Use of Subcutaneous Fluids in Paediatric Palliative Care: A Case Study

Abstract

Quality of life is a major consideration in paediatric palliative care, particularly at the end of life. Symptom management contributes to this, the ultimate objective being the child's comfort. Hydration is often a part of symptom management but can be difficult and contentious. This article presents a case study outlining the administration of subcutaneous fluids in the hospice environment. It discusses subcutaneous fluids generally, their use in paediatric palliative care, the range of factors requiring careful consideration and the case study of child and family outcomes.

Introduction

Quality of life is a major consideration throughout a child's palliative care journey, none more so than the final days of life (Together for Short Lives 2018). Symptom management is an important component of this and encompasses a wide variety of physical and psychological symptoms. The ultimate aim of symptom management is to ensure that the child is as comfortable as possible (Together for Short Lives 2016). When considering symptom control, careful thought must be given to how a child is hydrated. Hydration must be carefully planned and implemented, as there is a risk of unwanted symptoms such as fluid retention, including peripheral oedema, increased respiratory secretions and pleural effusion (Keeler 2010).

In the paediatric palliative care setting discussions take place to determine parental wishes for end of life care. These discussions include the type of treatment that parents would like to be considered and the preferred place of death (Hoell et al 2018). The place of death can be significant to a parent, and facilitating their wishes

is seen by palliative care staff as an important part of the care pathway (Basu and Swil 2018). The National Institute for Health and Care Excellence Guideline for Managing Hydration and Nutrition in End of Life Care for Infants, Children and Young People (NICE 2016) states that staff should be aware of the significant effect on care that enteral tube and intravenous fluids may have. Where, due to their condition, a child cannot receive fluids orally or via enteral tubes, the options are quite often limited to intravenous therapy. Many children's hospices do not provide intravenous therapy, so the child would need to be transferred to an inpatient hospital environment. This could be in conflict with the expressed wishes of the family. This article discusses a decision to administer subcutaneous fluids to Rosie (pseudonym) at end of life, and describes how this was achieved in the children's hospice setting.

Rosie

Rosie was a child recently admitted to the hospice for end of life care. Her parents had expressed their wish for Rosie to receive hospice based end of life care in her advance care plan. As is often the case in paediatric palliative care the duration of the end of life stage was uncertain (NICE 2016) and this influenced discussions about Rosie's care. Rosie had long term dysphagia associated with her primary condition, and as such, would not tolerate oral fluids. In days prior to admission to the hospice, Rosie had become acutely unwell, with a severe, life threatening gastrointestinal condition. Along with the risk of dehydration, Rosie had been noted to be experiencing increased episodes of myoclonus (involuntary muscle contractions). Dehydration was a likely principle cause of the increased symptoms. Rosie was unable to receive enteral fluids due to her condition so intravenous fluids

would normally be indicated. However, since the hospice does not currently have facilities to provide intravenous fluids, this would have necessitated a return to hospital, conflicting with her parents' wishes. This led to discussions between medical and nursing colleagues about how hydration could be managed. Administration of subcutaneous fluids was considered as a therapeutic trial. Discussion with family included exploration of definable outcomes of receiving the fluids, including possible improvements in symptom control.

Prior to the infusion being commenced, hyaluronidase was used to facilitate the diffusion of the fluids being delivered. Hyaluronidases are enzymes which breakdown hyaluronic acid, an essential part of the extracellular matrix. Therefore they increase tissue permeability and facilitate the absorption of subcutaneous fluids (Weber et al 2019). This was administered through the subcutaneous catheter, immediately prior to the infusion being commenced. The fluids were continued for 48 hours, and from observations recorded, Rosie's myoclonus symptoms had improved following the first 12 hours of the infusion. The infusion site was showing signs of infection after 72 hours, including erythema and warmth to the site. The infusion was discontinued, as it was apparent that Rosie was in the final hours of her life. Rosie died at the hospice, in accordance with her family's wishes.

Subcutaneous fluids

Administration

Indications for use of subcutaneous fluids include dysphagia, hypercalcaemia, nausea and vomiting, myoclonus and assisting sedation. Subcutaneous fluids are administered regularly in the adult palliative care setting, and their use is well

documented (Good et al 2014). Although the subcutaneous route is commonly used for symptom control in paediatric palliative care (Together for Short Lives 2016), there is a dearth of literature to underpin the administration of subcutaneous infusion of fluids in this field. However, there are studies relating to rehydration in acute settings (Kuensting 2011, Marikar et al 2014). In order to facilitate the use of subcutaneous fluids in a children's hospice environment, the guidance for acute paediatric settings (Horeczko 2016) was adapted, applying the principles of hydration rather than rehydration.

The subcutaneous tissue, also referred to as the hypodermis is the deepest layer of skin. It consists of elastic fibres, lymphatic vessels, loose connective tissue, and adipose tissue (Draelos and Pugliese 2011). Functions of this layer include support and cushioning from external force and recirculation of extracellular or interstitial fluid (Peate and Nair 2015). After administration, the fluids are transported to blood or lymph capillaries. The transportation of fluids to the circulatory systems occurs via diffusion and convection (Richter and Jacobsen 2014).

When considering the subcutaneous route versus the use of intravenous fluids, it should be noted that the subcutaneous route of fluid administration, or Hypodermoclysis as it is otherwise known, facilitates slow absorption of the infusion (Richter and Jacobsen 2014). Intravenous fluids are given at a much higher rate, and in larger quantities.

The fluids used for subcutaneous infusions are usually licensed for intravenous infusion only. The fluids used in subcutaneous infusion must therefore be considered as an unlicensed medication, and this should be communicated to the family when gaining consent for the treatment to take place. In such cases, the prescriber must

take responsibility for any adverse effects resulting from its use. Fluids used for subcutaneous infusions include 0.9% Sodium Chloride, which is the usual choice. Factors that can affect the area of administration include the concentration of the fluid used, and the pH of the solution.

The site of administration should be one with an adequate amount of subcutaneous tissue (Specialist Palliative Care Audit and Guidelines Group (SPAGG) 2017). Therefore recommended sites are the abdomen, chest and lateral aspects of the upper arm or thigh. Individual assessment of the site areas should be made as the child's physical condition may influence site choice. Site selection can be difficult in the end of life phase, as the child may have lost weight, so there is a deficit in the available subcutaneous tissue to accommodate an infusion. Rosie's comfort, convenience and safety were also taken into account when assessing the site choice. She was not mobile, so the subcutaneous tissue of her thigh was found to be most appropriate. During the administration process, subcutaneous tissues swell and there is expected to be an indurated area, which will become pink or red. Once the infusion is discontinued, the fluid should be absorbed, and the swelling will reduce. In Rosie's case, only a relatively small amount of fluid was required, but generally, it is recommended that no more than 2 litres of fluid should be infused at any one subcutaneous site. In line with the procedure described in the Royal Marsden Manual of Clinical Nursing Procedures, (Dougherty and Lister 2015), it was determined that the infusion site should be rotated every 24-48 hours to decrease the likelihood of irritation and to optimize absorption. Rosie was already receiving medication for symptom management via the subcutaneous route so care was taken to ensure that the fluid infusion site did not interfere with this.

Consideration was given to using a syringe driver; however this would not deliver the volume of fluid required. A gravity giving set was utilised in this instance (SPAGG 2017). This requires staff to calculate drip rates and be aware of the observations required to ensure that the infusion runs safely. Observations include continuous review of hydration status, and monitoring the child for any infusion or site related complications, (Dougherty and Lister 2015).

Potential Complications

Complications of subcutaneous fluid administration include; pain, bruising, redness and local inflammation. Localised oedema can occur if there is “pooling” of fluids in the tissues surrounding the cannula site. Rosie was already being checked hourly, in line with the hospice’s procedure for subcutaneous medication administration so the site of the subcutaneous fluid cannula was also observed hourly.

Any increase in fluid volume at the end of life can lead to overload of the circulatory system (NICE 2016). This may result in pulmonary oedema, increased respiratory secretions and respiratory distress (Keeler 2010), leading to increased anxiety for both the child and those providing care. Furthermore, increased urine output may distress the child, especially those who are unable to get out of bed and/or access a toilet. This may lead to additional medical intervention, such as use of continence aids and potentially catheterisation which may be poorly tolerated (NICE 2016).

A review of fluid requirements was advised after 24 hours by the prescribing clinician and a decision to continue the infusion was deemed to be in Rosie’s best interests. In total, Rosie received 72 hours of subcutaneous fluids. During the initial stages of

the infusion there were no complications. However when considering further infusions it was noted that oedema had developed around the cannula site, posing the risk of further irritation and infection.

Important Considerations

Discussions about hydration for children receiving end of life care must be held sensitively, between the whole team of professionals providing care and the parents or carers. The wishes of the child must also be taken into consideration. Clinical staff must ensure that all those involved understand the benefits and risks of giving fluids at this time. Other viable alternatives, such as a nasogastric tube or gastrostomy if already in situ, should also be considered. Indications and contraindications for subcutaneous fluids are shown in Table 1 below.

Table 1: Indications and contraindications for subcutaneous fluids	
Indications	Contraindications
Dehydration due to drowsiness due to reversible causes (e.g. infection).	Risk factors for fluid overload and existing ascites, heart failure or peripheral oedema due to hypoalbuminemia
Inability to swallow	Severe renal or hepatic failure
Unsuitable for gastrostomy, nasogastric feeding or other artificial feeding tube	Severe dehydration, shock or any condition requiring the rapid administration of fluid
Symptoms due to dehydration that is not responsive to other treatments (e.g. thirst, intractable vomiting and / or nausea, or severe dry mouth)	Major bleeding or coagulation disorders.
To meet fluid requirements in the short term when oral intake is inadequate	If the patient is imminently dying hydration will not improve survival or symptom management and may increase the risk of distressing respiratory secretions.
Inability to site and maintain intravenous fluids	For medication induced dry mouth
Strong patient (or carer where the patient lacks capacity) informed preference for artificial hydration where there are no contraindications	
Specialist Palliative Care Audit and Guidelines Group [SPAGG] 2017	

Having made a decision to commence subcutaneous fluids, it may be more difficult to withdraw this treatment if it is found not to be beneficial (Keeler 2010). Senior nursing and medical staff, with experience and skill in communicating difficult decisions to parents should be involved at all stages (de Vos et al 2015), particularly when treatment is being withdrawn (Larcher et al 2015).

Support for the team providing care also needs to be considered. There are training implications for the knowledge and skills required to administer subcutaneous fluids, particularly knowledge of indications and contraindications. The staff caring for the child must be an advocate for the child and family, ensuring that any care given is in the best interests of the child at all times.

Ethical principles

The ethical principles of beneficence and non-maleficence are paramount when considering a new treatment at the end of a child's life. Beneficence is the principle of doing good and non-maleficence is the principle of doing no harm (Melia 2014). It can be difficult to find the perfect balance between these two principles, necessitating the consideration of interventions on a case by case basis and frequent monitoring and assessment to ensure that the 'good' initially achieved does not result in consequences which subsequently harm (NICE 2008). The line between both can be very fine and on occasions, although there is some harm this is minimal compared to the positives achieved for the child and family.

The use of subcutaneous fluids can potentially have adverse consequences, as it can be unpleasant, uncomfortable, and at times painful, especially if the child experiences an adverse reaction. It is necessary to balance the benefits and harms that the treatment may cause. In considering the treatment to be administered, the treatment might involve less harm to the patient than would occur were they not to have it. As many treatments involve some pain or discomfort, there has to be an assessment of the degree of harm that may be caused. In considering Rosie's case, it was felt the benefits of administration of subcutaneous fluids outweighed the potential risks. The primary consideration was the risk of dehydration. With no other means of achieving hydration meaning that Rosie could have been admitted to hospital for intravenous fluids, which was not in line with the family's wishes. Also, by providing hydration, it was thought that the painful myoclonus that Rosie was experiencing may improve. This proved to be the case.

Conclusion

This piece presents the case of Rosie, a child nearing the end of her life, who received subcutaneous fluids to counteract dehydration and subsequent myoclonus. Subcutaneous fluid administration is paediatric palliative care is a relatively uncommon practice, and as such there is a paucity of research in this area of care. When caring for children at end of life, it is important to ensure that the wishes of the child and family are met as much as it is practically possible to do so. The choice of place of end of life care, and choice of interventions available can impact on the areas able to accommodate the child (NICE 2016).

In considering the use of subcutaneous fluids, clinicians must be aware of the relative risks and benefits to the child, and how this will impact on the family as a whole. There must be a team approach to the delivery of care at end of life, and education of staff members in the practical and ethical issues must be made available to ensure best interests of the child are met.

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