

BMJ Open Quality Enhancing care of children with complex healthcare needs: an improvement project in a community health organisation in Ireland

Maria Brenner ¹, Amanda Doyle,² Thelma Begley,¹ Carmel Doyle,¹ Katie Hill,¹ Maryanne Murphy¹

To cite: Brenner M, Doyle A, Begley T, *et al.* Enhancing care of children with complex healthcare needs: an improvement project in a community health organisation in Ireland. *BMJ Open Quality* 2021;**10**:e001025. doi:10.1136/bmjopen-2020-001025

Received 19 May 2020
Revised 9 February 2021
Accepted 13 February 2021



© Author(s) (or their employer(s)) 2021. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹School of Nursing & Midwifery, The University of Dublin Trinity College, Dublin, Ireland

²Primary Care General Manager, Health Service Executive, Ballyshannon, Ireland

Correspondence to
Professor Maria Brenner;
brennerm@tcd.ie

ABSTRACT

Background Integration of care for children with complex care needs is developing slowly internationally. There remains wide variation in the governance of, and access to, care for these children and their families.

Local problem There was a need to develop a service that would have a specific remit for organising the overall management and governance of the care of these children in the community.

Method A bespoke model was established specifically to support the needs of children with complex healthcare needs (CHNs). The sole focus of the team is to provide the highest standard of care to these children and their families, and to enable families to remain central to decision-making.

Intervention The service for children with CHNs was established in August 2017 with the appointment of a service manager and case managers. A comprehensive training and education programme was put in place to support care to the children and their families.

Results The service is viewed as delivering high-quality care. Parents and stakeholders highlighted the value placed within the service on individualised care, specialist knowledge and the importance of advocacy.

Conclusions The model recognises the exceptional lives these children and families live, given the complexities and challenges they have to overcome on a daily basis. The team have built a specialist knowledge and skill set in supporting families and others involved in the care of the child, as they are solely employed and dedicated to the provision of care to children with CHNs. The corporate governance structures seem strong and stand up to scrutiny very well in terms of parents' and stakeholders' perspectives and in the context of published international best practice.

INTRODUCTION

Problem description

Complex care needs refer to multidimensional healthcare and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis. They are individual and contextualised, are continuing and dynamic, and are present across a range of settings, impacted by healthcare

structure.¹ The management of care and the integration of health services for these children are generally found to be insufficient with wide variation in the governance of, and access to, care for these children and their families.¹ It is acknowledged that there remain extensive challenges to this. These include communication of the needs of the child and family at the acute–community interface, confusion over points of accessing care and no defined system of documenting care in a manner that can be accessible for the family and the multidisciplinary team.^{2–4} These challenges are shared internationally, with recommendations for the need for a seamless service to avoid overburden on parents and more effective communication processes to enhance continuity of care. A further challenge is the identification of the exact number of children who have complex healthcare needs (CHNs). This can be attributed to the ongoing clarification and refinement of the definition of complex care within and across countries, and an absence of registers to capture the number of these children.

Available knowledge

Many papers present and discuss core areas of care delivery and management of services by service providers for children with CHNs. These roles are often referred to by a number of different names in the literature, including family care coordinator, care coordination counsellor, nurse care coordinator and key worker.^{5,6} Managing the care of this group of children and their families involves a significant capacity for problem-solving and incorporates improving wait times for access to care, navigating the complexities of multiple service providers and/or establishing service provision links.^{7–11} Planning and assessment includes the coordination of future visits or referrals,^{9,10,12,13} ensuring treatment plans



are carried out,^{9 12} and the initial and ongoing identification of needs.^{5 9 13 14} Information and specialist support involves acting as a point of reference for all enquiries related to the child and family, and sharing information with professionals and families.^{9 13} Three other key elements inherent within the role include administration and logistics, self-care and continuing professional development.^{15–17} Collectively, the literature suggests that service providers for children with CHNs are expected to have multiple skills: sharing a common vision, having the freedom to be innovative and work collaboratively, functioning independently and working autonomously, managing time effectively, building networks, creating and maintaining relationships, and problem-solving when required.^{16 18–23}

Family-centred care is widely reported as the preferred model of care when working with children and their families, although often it is not implemented consistently or effectively.^{24–28} While no specific model of family-centred care is identified as optimum, it is suggested that, where one underpins practice, it enhances the experiences for children and their families and improves well-being.²⁹ Increasingly, the co-creation of a shared plan of care with the family is identified as a necessity in delivering individualised care,^{30 31} and care providers have a pivotal role in the facilitation and development of shared plans of care with the child and family.³²

Staffing and equipment are identified as key resource variables. For example: the challenges of recruitment and levels of pay as well as cover during sickness or leave are highlighted in the literature^{5 33}; there may be differences in the levels of communication between disciplines,^{11 12 33} while others consider success to be dependent on a leadership that values the skill base of nurses and that places emphasis on the importance of relationships within the team.²⁰ The ability of care providers to be effective is also based on the capacity of the healthcare system to manage the care issues identified in their assessment of the needs of a child and family.^{22 34} In addition, the nature of the interpersonal relationships between the care providers and families can vary. For example, an exploration of the lived care experiences of parents of children with complex needs identified that the professional is there to work with the family and not for the family, which can be a difficult balance to maintain.³⁵ The very nature of complex care needs means that the care of a child with these needs is provided by a wide range of services, incorporating health, education, social and voluntary sectors. The fragmented nature of this demands effective service management is in place, and case managers who are forward thinking and strong advocates for the families in their care are essential for ensuring a progressive and family-centred model of care.

Rationale

We describe the development and evaluation of an intervention to improve care for children with CHNs in a particular community health organisation. Drawing on

Box 1 Key constituents for the effective care of children with complex healthcare needs³⁶

- ▶ Effective health and multi-agency agreements and funding arrangements.
- ▶ Robust clinical governance, quality and safety policies.
- ▶ Effective discharge planning procedures.
- ▶ Appropriate and effective care package.
- ▶ Key worker delivered individually tailored family support and education.
- ▶ Accessible accommodation, equipment and transport.
- ▶ Ongoing hospital/community interface.

key constituents for the effective care of children with CHNs (box 1),³⁶ a specific service for these children was established. This bespoke team has a specific remit for organising the overall management and governance of the care of these children. The sole focus of the team employed is to provide the highest standard of care to children with CHNs, to enable families to remain central to decision-making and to focus on working in partnership with the child and family.

Specific aims

The quality improvement initiative described in this article was introduced to enhance care delivery to children with CHNs. The purpose of the review was to determine the perspectives of the families cared for, and key healthcare professionals, of the impact of this service. This was essential to inform the further development of this service.

METHODS

Context

This initiative was developed in a community health organisation (CHO) in Ireland. CHOs are community healthcare services outside of acute hospitals, such as primary care, social care, mental health, and other health and well-being services. These services are delivered through the Health Service Executive (HSE) in Ireland, and its funded agencies, to support people in local communities, delivering care as close as possible to their homes. Nine CHO areas have been established across the country. This initiative was developed in CHO 1, a region that comprises an area in the north west of Ireland, with an overall population of 389 048. Prior to this intervention, these children were cared for by public health nurses.

Intervention

The service for children with CHNs was established in CHO 1 in August 2017 with the appointment of a service manager to oversee and govern paediatric home care packages across CHO 1. Additional staff members including three nurse managers, employed as case managers, were recruited mid-2018, and formal handover from the Public Health Nurse service was completed by July 2018. The service manager has responsibility for the

management of services for children with CHNs; ensuring that there is collaborative working with parents; acting as an informed resource and link person for all CHN stakeholders; providing optimal and coordinated service to children with CHNs and to ensure the best use of available resources; and developing and managing working relationships with a large number of external stakeholders. To support the staff within this service to deliver on these responsibilities, a comprehensive training and education programme is in place, which includes over 120 clinical and over 40 non-clinical programmes related to the care of children with CHNs. Specific education needs for staff were identified and agreed from this suite of available programmes.

Service-level agreements were established with preferred providers to enhance governance and standardised criteria for referral pathways, and assessments were developed. This included systems for ordering and monitoring of clinical aids and appliances required in the child's home. An electronic database was established with links to case files which service manager, case managers and administration staff have access to.

Study of the intervention

Twenty families who had a child with CHNs in CHO 1, and 23 stakeholders (members of senior management, administrators, case managers, nurses and home care services) working with the health services, were asked for their perspectives of the intervention.

Measures

A local gatekeeper was appointed who identified potential participants and sought their permission to be contacted. They were then sent information on the evaluation, and those who wished to participate were asked to complete a survey comprising a series of open-ended questions. This included questions on their experience of delivering or receiving the service and on their views on progressing the service further. The survey was posted to parents with a stamped addressed envelope for return. The survey was sent by email to the staff working with the health service and returned to MB. No demographic data were gathered on the parents or other stakeholders to maintain confidentiality and avoid recognition in a rural setting.

Analysis

The data from each group were analysed separately using thematic analysis.

Ethical considerations

Ethical approval from a research ethics committee was not required for this quality improvement project. Each participant invited to take part was advised that participation was optional; they were provided with detail of the survey processes and of the confidential nature of the survey. They were advised that if they chose to participate they could not be identifiable in any reports, and thereby there was no potential risk of any bias in terms of care delivery (parents) or role (stakeholders).

Table 1 Themes and subthemes from parent feedback

Overarching theme	Subtheme
Professionalism and trustworthiness	Dedication of providers Experienced management Accountability Confidence in care
Advocacy	Child at centre Fighting for us
Progressing the service	Enhancing continuity Daytime care Backup planning

RESULTS

Parents' perspectives

Data were gathered from 80% (n=16) of all parents invited to participate. Three key themes emerged: professionalism and trustworthiness, advocacy and progressing the service. [Table 1](#) shows the relationship between overarching themes and subthemes.

Professionalism and trustworthiness

Parents who responded were unanimous in complimenting the team on their professionalism and their dedication to the care of their children. The team were held in very high esteem and highly valued for their experience in the care of children with CHNs. Parents highlighted that *having a manager who is also a nurse with actual experience in dealing with this has been invaluable in helping access services*. Parents also stated that they found the service manager to be *honest and direct ... I know exactly where I stand*. Overall, the level of expertise in the team instilled confidence in the parents and trust in the ability of the team to anticipate their child's needs and thereby be *an incredible course of security* for the families. Parents described the service as *wrapping the families in a hug ... it makes you feel safe*.

The majority of the families referred to the value of getting a good night's sleep when home care was in place, and overall parents commented widely on the positive impact of the service on their well-being. This included statements such as *being happy in myself, never forgotten or side-lined and feeling listened to for the first time*. They specifically referred to a more effective service in the last 2 years, describing the team as *approachable, dedicated and genuinely interested in our child*.

Advocacy

Parents identified that the service placed the needs of the child clearly at the centre and was very supportive in fighting for services for parents. This was portrayed in feedback stating that the nurses and case managers in the service are *fighting in our corner* and that parents feel that their child *matters for the first time*. They stated that the service *puts the child at the centre of everything*. This individualised care is extremely highly valued, with parents

explaining how much it means that their child's care is more than about their survival, that it is about enabling their child to thrive:

we have received excellent care and service from the HSE ... to ensure our child not only survives but has a chance to thrive fills us with gratitude beyond explanation.

This approach is extremely important to the families who responded. They stated that the importance of this approach *cannot be overemphasised* and that the quality of the current service *should be available to every child in Ireland ... an invaluable resource*.

Progressing the service

Parents offered some suggestions on how to progress the service. Suggestions were mixed, with individual parents identifying the need for the following: greater consistency in knowing which nights will be covered and having an enhanced backup plan if nights are cancelled; where possible having the same carers all the time; ideally having all nurses employed by the HSE for consistency in care delivery; consideration for more care provision during the daytime; and the need for school services in each county.

Stakeholders' perspectives

Data were gathered from 65% (n=15) of all stakeholders invited to participate. As this model of care provides a service that links care delivery across the public and private care sector, it was important to ascertain the views and opinions of key stakeholders working across these areas regarding their perception and experience of the current service. Fifteen stakeholders responded, and the responses comprised feedback from HSE senior management, administrators, case managers, nurses and home care services working with the HSE. [Table 2](#) presents the themes and subthemes from stakeholder feedback.

Child and family centred

Respondents repeatedly highlighted the value of the new model of service in the provision of child and family-centred care. This included reference to the responsiveness of the model of care to the needs of the child and family in relation to reducing family burden, providing responsive and timely care, the confidence of families in the care provided by the service and positive clinical outcomes including reduced admissions to hospital:

... great support for families and has taken away some of the burden of care as they are managing rotas, ensuring care up to date in the home and all appropriate equipment and supplies are in the home in a timely manner. (Nurse)

Children are getting out of hospital quicker when linked in with this service and many children have not had the need to come to hospital due to the nursing support they are getting at home. (Nurse)

Table 2 Themes and subthemes from stakeholder feedback

Overarching theme	Subtheme
Child and family centred	Reduced family burden
	Specialist knowledge
	Responsive and timely care
	Confidence in care
	Care in crisis
Enhanced governance	Reduced readmissions to hospital
	Transparency and trust
	Accountability
	Standardised care
	Enhanced integration of care
Progressing the service	Supported staff
	Communicating the new model
	Access to respite care
	Development of specialist nursing roles
	Ongoing enhancement of standardised care
	Ongoing development of communication pathways

Respondents identified that a key contributing factor to this enhanced care was the specialist knowledge of the service manager, case managers and nurses leading and delivering care to this population:

... a wide range of knowledge and experience ... able to answer questions relating to their child immediately. The families have voiced this has a major difference ... (Nurse)

Enhanced governance

Respondents reported enhanced standardisation of care and enhanced accountability of care within the service. Respondents also reported enhanced integration of care and more focused and seamless delivery of care:

Dedicated and accountable manager in place to oversee all aspects of service delivery in respect of assessment, liaison with other relevant services and in delivery of the approved home care package ... issues arising are being dealt with comprehensively & timely. (Management)

... we now having a dedicated team with access to a central database. This ensures that all staff are now aware of all children with complex health needs across CHO1 and can access relevant information in a matter of minutes, which is extremely beneficial when a parent makes contact looking for an update/information. (Administration)

Respondents stated that the new service brought enhanced transparency to the care of children with CHNs and their families, leading to a number of positive outcomes, including a reduction in the number of complaints on care delivery to this population in the community:

Confidence in the service has been created at different levels—parents/caregivers; senior management; other health services/disciplines; education partners; voluntary sector; public representatives. (Management)

Enhanced governance was also demonstrated through numerous references by stakeholders to increased staff support. Examples of this included enhanced opportunities for professional development, increased job satisfaction and reference to collegiality in the workplace:

Provides one clear route for information dissemination to ensure all nurses and midwives who work in this field have access ... This is particularly important for contemporary nursing/healthcare issues and to ensure that the nurses working within this service are aware of the opportunities available to support their continuing professional development. (Management)

the staff nurses involved are supported in every way possible, for example to develop professionally in order to enhance skills so as to deliver optimum care. (Nurse)

Progressing the service

Participants identified a number of areas that could enhance this service and improve the wider care of children with CHNs across the country. The need for a specific strategic plan for the future of this service was identified as an important next step for this service. It was also suggested that there was a continuous need to focus on standardised care assessment and reassessment of family needs, and communication of these processes and roles within the processes to families in the service. The dominant area for progress, although not within the CHN service to date, was the need for enhanced respite care for children and their families. Overall, participants were very supportive of the need for this to support families caring for their children in the home:

I think that families would appreciate it if funding could be extended to include respite provision to allow families to leave the home to run errands, go to dinner, or do something with their other children. (Administration)

The majority of respondents were very eager to see the development of this model of care disseminated widely to enhance care delivery to children in other areas in Ireland and further afield. This demonstrates the level of support for this service by those delivering it and linked to it, and a very strong commitment to positively influence

enhanced care delivery to the wider population of children with complex needs and their families:

I believe the new service processes are beneficial to the service user and should be implemented in the other CHO areas. (Home care service)

The service is vital and should continue and expand where necessary. (Nurse)

Respondents identified opportunities within this service for the development of further specialist nursing roles and the need to consider opportunities for advanced nurse practitioners and clinical nurse specialist roles to further support the service to parents and children. Individual suggestions for enhancing clinical care delivery included the following: the need for improved protocols for medication management, improved communication on rostering with agencies, improved access to medical records for staff delivering care, increasing the number of home visits, consideration to the needs of these children for transitioning to adult services and further consideration of opportunities for respite care.

DISCUSSION

Summary

The service is viewed as delivering high-quality care. Parents and stakeholders collectively demonstrated the value placed within the service on individualised care, specialist knowledge and the importance of advocacy. In planning for the future, focusing on further developments in these areas is important while disseminating the initiative to the wider healthcare and social care audience in Ireland and further afield.

Interpretation

The theme of good organisational leadership was threaded throughout the findings of the study, and the service, overall, would seem to be meeting the majority of needs of the users and wider stakeholders. This was supported in feedback from parents and stakeholders who highlighted good communication structures. Throughout the review, the quality of interagency collaboration, planning and coordination frequently demonstrated the sustainability of this service and reflects the key constituents of effective integration of care reported internationally.^{37 38} Increased access to respite care was identified as a challenge in CHO 1, and this is reflective of the continuous call for enhanced provision of this service internationally.³⁹ It is noted that although respite in home is not part of this service to date, parents and families in CHO 1 are facilitated to leave the home to attend social events, appointments and other family commitments based on individual family requirements, supported with an individual risk assessment and contingency plans in place. This is enabled through strong partnership with the service to ensure that both the child and the staff remain safe.

Parent feedback indicated trust in the care their child received and gave a number of examples where they felt particularly well supported in their interactions. The

**Box 2 Implications for practice**

- ▶ The leadership of the service manager, the progressive nature and responsiveness of the case managers, and the care delivery by the nursing and wider team are very highly valued. It is important that all current roles in the team continue to be supported.
- ▶ It would be important to develop a specific strategic plan for the next 5 years of this service.
- ▶ There is a continued need to increase the number of Health Service Executive nurses being employed to directly support the child and family in the home.
- ▶ There is a need to further explore and progress the inclusion of healthcare assistants in the care of children and families in the home.
- ▶ The quality of relationships between caregivers, children and their families was highly valued. It is important to continue to foster this level of trust.
- ▶ It is important to continuously seek to enhance standardisation of assessment, reassessments and care delivery.
- ▶ There is a need to continue to enhance communication pathways and access to documentation across the team.
- ▶ It is important to explore mechanisms for timely access to respite care service.
- ▶ There is a need to explore the potential, where possible, of additional support hours during the day for parents.
- ▶ It is important to continue to include families in making recommendations for service improvement.
- ▶ The value placed on integrated care was a central theme of this review. It is important to continue to promote collaborative working across healthcare and social care services to promote integrated care pathways.
- ▶ As the service develops, consider tailored education programmes for staff and seek to optimise the opportunities that may arise from national initiatives in the development of clinical nurse specialist and advanced nurse practitioner roles.
- ▶ Establish a plan of care for adolescents moving to adult services.

provision of emotional and practical support is identified as a cornerstone to effective care of children with CHNs; this enhances a trusting relationship between the family and care organisation, which is a central tenet of models of family-centred care,²⁹ and the absence of which can lead to breakdown in communication and subsequent difficulties in the child–family–carer relationship.^{35 40} Into the future, this will continue to be important to foster and manage to accommodate increasing diversity in culture and the social structure of family.⁴¹ Ongoing data collection on the experience of care from the perspective of the parents/guardians or siblings of children with CHNs will be important to continue to identify and address the real needs of the child and family. The competence and professional practice of those delivering care were the subject of repeated positive commentary in the feedback from parents and stakeholders. As the role of the children's nurse in the community continues to evolve in the coming years, it will be important to consider how more specialist roles can be supported within this service. Specific implications of this review are presented in **box 2**.

Limitations

The education programmes offered were not part of one full suite; rather, they were individual offerings on a wide range of topics relevant to the care of the child and family with CHNs in CHO 1. Therefore, there was no overall evaluation of the programme of education available to staff. This approach to continuous practice development in the community setting, though not traditional, reflects the diversity of children's needs and is therefore necessarily flexible and dynamic. The use of an open-ended survey as opposed to interviews could be viewed as a limitation of this evaluation. Our decision to use this approach was based on our collective experience of collecting data with vulnerable populations and our acknowledgement of the fact that the parents we sought to speak with often struggled to get time for their own family life. Therefore, we deliberately sought an approach that would not impose on them any more than was necessary and would afford them time to reflect and to take their time to complete the survey. There is the potential for bias when working with such small numbers from a small geographical region; however, we are satisfied that the processes in place to support confidentiality were robust enough to prevent this. We acknowledge that the findings are very positive in terms of the service delivery. It is likely that the positive findings were related to the fact that such a service was very badly needed. This is reflected in the literature on the needs of children with complex care needs in the community setting.

CONCLUSIONS

This service for children with CHNs was welcomed by all those who took part in the study. The model recognises the exceptional lives these children and families live, given the complexities and challenges they have to overcome on a daily basis. The team have built a specialist knowledge and skill set in supporting families and others involved in the care of the child as they are solely employed and dedicated to the provision of care to children with CHNs. The corporate governance structures are strong, and there are clear lines of reporting and accountability. Collectively, participants were supportive of the need for the continuation and further development of this model of care. There is strong evidence from respondents that the service is meeting many of the targets set out at its initiation. This includes collaborative working with parents, delivery high-quality clinical care, providing an optimal and coordinated service, and developing and managing working relationships with a large number of external stakeholders. Tangible issues were identified from the review that could be addressed to support this service as it develops. The service has been identified as a significant success in CHO 1 with commitments made to its continued availability. Central to this is a clear strategy for its future and ongoing investment in this critical area of care delivery at the acute–community interface.

Twitter Maria Brenner @MariaBrenner

Acknowledgements We would like to thank the parents and healthcare professionals for taking time to participate in this evaluation.

Contributors MB and AD planned the study. MB collected data. MB, CD, TB, MM and KH analysed the data and wrote the findings. All authors contributed to the discussion of the findings and the write-up of this paper.

Funding This review was funded by the Health Service Executive, Ireland (no award number).

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Maria Brenner <http://orcid.org/0000-0001-8779-5288>

REFERENCES

- Brenner M, Kidston C, Hilliard C, *et al*. Children's complex care needs: a systematic concept analysis of multidisciplinary language. *Eur J Pediatr* 2018;177:1641–52.
- Robert R, Zhukovsky DS, Mauricio R, *et al*. Bereaved parents' perspectives on pediatric palliative care. *J Soc Work End Life Palliat Care* 2012;8:316–38.
- Brenner M, Larkin PJ, Hilliard C, *et al*. Parents' perspectives of the transition to home when a child has complex technological health care needs. *Int J Integr Care* 2015;15:e035.
- Brenner M, O'Shea M, Larkin P. Development of vignettes to explore integration of care for children with complex care needs across the EU and EEA. *Int J Integr Care* 2017;17:1–5.
- Howitt MJ. The family care coordinator: paving the way to seamless care. *J Pediatr Oncol Nurs* 2011;28:107–13.
- Taylor A, Lizzi M, Marx A, *et al*. Implementing a care coordination program for children with special healthcare needs: partnering with families and providers. *J Healthc Qual* 2013;35:70–7.
- Greco V, Sloper P, Webb R. *An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs*. UK: Department for Education and Skills Publications, 2005.
- Albanesi F, Invernizzi V, Meucci P, *et al*. Role of disability-case manager for chronic diseases: using the ICF as a practical background. *Disabil Rehabil* 2009;31(Suppl 1):S50–4.
- Robinson KM. Care coordination: a priority for health reform. *Policy Polit Nurs Pract* 2010;11:266–74.
- McSpadden C, Therrien M, McEwen IR. Care coordination for children with special health care needs and roles for physical therapists. *Pediatr Phys Ther* 2012;24:70–7.
- Rea CJ, Wenren LM, Tran KD, *et al*. Shared care: using an electronic consult form to facilitate primary care provider-specialty care coordination. *Acad Pediatr* 2018;18:797–804.
- Brustrom J, Thibadeau J, John L, *et al*. Care coordination in the spina bifida clinic setting: current practice and future directions. *J Pediatr Health Care* 2012;26:16–26.
- Sheftall AH, Chisolm DJ, Alexy ER, *et al*. Satisfaction with care coordination for families of children with disabilities. *J Pediatr Health Care* 2019;33:255–62.
- Armijo-Olivo S, Stiles CR, Hagen NA, *et al*. Assessment of study quality for systematic reviews: a comparison of the Cochrane collaboration risk of bias tool and the effective public health practice project quality assessment tool: methodological research. *J Eval Clin Pract* 2012;18:12–18.
- Beecham J, Sloper P, Greco V, *et al*. The costs of key worker support for disabled children and their families. *Child Care Health Dev* 2007;33:611–8.
- Antonelli RC, Stille CJ, Antonelli DM. Care coordination for children and youth with special health care needs: a descriptive, multisite study of activities, personnel costs, and outcomes. *Pediatrics* 2008;122:e209–16.
- Law J, McCann D, O'May F. Managing change in the care of children with complex needs: healthcare providers' perspectives. *J Adv Nurs* 2011;67:2551–60.
- Carter B, Cummings J, Cooper L. An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. what works well and what needs to be done to improve practice for the future? *J Clin Nurs* 2007;16:527–39.
- Fitzgibbon TM, Popalisky J, Myers K, *et al*. Care management for children with special needs: Part II: the role of primary care. *J Ambul Care Manage* 2009;32:205–15.
- Ehrlich C, Kendall E, St John W. How does care coordination provided by registered nurses "fit" within the organisational processes and professional relationships in the general practice context? *Collegian* 2013;20:127–35.
- Tschudy MM, Raphael JL, Nehal US, *et al*. Barriers to care coordination and medical home implementation. *Pediatrics* 2016;138:e20153458.
- Lyles AA, Overgaard PM, Caputo GL, *et al*. Stakeholders' perceptions of care coordination: a participatory process. *J Pediatr Health Care* 2017;31:555–9.
- Cordeiro A, Davis RK, Antonelli R, *et al*. Care coordination for children and youth with special health care needs: national survey results. *Clin Pediatr* 2018;57:1398–408.
- Murphy M, Fealy G. Practices and perceptions of family-centred care among children's nurses in Ireland. *J Child Young People's Nurs* 2007;1:312–9.
- Shields L. What is 'family-centred care'? *Eur J Pers Cent Healthc* 2015;3:139–44.
- Coyne I, O'Neill C, Murphy M, *et al*. What does family-centred care mean to nurses and how do they think it could be enhanced in practice. *J Adv Nurs* 2011;67:2561–73.
- Tallon MM, Kendall GE, Snider PD. Rethinking family-centred care for the child and family in hospital. *J Clin Nurs* 2015;24:1426–35.
- Feeg VD, Paraszczuk AM, Çavuşoğlu H, *et al*. How is family centered care perceived by healthcare providers from different countries? an international comparison study. *J Pediatr Nurs* 2016;31:267–76.
- O'Connor S, Brenner M, Coyne I. Family-centred care of children and young people in the acute hospital setting: a concept analysis. *J Clin Nurs* 2019;28:3353–67.
- Brenner M, O'Shea MP, Larkin P, *et al*. Management and integration of care for children living with complex care needs at the acute-community interface in Europe. *Lancet Child Adolesc Health* 2018;2:822–31.
- Brenner M, O'Shea MP, McHugh R, *et al*. Principles for provision of integrated complex care for children across the acute-community interface in Europe. *Lancet Child Adolesc Health* 2018;2:832–8.
- McAllister JW, Keehn RM, Rodgers R, *et al*. Care coordination using a shared plan of care approach: from model to practice. *J Pediatr Nurs* 2018;43:88–96.
- Vaz EMC, Collet N, Cursino EG, *et al*. Care coordination in health care for the child/adolescent in chronic condition. *Rev Bras Enferm* 2018;71:2612–9.
- Van Cleave J, Boudreau AA, McAllister J, *et al*. Care coordination over time in medical homes for children with special health care needs. *Pediatrics* 2015;135:1018–26.
- Rodríguez A, King N. Sharing the care: the key-working experiences of professionals and the parents of life-limited children. *Int J Palliat Nurs* 2014;20:165–71.
- Noyes J, Brenner M, Fox P, *et al*. Reconceptualizing children's complex discharge with health systems theory: novel integrative review with embedded expert consultation and theory development. *J Adv Nurs* 2014;70:975–96.
- Seear M, Kapur A, Wensley D, *et al*. The quality of life of home-ventilated children and their primary caregivers plus the associated social and economic burdens: a prospective study. *Arch Dis Child* 2016;101:620–7.
- Edelstein H, Schippke J, Sheffe S, *et al*. Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child Care Health Dev* 2017;43:323–33.
- Brenner M, Connolly M, Cawley D, *et al*. Family and healthcare professionals' perceptions of a pilot hospice at home programme for children: a qualitative study. *BMC Palliat Care* 2016;15:89.
- Mengoni S, Oates J, Bardsley J. *Developing key working*. UK: Council for Disabled Children, 2014.
- Gravdal Kvarme L, Albertini-Früh E, Brekke I, *et al*. On duty all the time: health and quality of life among immigrant parents caring for a child with complex health needs. *J Clin Nurs* 2016;25:362–71.