

Decision making – caring for children with complex needs

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Abstract

As a consequence of advanced technology and enhanced care, increasing numbers of children with complex needs are now surviving. Enshrined in strategic direction for care of children with complex health care needs is that care should be provided in the child's own home as much as possible. Thus, this small but distinct group of children and their families require high intensity care and support from a range of professionals and services. Given that many of the disorders in childhood are rare, the knowledge and skill mix required to provide care for such children can be challenging. This paper uses an example of a child with a rare disorder and associated complex needs with the aim of expanding the knowledge base regarding decision-making around best care for both the child and family. Ethical safeguards were employed to protect the child and family.

In recent years the numbers of children with complex and continuing health care needs have been increasing within the United Kingdom (Kirk, 2008; Hobson and Noyes, 2011). Whilst a relatively small group, these children and their families require a high level of care and support from a wide range of professionals, services and organisations, to ensure their needs are met as much as possible in their own home (Ward et al., 2014).

Liam is a ten month old boy who was diagnosed as having Cardifaciocutaneous (CFC) syndrome at birth. As a direct result of his condition he has ongoing complex health care needs. Liam lives with his parents, Alan and Cora, in a 2 bedroom house. Liam was a much longed for first child. After Liam's birth and his diagnosis, Alan and Cora experienced both emotional and practical chaos

(Price et al., 2011). Alan works away a lot and Cora (who gave up her job after Liam was diagnosed) carries out all Liam's care with input from the community children's nursing team. Close links are maintained with the Paediatrician at the local hospital.

CFC syndrome is a rare genetic condition (present at birth), typically characterised by its effect on the heart (cardio), facial features (facio), skin (cutaneous), resultant learning disability, and feeding difficulties in early life (Contact a family, 2014). As one of the RASopathies CFC bears many clinical features in common with the other syndromes in this group, most notably Noonan syndrome and Costello syndrome (Pierpoint et al., 2014). CFC is classed as an autosomal dominant condition, which means one copy of an altered gene in each cell can

lead to the disorder. CFC usually results from new gene mutations and occurs in people with no history of the disorder in their family. Due to the multi-pathological nature of CFC syndrome, this paper focuses on Liam's feeding problems, particularly gastroesophageal reflux (GER) and faltering growth, alongside the new recently experienced issue of seizures.

Schwartz (2014) state that GER is caused by immature function of the lower oesophageal sphincter, which frequently relaxes, allowing an involuntary retrograde flow of gastric contents into the oesophagus (Mersch, 2014). As a consequence of the increased acid the child can experience persistent vomiting after feeding as well as discomfort in their mouth and throat. Resultant problems are therefore often directly related to poor weight gain and faltering growth (Czinn & Blanchard, 2013). Such problems were evident with Liam as he had not been successfully bottle feeding and had a history of vomiting - subsequently his weight had decreased. A Percutaneous Endoscopic Gastrostomy (PEG) had previously been inserted, essentially bypassing the oesophagus, and feeding directly into the stomach (Marks, 2015). Seizure activity is also a common symptom in CFC syndrome (Armour & Allanson, 2008), caused by a possible delay or absence of myelination in the neural pathways (Aizaki et al

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Acknowledgements

The lead author would like to say a special thank you to clinical colleagues who shared their knowledge so freely with me during placement, and also Cameron Cox and Dr. Jim Richardson for their encouragement and support.

Key words:

Complex needs, decision making,
community, enteral feeding,
evidence based practice

2011). Liam had recently been experiencing seizures.

Whilst decision making is continuous within care planning and provision, the focus here is on a day when both the community nurse and health visitor visited the family home. Providing quality care for Liam and his parents involved a process of identifying problems, setting goals based on an assessment of their needs and making decisions about the plan of care (Nazarko, 2013). Corkin and Cardwell (2011) identify the process of goal setting as devising mutually agreed goals which endeavour to address the child and family problems through nursing care.

These mutually agreed goals involved a partnership approach and included Cora, the health visitor and the community nurse. In developing goals, Wright (2005) proposed that they be SMART: specific, measurable, achievable/agreed, realistic and time - limited. Since Liam's recent failure to gain weight initially prompted the home visit (he had dropped a weight centile due to insufficient bottle feeding), his weight loss and reduced nutritional status was the focus and main goal of care.

The first goal set was specifically regarding the aim of promoting Liam's nutritional status, to be measured through a desired increase in his weight at the next visit in two weeks.

In addition, Liam had experienced a new problem, seizures. The goal here was to maintain Liam's safety during seizures, something also to be reviewed at the next visit. Since Cora was expressing increased anxiety and isolation stemming from both the feeding difficulties and from fearing her son suffered during a seizure, a third goal was set. This was a longer term goal and aimed to reduce Cora's anxiety and isolation through information and support.

Given the goals set, decisions about the plan of care therefore centered around managing Liam's feeding problems and associated weight loss, managing his seizures and addressing associated maternal anxiety. The use of best evidence was employed to inform decisions regarding management of Liam's GER and seizures. The evidence based model

of decision making originally identified by Sackett (2000) involves a tripartite approach which includes best available research evidence, professional expertise and patient preferences/needs. Decision making does not solely incorporate research evidence but is often based on a combination of evidence types (Holland and Rees, 2010). A good example of an evidence based decision using all 3 types of evidence identified by Sackett (2000) related to Liam's feeding problems and associated goal. Research evidence suggests that the use of enteral tube feeding has positive effects on children with complex needs who experience faltering growth, by compensating for nutritional loss (Falconer, 2010; NICE, 2015). In addition, the PEG device is viewed as the most effective means of achieving long term feeding (Braegger et al, 2010; Singh et al, 2013). The experience of the professionals (nursing and dietetics) involved in Liam's care endorsed that long term enteral feeding can enhance quality of life for children with complex health care needs.

Experiences of parents also endorse the relative merit of PEG feeding in addressing feeding problems for children with complex health conditions in childhood, however, they also highlight that the shift from oral feeding to enteral feeding can result in a potential grief reaction within the family given that eating is such a social activity (Hebblewhite, 2012). Such a shift therefore requires support for the family from knowledgeable professionals (Hunt, 2007). Furthermore, Cora felt that increasing PEG feeds was preferable given her worry about Liam's weight loss. Taken in the round, such combined evidence on the effectiveness of enteral feeding drove the decision to increase Liam's nutritional intake through the use of a PEG, whilst reducing his bottle feeds.

Since the Community Nurse visited once every 3 weeks currently, a decision had been made to increase this to once every 2 weeks to provide support to Cora but also to closely monitor how the care being provided was aiding in meeting the goals set. Cora was provided with contact numbers for all the professionals involved if she had any concerns in between that. The evidence underpinning such a decision is a piece of seminal work, which identifies the stress buffering effect of social support - that is,

how knowing support is available even if it is not required helps to buffer some of the stress being experienced (Cohen and Willis, 1985). If upon review at the next visit any of the goals were not being met, a new assessment and further decision making and planning would need to take place (Corkin and Cardwell, 2011).

Whilst the Paediatrician and GP had prescribed pharmacological intervention in the management of these seizures and Cora had reported a significant reduction in seizure activity, she still remained highly anxious about seeing Liam having a seizure - something that parents also identified in a study carried out by Nuutila and Salanterä (2006). A risk assessment indicated that Cora was knowledgeable about the drugs and administration of the same, however, decision making around how to best support her was required. Moreover, it was decided that Cora required some further education around the safety of Liam during her seizure.

Cora indicated that Alan had become involved in Liam's care when he was at home but that he was particularly fearful of the seizures and enteral feeding. Although Alan was away from home a lot it was essential to remember his role and needs, as the unique needs of dads whose children have complex health care needs are often forgotten (Hobson and Noyes, 2011).

Since Liam's condition had deteriorated over recent weeks, they were not able to get out much; Cora described feeling overwhelmed and isolated, something commonly reported by parents of children with complex needs (Price et al., 2011; Whiting, 2014). Decisions had to be made regarding how to best reduce anxiety and stress and increase Cora's confidence when caring for Liam, whilst also attempting to combat the isolation experienced by her. The Council for Disabled Children (2013), state the importance of assisting parent's in becoming the 'expert' in their child's care and building their confidence in caring for their child, this was an important consideration with Liam. However, it was important to be cognisant of the fact that the needs of children such as Liam oscillate between periods of stability and also periods where deterioration is noted, and that regular review and decisions regarding the amount of

parental support required is a necessity (Together for Short Lives, 2013). Evidence suggests that parents who care for children with complex needs become exhausted (Whiting, 2014), however despite exhaustion, reluctance about the uptake of respite is apparent (Brett, 2004; Price et al., 2011). Such parental reluctance is often borne from the difficulty of admitting the need for a break from caring (Price et al., 2011). Cora was indeed reluctant to accept respite at this stage, however she did express a desire to interact with other mothers and so it was decided to initially access community mother and baby groups with the goal of increasing socialisation for her and Liam, and reducing her feelings of isolation (Windle, Francis & Coomber, 2014). Seal (2013) states that hearing the parents' perspective is vital to the success of early intervention; as Cora was the main carer for Liam it was important that her mental health and wellbeing were addressed as this was integral to Liam's care - mother and baby mental health and wellbeing are inextricably linked.

Caring for children with complex needs can raise a plethora of ethical dilemmas that can become apparent at different stages of the child's life trajectory (Teare, 2009). Nurses have a professional responsibility to act in the child's best interests and to that end the Code of Conduct (NMC, 2015) promotes ethical principles which must be applied in practice. Four ethical principles are identified and include autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress, 2009). These however have been contended in children, particularly the principle relating to autonomy. Baines (2007) argues that children are not autonomous, and indeed Liam would not be deemed as autonomous given his age and his cognitive ability. However, the role of parents in relation to autonomy and decision making therefore cannot be understated. Decision-making involving children includes the family unit, usually the parents, and in this

case Cora acted as surrogate decision maker regarding care and consenting to medical treatment (BMA, 2008). Ethical considerations must therefore underpin all decisions made about Liam's care. The main ethical principles that were relevant in the decisions made in terms of weight loss and safety regarding seizures were related to beneficence (to do good) and non-maleficence (to do no harm). In relation to justice, this principle supports the notion that every child has a right regardless of their situation or circumstances. Liam has very specific and ever changing health care needs and whilst he may have a limited lifespan, he has the same right to quality of life and best care as any other child (Together for Short Lives, 2012)

As already alluded to by Sackett (2000), the evidence based model identifies the centrality of the views of other professionals in influencing practice. Further, Casey's (1988) seminal Partnership Model highlights the importance of involving other professionals in the planning and provision of quality care for children and families. Inter-professional decision making involves the collaboration of a range of professionals, to achieve a mutually common goal (Standing, 2014). In keeping with the directive that care for children with CFC should be multi-disciplinary (Pierpoint et al., 2014), a range of professionals were involved in Liam's care at this point in time, including the Health Visitor, Community Nurse, GP, Paediatrician and Dietician. A good example of collaborative decision making in Liam's case was illuminated through the problem he had with feeding and weight loss, as in addition to the Health visitor and nurse, the dietician and GP also inputted into the decision made.

McNeilly and Gilmore (2009) endorse the fact that children with complex needs often have very large and varied teams of professionals working together and that the members of the team may change

in tandem with the child's condition. A range of professionals working together can pose problems, hence Standing (2014) asserts that collaborative decision making is particularly important for those with complex health needs. Parents are central to team functioning, with Smith et al., (2013) stating that expert parents often emerge as manager of their child's care - a role they often feel in supported in. Such a belief was explored in a qualitative study with 47 parents of children with complex health care needs (Miller et al., 2009) with findings indicating that many parents appear to take on the role of co-ordinating their child's care in addition to carrying out the often technical care their child requires. Miller et al. (2009) further recognized that whilst parents had much to offer, some parents did not wish to take on such a role, welcoming the role that a professional key worker played in helping to permit continuity within care planning and provision (Teare, 2009; Together for Short Lives, 2012). In Liam's case, upon discussion it was established that whilst Cora and Alan wanted to be actively involved in their son's care (with necessary support), a collaborative decision was made so that the key worker would be the community nurse. The nurse would co-ordinate care, family support and services, alongside acting as the one point of contact for the family and all professionals involved (Together for Short Lives, 2012).

In conclusion, this paper gave important insights as to how decisions were made regarding the plan of care for Liam and his ever-changing health care needs. Whilst this provided a mere snapshot of decision making at one point in time, the view that decision making is a continuous process cannot be understated, and takes place within the context of the individual child and family needs. The tripartite evidence based decision making model permitted an all-encompassing approach which upheld the imperative of safe, ethical and high-quality care provision for Liam and his family (NMC, 2015).

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