All Ireland Institute of Hospice and Palliative Care (AIIHPC) International Education and Practice Fellowship 2013

Report: Dr Maria Brenner

Location: Complex Care Team, Boston Children's Hospital

Aim

The aim of my visit to Boston Children's Hospital (BCH) was to gain knowledge on what constitutes best practice for the discharge management of a child with complex care needs in one of the largest children's hospitals in the US, with an established complex care team at the hospital/community interface.

Objectives Developed with BCH Prior to Visit

- To learn about best practice in the clinical care delivery to children with complex care needs
- To learn about innovations and effective strategies to deliver high quality hospital discharge, transition and care planning for children with medical complexity in the US.
- To inform and teach US clinicians, administrators and parents about such innovations and strategies in Ireland.
- To learn about the current state of work on benchmarks and measures of care for children with complex care needs.
- To collaborate with the paediatric discharge team in the development of a parent and patient-facing guide, framework and checklist of discharge planning.

Background

Although international definitions vary complex care generally refers to when a child has health issues requiring a range of additional support services which require a high level of effective integration between specialised and general services. This can include children with a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, and/or technology dependence for activities of daily living (Cohen et al. 2011). Problems in organising an efficient, child-centred and timely discharge process from hospital to home have been known for over two decades and are compounded by a steady increase in the numbers of children with complex needs (Kirk 2008, Goodwin et al. 2011). Parents generally become expert in the clinical care of their child during their time in hospital, however there is evidence of burn-out in parents in the absence of adequate support and due recognition of their new role when they go home, which can induce partial or total disengagement from the process of being able to care for their child (Manhas & Mitchell 2012, Toly *et al.* 2012). If the family are to cope with being the primary caregivers, then a number of structures need to be in place to ensure a dynamic partnership between service providers and the child's family. Knowledge of best practice internationally and exchange of innovations and strategies for the care for these children and their families is important

to provide optimum care for this growing population to ensure they can adapt their lives in a positive way to their changing circumstances.

Report

During the first two days of my visit I attended the Pediatric Complex Care National Network Conference, in Dallas, Texas, with members of the complex care team from BCH. The conference was attended by clinicians, researchers and administrators from the acute/community care interface across the United States with the objective of preparing children's hospitals to create the practice, administrative and systems expertise necessary to accept and successfully manage risk for their complex care population. During the conference I had the opportunity to inform delegates on the initiatives being developed in the Irish and wider European context and discussion took place on our many shared challenges including funding, geographical difficulties, and clinical competence and governance issues.

On returning to BCH I attended rounds in the complex care unit with Dr Jay Berry and had meetings with a variety of staff involved in the care delivery to children with complex care needs including Nurse Practitioners, Director of Inpatient Nursing, Outpatient Director of Complex Care Service, Case Managers, Medical Director Children's Hospital Integrated Care Organisation, Associate Chief of Hospital Medicine and Chief of Paediatric Palliative Care. I took part in a number of consultation meetings with parent advocacy groups for children with complex care needs within BCH and across states and I also visited a large step-down facility for children with complex care needs who are transitioning to home, based in the Franciscan Hospital for Children. The key areas I focused on throughout my visit were clinical complex care delivery, standards of care for children with complex care needs, management of the discharge and transition process, strategies for care coordination and the needs of the parents who were becoming the primary care givers.

The complex care service in BCH was initially established as an out-patient service in the 1980s, with the commencement of an in-patient service a decade later. The service currently delivers care to children with complex care needs in Boston and the wider Massachusetts area and is a referral centre for children across the US and internationally. Discussion with the complex care team centred on optimal approaches to caring for children with complex health needs, who are varying stages of their illness, across a broad range of geographic, socioeconomic and provider environments.

In addition to clinical care, BCH Case Managers work closely with the families of children who are preparing for transitioning to home, guided by established criteria for assessing the needs of the family prior to discharge. During the transition period there are set times for assessment and re-assessment of the needs of the family and home care assistance is often front-loaded to help establish a home care routine. For some families moving directly to home there is an opportunity for parents to manage the child's entire care, for defined periods of time, while the child is still in hospital. For others the transition to home may include staying in a step-down unit in the Franciscan Hospital for Children. This facility is one of the largest of such programs in the country and preparation for the transition to home continues here with the family, including care coordination with medical, nursing, and therapeutic services.

There is a strong focus in BCH on developing meaningful telemedicine and technology to support the coordination of care for children with complex care needs and there is ongoing discussion and debate on both innovations specifically for child health and on options to adapt innovations established in the adult care setting. A number of tools are already in use to enhance care coordination, for example the Care Coordination Measurement Tool, and others which have been successfully trialed are now in the process of moving to full roll-out.

Finally, as part of my ongoing work with the discharge research team in BCH and Harvard this visit afforded me the opportunity to collaborate more fully in their development of a parent and patient-facing guide, framework and checklist of discharge planning. I engaged in meetings with parent advocacy groups from BCH and across the US exploring their needs at the point of transitioning to home with a child with complex care needs. While many of the parents' concerns about transitioning to home often mirrored those of parents in Ireland, a particular issue of concern raised by US parents was *how* health care professionals should begin the conversation about care coordination and transitioning to home.

Outputs from Visit

1. Summary report to the AIIHPC and present at the AIIHPC symposium on best practice on discharge of a child with complex care needs
2. Inform curricula for undergraduate and graduate nursing and multi-disciplinary education programmes in UCD on care of the child with complex care needs

3. Inform and deliver on a collaborative research agenda across academic, clinical and policy stakeholders in acute and palliative care services, with a specific focus on transitioning children with complex care needs from hospital and respite services to home
4. Use the information gathered and links established to enhance my work with clinical partners and the HSE in implementing and evaluating practice change in this area of care delivery.

Acknowledgements

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References

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