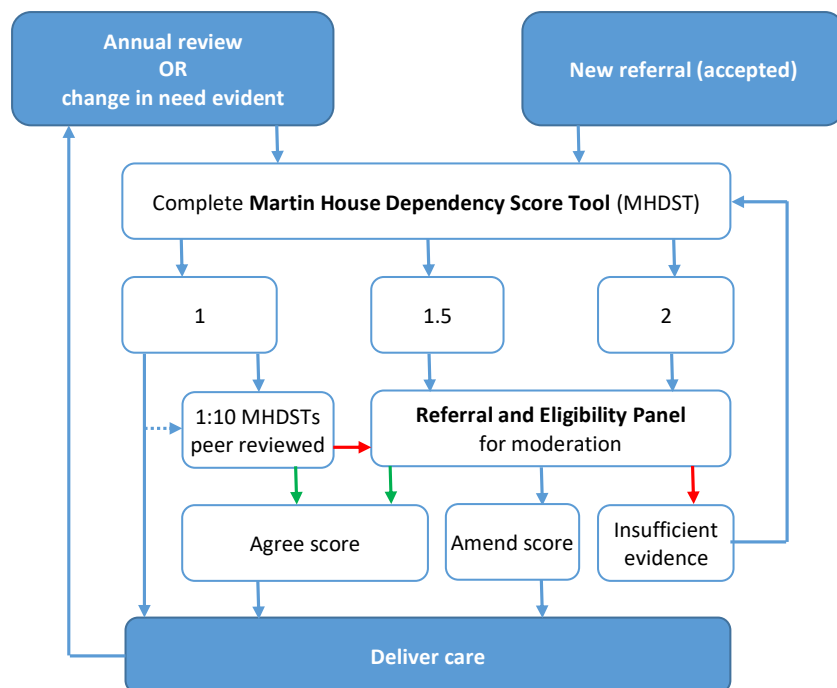


Figure 3: dependency scoring process

Discussion

At the time of writing, we have 431 active referrals on the caseload. A total of 407 children were scored, representing 93.1% of children on the caseload; this is due to unborn, antenatal referrals who cannot be scored antenatally. The allocated scores, and caseload percentages are shown in table 4. 68% of children were scored as 1, indicating that the standard model of care is appropriate to meet their needs. Scores awarded using the dependency tool were congruent with the informal list held by the hospice. On discussion, it was concluded that the tool facilitated objective and systematic assessment, and an accurate representation of care dependency. 53 members of the Care Team were involved in scoring children. Internal moderation found consistency in approaches to scoring and scoring decisions across the workforce; less than 2% of scores were questioned, and one changed following internal moderation. This is attributed to the provision of robust training and the clarity of the scoring tool.

		1	1.5	2	Caseload totals
Number of children		306 (75.2%)	76 (18.7%)	25 (6.1%)	407 (100%)
Respiratory			30 (7.4%)	12 (2.9%)	42 (10.3%)
Medication			21 (5.2%)	3 (0.7%)	24 (5.9%)
Behaviour and communication			25 (6.1%)	10 (2.4%)	35 (8.6%)
Gender	Male	171 (55.9%)	41 (10.1%)	11 (2.7%)	223 (54.8%)
	Female	135 (44.1%)	35 (8.6%)	14 (3.4%)	184 (45.2%)

Table 4: dependency score breakdown of scored caseload

Caseload management

Using the dependency tool has allowed us to adopt a consistent approach to the dependency assessment of children. The nature of work in British children's hospices is to offer '*home from home*' care (Arslanboga 2018), delivering care as families do at home. On occasions, this can lead to organisations underestimating the complexity of needs and individual demands (Taylor and Aldridge 2017), which, when combined with the needs of other resident children can lead to increased demand on the workforce, and unsafe or unsustainable levels of provision. The tool has allowed us to vary the number of resident children at any one time, leading to less fluctuation in the demands on the team from those on planned stays. Through scoring all children on the caseload, we have become more aware of those with higher dependency needs. This has enabled the Care Team to be more proactive in contacting families and offering planned short breaks and more responsive in meeting the needs of children and providing education support and development to staff at the bedside.

As we have created consistency in the dependency needs of resident children and have a better understanding of the needs of individual children, we are able to match the needs of children with the most appropriate members of the workforce. Improvements to the way we manage skill mix of the team mean that we have been able to ensure staff can achieve, consolidate and maintain technical skills, including tracheal ventilation and managing parenteral nutrition. This has been achieved through implementing the tool, pre-allocating staff to children and integrating practice and education and development with care provision.

The standardisation in the needs of resident children means we are better resourced to meet the needs of those requiring symptom management and end of life care in the hospice, without needing to draw on additional staff to meet clinical demand. The dependency tool

has developed our model of care, improving safety and effectiveness, with fewer reported incidents relating to staffing issues/levels. Our ability to respond to and to care for children and families with emergency needs has also improved following the implementation of the tool, demonstrated through reduced reliance on additional staffing above establishment, faster response times from request to admission, and a reduction in the number of cancellations of planned stays to accommodate those with emergency needs.

Finally, as all caseload holders have been trained to complete the dependency assessment and owing to the unambiguous and simple process of using the tool, we have found that children are being efficiently reviewed and rereviewed as needs change. This has led to a contemporaneous and dynamic understanding of the dependency needs of those on the whole caseload in ways we have been unable to achieve previously. This enables the hospice to respond quickly to increased needs, improving our responsiveness of our care services, allocation of resources and clinical leadership.

Challenges

The implementation of the tool has not been without challenges; prior to using the tool and the global understanding we now have of the dependency needs across the caseload, we would admit children based on expressed wishes of families, without consistently considering the needs of others who would be resident at the same time. The increased awareness of clinical dependencies, and revised booking rules has led to some practitioners expressing concerns around the hospice being less flexible. We have acknowledged this and reflected it in the training delivered to the team, helping staff to understand the paramountcy of safety and the need for the hospice to deliver care that is safe, effective and responsive to children

on planned stays as well as maintaining our ability to meet the needs of those requiring symptom management and end of life care.

Implications for practice

The development of a bespoke dependency model allows a consistent and transparent process, ensuring a safe, effective and responsive approach to bed management in children's hospices both in the UK and internationally. Key to the successful implementation of the tool was the data collection form, which was designed to be completed by the child's named nurse on an annual basis.

Limitations

Whilst we are confident in the quality and robustness of the tool we have developed; we acknowledge that it is not without limitations. Having considered many other tools already used across the UK and internationally, we accept that a one size fits all model cannot be applied across children's hospices, due to the variation in care models. However, we hope that we have presented the model with sufficient transparency and explanation, allowing the model to be adapted to suit others offering similar services. In addition, although the tool has been in use since October 2019, it has included a number of months of reduced planned activity due to the COVID-19 pandemic. Although we are confident in the approach to scoring, the implications of the score on planned activity has had limited testing.

Conclusion

The robust, evidence-based approach taken to developing and implementing the hospice dependency score has enabled us to consistently and transparently assess children on the caseload, whilst reflecting the needs of the hospice. The contemporary understanding of the needs of the whole caseload has led to improvements in the safety, effectiveness and responsiveness of the care offered. The dependency tool has enabled the skill mix of staff and the needs of resident children to be matched, assuring the safety of those on planned stays, in addition to preserving nursing resources, enabling the hospice to respond to those with unplanned needs, including end of life care.

Using a transformational leadership approach, staff have been supported to understand and use the tool effectively. The standard approach to assessing the dependency needs of children for planned stays has allowed the hospice to take a consistent approach to bed management and the management of the workforce and resources. The tool has enabled us to prioritise safety and effective use of planned beds, and to ensure we can respond to those requiring symptom control and end of life care.

References

- Arslanboga E. 2018. "Time for a Promotion? No, It's Not for Me..." How Caring for Children with Life-Limiting Conditions Affects Health Care Assistants' Career Decisions. *J Undergrad Ethnogr.* 8(1):53–68. doi:10.15273/jue.v8i1.8617.
- Birch D, Fisher M, Grey A, Veitch J, Williams A. 1997. The development of holistic dependency criteria for a specialist palliative care service. *Int J Palliat Nurs.* 3(6):306–316. doi:10.12968/ijpn.1997.3.6.306.
- Bracken M, McLoughlin K, McGilloway S, McMahon E. 2011. Use of dependency and prioritization tools by clinical nurse specialists in palliative care: An exploratory study. *Int J Palliat Nurs.* 17(12):599–606. doi:10.12968/ijpn.2011.17.12.599.
- Cochrane H, Liyanage S, Nantambi R. 2007. *Palliative Care Statistics for Children and Young Adults: Health and Care Partnerships Analysis.* London, UK.
- Constantinou G, Garcia R, Cook E, Randhawa G. 2019. Children's unmet palliative care needs: A scoping review of parents' perspectives. *BMJ Support Palliat Care.* 9(4):439–450. doi:10.1136/bmjspcare-2018-001705.
- Critical Appraisal Skills Programme. 2018. 10 Questions To Help You Make Sense of Qualitative Research. 10 Quest To Help You Make Sense Qual Res. doi:10.1371/journal.pmed.0040323.
- Department of Health. 2016. *National Framework for Children and Young People's Continuing Care.* London, UK.
- García-López I, Cuervas-Mons Vendrell M, Romero IM, de Noriega I, González JB, Martino-Alba R. 2020. Off-label and unlicensed drugs in pediatric palliative care: a prospective observational study. *J Pain Symptom Manage.* doi:10.1016/j.jpainsymman.2020.06.014.
- Garfield M, Jeffrey R, Ridley S. 2000. An assessment of the staffing level required for a high-dependency unit. *Anaesthesia.* 55(2):137–143. doi:10.1046/j.1365-2044.2000.055002137.x.
- Graves J, Payne D. 2007. *The prioritisation of care in the Marie Curie nursing service.* Marie Curie Nursing Service. London, UK.
- Hatfield A, Hunt S, Wade DT. 2003. The Northwick Park Dependency Score and its relationship to nursing hours in neurological rehabilitation. *J Rehabil Med.* 35(3):116–120. doi:10.1080/16501970310010457.
- Hatzmann J, Maurice-Stam H, Heymans HSA, Grootenhuis MA. 2009. A predictive model of Health Related Quality of life of parents of chronically ill children: The importance of care-dependency of their child and their support system. *Health Qual Life Outcomes.* 7(1):1–9. doi:10.1186/1477-7525-7-72.

- Kosakowska J, Grabowska-Fudala B, Smelkowska A, Wilkiewicz M, Górna K, Jaracz K. 2018. Northwick Park Dependency Score — a New Scale for Use in Nursing Practice. *J Neurol Neurosurg Nurs.* 7(1):4–11. doi:10.15225/pnn.2018.7.1.1.
- Moreno R, Morais P. 1997. Validation of the simplified therapeutic intervention scoring system on an independent database. *Intensive Care Med.* 23:640–644.
- Plantinga E, Tiesinga LJ, Van Der Schans CP, Middel B. 2006. The criterion-related validity of the Northwick Park Dependency Score as a generic nursing dependency instrument for different rehabilitation patient groups. *Clin Rehabil.* 20(10):921–926. doi:10.1177/0269215506072187.
- Post MWM, Visser-Meily JMA, Gispen LSF. 2002. Measuring nursing needs of stroke patients in clinical rehabilitation: A comparison of validity and sensitivity to change between the Northwick Park Dependency Score and the Barthel Index. *Clin Rehabil.* 16(2):182–189. doi:10.1191/0269215502cr474oa.
- Price J, McCloskey S, Brazil K. 2018. The role of hospice in the transition from hospital to home for technology-dependent children—A qualitative study. *J Clin Nurs.* 27(1–2):396–406. doi:10.1111/jocn.13941.
- Quinn H, Allan H, Bryan K. 2004. An evaluation of dependency assessment: experiences of staff, patients and carers in a UK hospice. *Int J Palliat Nurs.* 10(12):592–599. doi:10.12968/ijpn.2004.10.12.17284.
- Roberts D, Hurst K. 2013. Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data. *Palliat Med.* 27(2):123–130. doi:10.1177/0269216312447593.
- Svensson S, Sonn U, Stibrant Sunnerhagen K. 2005. Reliability and validity of the Northwick Park Dependency Score (NPDS) Swedish version 6.0. *Clin Rehabil.* 19(4):419–425. doi:10.1191/0269215505cr808oa.
- Tatterton MJ, Summers R, Brennan CY. 2019. A qualitative descriptive analysis of nurses' perceptions of hospice care for deceased children following organ donation in hospice cool rooms. 25(4): 166–175. doi:10.12968/ijpn.2019.25.4.166
- Taylor J, Aldridge J. 2017. Exploring the rewards and challenges of paediatric palliative care work - A qualitative study of a multi-disciplinary children's hospice care team. *BMC Palliat Care.* 16(1):73. doi:10.1186/s12904-017-0254-4. [accessed 2020 Apr 28].
- Turner-Stokes L, Tonge P, Nyein K, Hunter M, Nielson S, Robinson I. 1998. The Northwick Park Dependency Score (NPDS): A measure of nursing dependency in rehabilitation. *Clin Rehabil.* 12(4):304–318. doi:10.1191/026921598669173600.
- Weaver MS, Wichman B, Bace S, Schroeder D, Vail C, Wichman C, MacFadyen A. 2018. Measuring the Impact of the Home Health Nursing Shortage on Family Caregivers of

Children Receiving Palliative Care. *J Hosp Palliat Nurs.* 20(3):260–265.
doi:10.1097/NJH.0000000000000436.

Widdas D, McNamara K, Edwards F. 2013. A core care pathway for children with life-limiting and life-threatening conditions. Third. Bristol, UK: Together for Short Lives.