NURSES' VIEWPOINTS ON GROWTH HORMONE DELIVERY DEVICES

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BACKGROUND

There are a variety of growth hormone delivery devices (GHDD) available to children requiring growth hormone (GH) therapy. Many paediatric endocrine nurses can offer patients and their families a choice of the products that are available, which can sometimes be overwhelming. However, factors such a licensed clinical indications have to be considered, as well as cost.

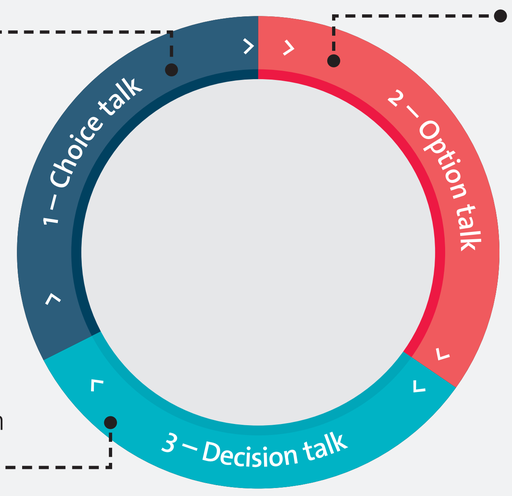
Patient choice for growth hormone devices is well documented in the literature, with regards to compliance (Ahmed et al. 2008, Gau & Takasawa 2017, Kapoor et al. 2008, van Dongen & Kaptein 2012, Wickramasuriya et al. 2006), with onus on the parents and children making the final choice for the delivery of growth hormone.

However, research has shown (Ayyar & George 2016) that involving the health care professional (HCP) within the decision making process can have an influence on the desired GHDD, although the HCP referred to was the prescribing Doctor . The proposed model (Elwyn et al. 2012) is seen below.

SHARED DECISION MAKING MODEL

1 – Choice talk

Parents and children are shown GH devices with no Dr input



2 – Option talk

Discussion is held regarding knowledge, looking at options, pros and cons, and exploring why they have chosen their preferred device, with the Dr explaining reasons for different options

3 – Decision talk

Move to a decision with further information on the device

AIMS

The purpose of this project was to explore whether other factors suggested by paediatric endocrine nurses should be considered when exploring choice of GHDD, within the shared decision making model.

METHODS

Participating nurses (N=10) attended an interactive and detailed training session on all of the GHDD currently available within the UK. Subsequently, each nurse was given a box of marketing materials for each GHDD, including training materials, patient information literature and DVDs. The nurses were given five case study scenarios on different conditions. The scenarios reflected the five licensed indications for GH in children in the UK. The patients were fictional but were representative of the typical complex patient that paediatric endocrine nurses see within the clinic environment. Nurses were advised to work in pairs. In their pairs, the nurses were asked to feed back =on their choice of GHDD, detailing why they had chosen that specific device, utilising a problem based learning approach. Themes were extrapolated using thematic analysis.

CASE STUDY SCENARIOS

TURNERS SYNDROME

Jade is 7 and lives at home with both parents. Mum has learning difficulties and Dad is partially sighted. They are known to social services and receive support. Jade is on the autistic spectrum and has challenging behaviour. She has recently been diagnosed with Turner syndrome. She is to start GH at a dose of 1.5mg daily.

SHOX DEFICIENCY

Neelam is 14 and has recently been diagnosed with SHOX deficiency. She lives with her parents and two younger brothers in a two bedroom flat. Neelam speaks good English and has to translate for her parents at hospital appointments. Neelam is very small for her age – only 138cm and keen to start treatment. She is 38kg.

GROWTH HORMONE DEFICIENCY

Joseph is 6 and the second of four children (youngest sibling is 3 months old). He lives with both parents but Dad works long hours and is often not around at bedtime. Joseph is adamant he will not have injections. His Mum is struggling with the new baby and doesn't have any support from Dad with regards to GH treatment as Dad is on the 2nd centile for adult Male height and doesn't see being small as an issue. The Consultant at the local hospital wants him to start on 0.5mg daily.

PRADER WILLI SYNDROME

Bonnie is 3 years old and lives at home with her Mother, two older siblings and two dogs. Bonnie stays overnight with her Dad for one night every other weekend. Bonnie has been diagnosed with PWS and has been advised to start GH. She weighs 20kg. She has only recently begun walking and prefers to 'bottom shuffle'.

SMALL FOR GESTATIONAL AGE

Arthur is 4 and starting school soon. He has always been small and had failure to thrive in his first year – he remains a picky eater. Mum and Dad are concerned that he looks about 2 and worried he will be picked on at school. They both work full time and have a lot of support from both sets of Grandparents – Arthur frequently goes to stay with his grandparents if Mum and Dad are travelling with work. Arthur has recently had his pre-school vaccinations and reacted very badly to having the injections. Mum is very concerned about how Arthur is going to manage having GH every day. He is to start on 0.3mg daily.

RESULTS

Nurses had a variety of devices to choose from (N=11): three groups had chosen different devices (N=3) apart from two groups had chosen the same device. Influencing themes that emerged included: knowledge of patients learning difficulties, social and housing implications, child's body composition, child friendly device design, and ease of use. Cost was also discussed, but was not the deciding factor for a final decision.

RESULTS – THEMES

Theme	Influencing factors	Aspect of GH device
Child	- Fear of needles - Learning disability - Body composition: - SGA ↓ body fat - PWS ↑ body fat	- Ease of use - Needle length - Smaller needle - Hidden needle
Parent	- Learning disability - Partially sighted - Language barrier	- Audible sounds - No reconstitution - Simple cartridge replacement - Pre set dose - Adherence monitoring - Translated instructions
Social and housing	- Parents work full time - Grandparents main carers - Living in different home /split family	- No need to refrigerate - Ease of use - No reconstitution - Pre set dose

GROWTH HORMONE DELIVERY DEVICES

CONCLUSIONS

Themes that emerged from the study demonstrate that the nurses' clinical judgement and prior knowledge of the patient's needs is an intrinsic factor to consider when implementing patient choice in GHDD.

CLINICAL IMPLICATIONS

Further research needs to be conducted on a larger scale to examine nurses' thoughts and opinions on the different GHDDs available, and the need to remain conscious of underlying issues which may not be obvious or apparent to the child and family. From this, a reduced number of choice of devices can therefore be demonstrated to children and their families, thereby giving the nurse more time to focus on the most appropriate devices. Implementation of the shared decision making model utilizing paediatric endocrine nurses, and not necessarily the prescribing doctor, is suggested to be used within the GHDD choice process.

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FOR FURTHER INFORMATION

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