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Mothers' Experiences of Caring for Children Receiving Growth Hormone Treatment

Rasha Alsaigh, PhD, RN, BSN, MSc, Dr [a,*], Imelda Coyne, PhD, MA, BSc, RNT, RGN, RSCN, FEANS, FTCD [b]

[a] *College of Nursing, Department of Maternity and Child Nursing, King Abdulaziz University, Jeddah, Saudi Arabia*
[b] *School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland*

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ABSTRACT

Purpose: To achieve understanding of the meanings of mothers' experiences of caring for children receiving growth hormone treatment (GHT).
Background: Children generally begin GHT at a very early age which means parents have significant responsibilities and often endure a complex and difficult pathway with GHT.
Design and methods: Hermeneutic interpretive phenomenology based on the approach of Gadamer that adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines. See Supplementary File 1. Data collected through interviews and diaries with mothers (n = 16).
Results: Mothers' experiences were framed by three concepts: uncertainty, normalisation and stigma. These concepts were used to elaborate on the four major meanings encapsulating their experience of caring for their children receiving GHT: (1) “It's the right thing to do” (Striving for the security and the wellbeing of the child), (2) “Doubting yourself constantly” (Constant uncertainty), (3) “But then you just get used to it I suppose” (Adhering to GHT and lifestyle changes - the new normal), (4) “I hadn't been told anything about it” (Information behaviour; looking for normality and certainty).
Conclusion: Mothers experienced significant challenges coping with the uncertainties associated with GHT and needed more information and support. The felt stigma of restricted growth, rare medical condition and GHT appeared to hinder some mothers from seeking support. Practice Implications: Healthcare professionals and policy makers need to ensure that services for children receiving GHT include the necessary continuous practical and emotional support for parents along the treatment journey.

Introduction

The last five decades have seen a rapid expansion in the number of children needing growth hormone treatment (GHT), a ‘biosynthetic’ growth hormone that is a metabolically active hormone that affects multiple organ systems which aims to normalise growth to achieve a normal height in early childhood (Kirk, 2012). GHT aims to treat growth failure that causes height deficit and increase height in early childhood by normalising growth velocities and then preserving a growth pattern that is suitable for age and gender and permits a final height that is within the genetic target range (Kappelgaard & Laursen, 2011). Growth hormone deficiency (GHD) remains the main indication for GHT in children and can be idiopathic or due to congenital or acquired causes. Acquired causes include trauma, infiltrations, tumour or radiation therapy. The congenital arises either as a result of anomalies in the pituitary GH-producing cells or in the hypothalamus, sometimes associated with genetic mutations. Despite the large number of organic and acquired aetiologies, there are GH deficient children who have “idiopathic” GH deficiency (Audi, Fernández-Cancio, Camats, & Carrascosa, 2013; Kirk, 2012; National Institute of Health and Care Excellence, 2010).

GHT is approved in the USA and Europe for non-GH paediatric conditions associated with severe short stature, including, Turner syndrome (TS), small for gestational age (SGA) with failure to catch-up, Russell Silver syndrome (RSS), Prader-Willi syndrome (PWS), short stature homeobox-containing gene (SHOX) deficiency, chronic renal insufficiency (CRI), and Noonan syndrome (NS). Idiopathic short stature (ISS) is approved as a diagnostic indication for GHT only in the USA (Cappa, Iughetti, Loche, Maghnie, & Vottero, 2016; Kirk, 2012; Van Dongen & Kaptein, 2012). GHT is usually prescribed when the condition is associated with growth failure or severe short stature is diagnosed or height velocity falls below the normal level (Kirk, 2012). GHT is also used in PWS to treat the concomitant GH deficiency associated with the condition, which improves body composition, bone density and cardiovascular risk including to improve respiratory function, behaviour, socialisation, and self-esteem (Kirk, 2012).

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[*] Corresponding author at: School of Nursing and Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2, Ireland.
E-mail addresses: ralsaigh@kau.edu.sa (R. Alsaigh), coynei@tcd.ie (I. Coyne).

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Growth hormone treatment in childhood is considered safe, with serious adverse events rarely reported (Sävendahl et al., 2012). However, evidence of conditions such as pancreatitis, benign intracranial hypertension, worsening of scoliosis, and slipped capital femoral epiphysis has been reported in small samples of patients (Darendeliler, Karagiannis, & Wilton, 2007). These adverse effects may occur at any time during treatment, and are usually associated with treatment initiation or dose changes. National Institute of Health and Care Excellence (2010) guideline advise paediatricians to pay particular attention when prescribing GHT to children with diabetes mellitus or its risk factors, slipped capital epiphyses, idiopathic intracranial hypertension or malignancies. Although the average age at diagnosis is usually older, many children commence GHT around 2 years of age which means parents have to assume responsibility for nightly GHT injection administration from early childhood (Kaptein, 2013; Van Dongen & Kaptein, 2012).

Background

Parental concerns can influence the decision-making process and increase both referrals to specialists, prescribing of GHT by endocrinologists and affect parents' acceptance of treatment recommendations (Cousounis, Lipman, Ginsburg, & Grimberg, 2013). Parental concerns about child growth and parental perception of GHT efficacy, benefits, side effects, child health and psychosocial function influence parents' decision to start GHT (Grimberg, Cousounis, Cucchiara, Lipman, & Ginsburg, 2015) and influence their acceptance and adherence to GHT (Van Dongen & Kaptein, 2012).

Few studies have examined parents' views of providing GHT and the associated treatment burden (Van Dongen & Kaptein, 2012). Parents perceive GHT injections to be painful and this was predictive of non-adherence for children, but not for adult patients on GHT (Kremidas et al., 2013; Rosenfeld & Bakker, 2008). Kremidas et al. (2013) also found that although parents knew the significance of adherence they still missed more than one injection a month. Younger children may need more help from their parents/caregivers to inject (Kaptein, 2013) and poor adherence by children may reflect parental lack of understanding of the treatment (Rohrer, Horikawa, & Kappelgaard, 2017). Parents' worries about potential side effects, lack of reassurance and being ill-informed about side effects could lead to decreased adherence by parents (Marini et al., 2016). Unfortunately, a lack of adherence to GHT is still reported (Van Dongen & Kaptein, 2012).

Studies conducted in Europe and USA, revealed that denying parents a choice in type of GHT device that best suited their needs, and inadequate support or reassurance about side effects affected GHT adherence (Brod et al., 2017; Kremidas et al., 2013; Marini et al., 2016; Van Dongen & Kaptein, 2012). These studies noted that parents faced numerous organisational and technical difficulties including medication preparation, administration and storage. Additionally, GHT could interfere with parents' daily and social life in relation to travel arrangements and the length of time for injection preparation (Brod et al., 2017). Often parents feel guilty, sad, frustrated, worried and anxious about causing pain to their child while administering GHT (Brod et al., 2017; Lagrou et al., 2008; Van Dongen & Kaptein, 2012). Furthermore parents may be challenged with refusal and intolerance amongst adolescents (Marini et al., 2016; Van Dongen & Kaptein, 2012).

Van Dongen and Kaptein (2012) identified a need for support and participation of parents in choosing a GH device. Similarly, a Swiss study examining parents' preference for GH injection devices found that parents were willing to pay for device features facilitating ease of use (Meinhardt, Eiholzer, Seitz, Bøgelund, & Kappelgaard, 2014). It has also been reported that parents welcome training to support self-administration, and support from parents with experience of administering GHT. Parents desired their doctor's support, and psychological support to overcome their children's anxiety towards injections and their adolescents' reluctance and unwillingness to accept GHT (Van Dongen & Kaptein, 2012). Parents preferred more flexibility with storage requirements and wished to be able to store GHT outside the fridge for longer periods of time. In addition to storage requirements, reconstitution of GHT before use was found to be inconvenient and burdensome (Kremidas et al., 2013).

Kremidas et al. (2013) suggested that a better appreciation of parent administration practices of GH and inconvenience accompanying the use of GHT products will help educate health care professionals and potentially improve patient education and training. A better understanding of real-world administration practices would help nurses recognise areas of need in relation to patient education and training (Bhosle, Klingman, Aagren, Wisniewski, & Lee, 2011). A fundamental part of the role of paediatric endocrine nurse specialist (PENS) is to maintain long-term relationships with families and this relationship is strengthened by recognising and respecting the developing expertise of families as they gain confidence and competence to manage GHT (Collin, Whitehead, & Walker, 2016).

While results from previous studies provide valuable information for healthcare providers, they leave the lifeworld of the parent that consists of emotional, psychological, psychosocial, practical and taken-for-granted dimensions largely unexplored, thus leaving a knowledge deficit justifying the scope of the present study.

Methods

Theoretical framework

This qualitative study was guided by the philosophy of hermeneutic phenomenology, based on Gadamer's hermeneutics (1975). Gadamer's version of hermeneutics is that, firstly, our own preconceptions are fragments of our individual linguistic experience which makes understanding likely, and secondly, people who express themselves, and those that understand them are connected by human consciousness - 'universality' a 'fusion of horizons' - which makes understanding conceivable (Morse, 1994). The fusion of horizons and the hermeneutic circle consequently play a vital role in hermeneutic philosophy, and Gadamer considers interpretation as a fusion of horizons, a dialectical interaction between the pre-understandings of the interpreter and the meaning of the text (Polkinghorne, 1983).

Ethical approval

Ethical approval was obtained from the University Faculty Ethics Committee and three children's hospitals in Ireland. Ethical approval was also obtained to recruit from four support organisations: Major Aspects of Growth in Children (MAGIC) Foundation, Prader-Willi Syndrome Association Ireland (PWSAI), Turner Contact Group Ireland (TCGI) and Child Growth Foundation (CGF).

Sample and recruitment

Sampling in phenomenology is usually via snowball and purposeful method (Kleiman, 2004). Therefore, purposeful sampling was used to recruit parents who met the criteria of being older than 18 years with a child aged 2 to 18 years receiving daily GH injection for at least 6 months. Since no registry for GH treated children exists in Ireland (Hawkes & O'Connell, 2016), the sample was recruited from the three major paediatric endocrinology clinics from three children's hospitals to maximise recruitment. Gatekeepers distributed information packs to parents of children attending the clinics and displayed study posters at the clinics. To increase recruitment rate, potential participants were invited to the study through four support organisations that distributed invitation emails to all parents living in Ireland and advertised the study on their websites. The recruitment phase lasted 13 months and although both mothers and fathers were invited, only 16 mothers from

Table 1
Geographical location of the sample.

Geographic location in Ireland	Number
Co Cork	4
Co Dublin	7
Co Galway	1
Co Mayo	1
Co Meath	1
Co Sligo	1
Co Wicklow	1

Ireland agreed to participate (see Table 1 for the geographical location of the sample).

The mothers were caring for children receiving GHT for conditions including growth hormone deficiency (GHD), Prader Willi syndrome (PWS), Russell Silver syndrome (RSS), small for gestational age (SGA) and Turners syndrome (TS). Most were receiving GHT for growth failure and to improve short stature. However, in the cases of PWS, the treatment was to improve muscle strength, maintain normal body weight, prevent obesity and improve short stature. The mothers were mostly stay at home carers although some were professionals and were caring for more than one child. Thus, the length of time caring for a child with GHT ranged from six months to eight years. So, the sample provided a wide range of experiences (see Table 2).

Data collection

Data were collected through in-depth face-to-face interviews ($n = 16$) and diaries ($n = 8$). Mothers were interviewed by the first author (RA) at a location of their choice and the interviews lasted from 40 to 60 min. All interviews started with an open question 'Tell me about your experience caring for your child receiving GHT' and then probing questions followed. Eight of the 16 mothers completed diaries and posted them to the first author (RA).

Data analysis

Data were analysed using an analytical framework modified from Fleming, Gaidys, and Robb (2003) and Ajjawi and Higgs (2007) (see Table 3) based on the philosophical concepts of Gadamer's (1975) hermeneutics (pre-understandings, hermeneutic circle and fusion of horizons). This framework offered a template for analysing Gadamerian-underpinned research covering the main concepts of Gadamer's philosophy. The data were analysed by the first author (RA) and rechecked by the second author (IC).

Initial understanding of dialogue with participants was gained through organising the text via transcribing recorded interviews and diaries. Further understanding was gained through iterative reading of the text and listening to the recordings of the interviews resulting in a preliminary interpretation of the whole text. Then with the assistance of Nvivo 11 to manage the data, first order constructs were identified (participant's ideas expressed in their own words- participant's horizon) composing open codes, followed by second order constructs (researchers' theoretical and personal knowledge- researcher's horizon) creating categories. Then, subcategories under these categories were generated manually. Subsequently, the core categories and subcategories were grouped manually into sub-themes followed by the synthesis and theme development phase where grouping of sub-themes into themes was initiated. Themes were then further elaborated and related to the meaning of the whole text. This movement from the parts back to the whole is the core of the hermeneutic circle (Gadamer, 1975). When articulating the themes, the question put to the text concerned meanings of caring for a child receiving GHT. Themes were constantly being challenged by the first author (RA) and in turn challenged by her pre-understandings. This was followed by the illumination and illustration of phenomena phase where the literature was linked to the themes identified, and interpretations were reconstructed into stories ending with a fusion of horizons. Field notes and continuous reflexivity were used throughout data collection and analysis. The study adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines (see Supplementary File 1).

Results

Mothers' experiences of caring for their child receiving GHT were framed by three concepts: uncertainty, normalisation and stigma which underpinned the four major themes and associated subthemes (see Table 4 which outlines the main concepts, themes, subthemes and additional quotes).

Theme 1: "It's the right thing to do" striving for the security and the wellbeing of the child

Mothers expressed a great sense of parental duty towards protecting their children which was their main concern. This concept of being a 'good' parent could be detected in accounts spanning prenatal, infancy and childhood through to the potential future of their children when they reach adulthood. Prior to starting GHT, mothers were constantly trying to help their children maintain a normal life and meet the challenges due to being different.

Table 2
Description of the sample.

Mothers names (pseudonyms used)	Age	Occupation	Number of children	Child's gender	Child's age	Duration on GHT	Condition
Francis	51	Child minder	3	M	11 years old	2 years and 9 months	GHD
Sandra	44	Nurse	5	M	12 years old	1 year	GHD
Joan	40	Home parent-PhD	2	M	12 years old	8 years and 4 months	PWS
Rose	39	Home parent (Cardiac physiologist by training)	3	M	8 years old	2 years and 3 months	GHD
Emma	NA	Nurse	3	M	9 years old	5 months	RSS
Michelle	NA	Photographer	1	M	8 years and 3 months old	7 years	PWS
Berny	43	Special Needs Instructor	1	F	5 years old	8 months	TS
Steph	51	Home parent (Non-practicing engineer)	3	M	6 years old and 9 months old	2 years and 7 months	RSS
Liz	NA	Home parent	1	M	4 years old and 11 months	4 years	GHD
Louise	46	Home parent (Non-practicing solicitor)	4	M	5 years old	4 years	PWS
Mary	51	Marketing Consultant	3	F	11 years old	6 years	TS
Nora	NA	Home parent	2	F	6 years old	8 months	SGA
Bridget	41	Home parent	3	M	10 years old	1 year and a half	GHD
Loran	38	Home parent	5	M	9 years old	1 year	GHD
Kelly	55	Home parent	3	F	≥ 13 years old	1 year	PWS
Loretta	42	Midwife	4	M	8 years old	2 years and 2 months	GHD

GHD: Growth Hormone Deficiency ($n = 7$); PWS: Prader-Willi Syndrome ($n = 4$); RSS: Russel Silver Syndrome ($n = 2$); SGA: Small for Gestational Age ($n = 1$); TS: Turner Syndrome ($n = 2$).

Table 3
Used analytical framework modified from Fleming et al. (2003) and Ajjawi and Higgs (2007).

	Step 1	Step 2	Step 3	Step 4					Step 5
Fleming et al. (2003)	Appropriate open research question	Identification of Pre-understandings	Gaining understanding through dialogue with participants	Gaining understanding through dialogue with text (hermeneutic circle and fusion of horizons)					Establishing trustworthiness
Ajjawi & Higgs (2007)				Analytical Stages					
			Stage 1	**Stage2**	**Stage 3**	**Stage 4**	**Stage 5**	**Stage 6**	
			Immersion	Understanding	Abstraction	Synthesis and theme development	Illumination and illustration of phenomena	Integration and critique	
Steps followed	Choosing an appropriate open research question	Identification of Pre-understandings	Gaining understanding through dialogue with participants (interviews and diaries)	Transcribing/ Iterative reading/ Preliminary interpretation of texts to facilitate coding	Identifying first order (participant) constructs/ Identifying the researcher's horizon	Meshing the horizons/ Themes are developed and challenged by the researcher	Linking the literature to the themes identified/ Reconstructing stories	Critique of the themes/ Reporting final interpretation (fusion of horizons)	Establishing trustworthiness
Step	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**

Subthemes

Mothers' duty to protect

As early as the prenatal stage, mothers noted differences that could potentially affect their children's health. As their children developed, mothers tried to maintain and protect their children's physical and emotional wellbeing.

Advocating for the child

Mothers felt obliged to advocate for their children's medical needs and tried to play a significant role in the attempt to find a diagnosis and seek answers to the lack of growth or other health manifestations displayed by their children.

Decision to start GHT/normalising GHT

Mothers strongly invested hope that GHT would enable their children to 'fit in' by normalising their function and appearance. They hoped that GHT would aid growth, normal development as well as enhance their children's emotional well-being long-term. Mothers often claimed to understand their children's inner emotions, making direct connections between a child's negative self-image and the power of GHT to enhance the child's confidence and sense of well-being. There was an assumption that GHT which aimed to 'normalise' a child's function/appearance and enhance their self-esteem would enable the child to fit more easily into society. It was comforting to mothers that such 'normalising' could provide their children with a degree of protection from anticipated social stigma and this belief sustained them during the treatment course. Mothers stressed their belief that the end results justified the costs involved and that they had done the 'right' thing in sanctioning GHT for their child.

Adapting and being sensitive to the child's needs

Mothers constantly tried to adapt as a result of being sensitive to their children's needs. When children refused to take the injection, they turned to mostly self-discovered ways that proved to help. They constantly reminded their children of the benefits and the consequences of not adhering to the regimen. They tried to adapt to how and when to inject their children and respected their wishes to minimise or avoid distressing them. Sometimes they considered the risk of distress, pain, and social isolation and balanced this against the benefits to the children's emotional well-being.

Continuity of GHT as a source of wellbeing

Observing the benefits of GHT appeared to help mothers and children to be more positive about the future. After much doubt, physical and psychosocial improvements reassured many mothers that they had made the right decision to start GHT.

Future well-being of the child

Mothers expressed great concerns about their children's future wellbeing and worried about side effects that could appear at a later stage. They worried about their children being capable of adapting to the treatment regimen independently when they reached an age where they would have to take full responsibility for their treatment. Mothers often questioned their children's quality of life as young adults receiving GHT. They also expressed feeling uneasy about the

Table 4
An overview of the main concepts, themes and subthemes outlining the mothers' experiences with quotes.

Concept	Theme (meaning)	Subthemes	Quote
Normalisation Stigma	"It's the right thing to do" Striving for the Security and the Wellbeing of the Child	Mothers' duty to protect	Shortly before [Ryan] started school a teacher in school (he would have been 4 when this comment was made) "Ah look at him he looks like he should be in a buggy with a dody (pacifier) in his mouth"! Then the shock when I told her his age and that I hoped he hadn't heard her say that. She didn't mean it in a mean way but it was still hard to hear (Rose's diary). As he got older other boys and girls commented about his height. This always annoyed me especially older people saying things. In my mind they should have more sense. I remember once I told the person that he wasn't deaf. I knew once they went by he would ask why did they say that he was very small. I would always say to him that they said he was getting tall. I felt very protective (Francis).
Uncertainty Normalisation		Advocating for the child	I kept pointing it out to her, but because he was low on the growth scale, he's a little bit on the small side and it wasn't until he was four… and I said, "He's small, he isn't growing. His feet don't grow, his nails don't grow. Nothing grows. He never has a haircut." and she (paediatrician) said, "No that's perfectly normal." (Loran). The Endocrinologist was moving towards a decision to discharge [Ryan] from their care. This was so difficult as I knew in my heart there was a problem and to know that he wouldn't be helped was so difficult. I had to fight for another appointment and was made to feel so over the top for asking for this… Thank goodness I did push for another appointment as it was at his next appointment a year later that I met with a different consultant and had a completely different experience. He decided at that appointment that we need to do stimulation test for GHD (as Ryan's growth rate had dropped significantly as he had fallen very low on growth chart) (Rose's diary).
Normalisation Stigma		Decision to start GHT/normalising GHT	So we had discussed it quite a lot and discussed it with our own families and there was a lot of mixed feelings about it, but we both felt that it would benefit her in the long run and we'd give it a go and if it didn't work out, then maybe after six months or a year that we'd stop doing them, but there was a lot of people suggesting that she doesn't need them. There's nothing wrong with being small and all that. It was hard, but we just said we're the parents and we're going to decide… There was family, sister, father, your mum. There was people, but I think everyone was, "Ah, she doesn't really need." and people say, "If that was my daughter I wouldn't give it to her." but it's very hard when it's you have to make that decision and you have to think the benefits (Berny). I felt it was the right thing to do for him… it was only a narrow window in which to start and I said I think he'll appreciate it when he's older (Emma).
Normalisation		Adapting and being sensitive to the child's needs	Now the fact that we've been told by the nurse now that she can skip a day, you can skip a night. We skipped our first night only about a month ago when she had a sleepover because she was going to her friend's house at 3 o'clock in the day and it would have been awkward for me to come in and she didn't want it in the fridge, she doesn't want her friends knowing about it (Mary). So I've actually changed my procedure now and I wait until he's asleep and I go up to bed and I'll do the jab then because it's just easier for all of us (Michelle).
Stigma Normalisation Uncertainty		The continuity of GHT as a source of wellbeing	When people stopped speaking to him like a baby that was huge. His image changed. Everything about himself changed and now after spending three or four years on growth hormones he is typical of average size… For a long time he was called stumpy. These are all the little labels that were attached to him because of his height and now he has grown out of all these labels and he's delighted and he's quite proud that he gets injections. He's quite confident about the whole experience (Loran).
Normalisation Stigma Uncertainty		The future well-being of the child	I was afraid of premature puberty, I know and then I was going, "Oh god will there be an impotence or a fertility issue in years to come?"… Me as a mother, I suppose my big thing really is that I hope to god that in years to come there isn't a side effect (Loretta). I think once he gets to a certain level and maybe his growth might plateau, I'm not sure if he will be as happy about it. I think the teenage years might be hard because I think they get to a certain level and it's like a maintenance dose then. When the plates fuse, I think that might be the, "I don't need this anymore." I will just have to deal with that when I get there (Liz).
Uncertainty	"Doubting yourself constantly" Constant Uncertainty	Diagnostic uncertainty	He said we will weigh him but my doctor is laid back, had a measuring tape laid out like this. I said you don't want to be very accurate you know it wasn't very accurate he laughed I said when you are going through this every mm counts so at least the hospital one was perfect a said would you not try and get and he said I have one but just never put on the wall surgery probably too busy and then he has a family of his own so he is probably up you know between work and kids so yeah he just measured him and he had an old scales like my own bathroom one would probably be better you know and I was saying same thing every ounce counts (Francis). First time I approached a GP about my concerns he was completely dismissive. I felt stupid for thinking there was a problem and then relieved at the time that he must be ok as GP had said he was fine (in hindsight I know he never measured his height correctly). Down the line I felt really annoyed at this experience as all it served to do was to delay getting a referral to an endocrinologist when I again knew there was definitely something wrong (Rose's diary).

(continued on next page)

Table 4 (*continued*)

Concept	Theme (meaning)	Subthemes	Quote
Uncertainty		Treatment uncertainty	The growth hormone started pretty much after his fourth birthday. We were hoping to try and get growth hormone earlier because in the States you can have growth hormone earlier, but we were told under no circumstances in the UK and Ireland could you have growth hormone until four years old… Well I was frustrated because the majority of information that I was seeing was from America and very positive stories about kids. Either failure to thrive or Russell-Silver or SGA or whatever, they were all doing very well on growth hormone and I could see this child, who even at that stage was falling behind his peers. So it was frustrating, but at the end of the day we had what we had (Steph). It should work, but it may not. Some people it doesn't work on. So it's kind of knowing, is this nightly injection actually going to benefit her at all or is just going to, we won't know. We'll never know really (Berny).
Uncertainty Normalisation		Future uncertainty	What I think is going to be hard is when they're a young adult. I think when they're 17 to 23, just thinking about if there's a Scout camp or you're in college and you don't plan to come home and they decide, "Actually, let's go out straightaway from college." Those kind of flexible things, I don't know how all those things will be. I think that will be really hard. So I am hoping it won't be daily by then. That's wishful thinking (Bridget). She (the child) asks how long more do I have to be on it? I suppose I don't really know. I know that she'll be on it for a couple more years, but as to what that timeframe is, I don't really know (Mary).
Normalisation Uncertainty	"But then you just get used to it I suppose" Adhering to GHT and Lifestyle Changes - the new normal	Managing GHT injections	There was an ad for a smaller size and I was like, "Why is he not getting those smaller ones?" So I just rang up the-, I think I rang up the [drug company] nurse and said, "Can we not get a smaller needle?" and she said, "Oh yes, we'll order them for you?" and there was no pain then… Actually, I have to admit I tried poking myself with the needle as well just to see what it was like because I know if I do it a certain way it doesn't hurt. So it's just the technique, it's up to the technique whether it hurts or not. (Liz). It was terrible jabbing him with a needle…he had no meat on him, and he was very skinny so we kind of tried to pinch around (Francis).
Normalisation Stigma		Lifestyle adjustments	After (soap programme) it's time for the needle. So she's like, "The needle." If I'm on the phone or just reading or whatever, "The needle."… She went to stay with her dad and they forgot to take it one night. I've never forgotten to give her it, ever (Kelly). I find that part of it a pain in the neck because say as an example, Monday is the day I work. My husband has to go to his mother's in the evening because she collects them from school. He has to remember to take it out of the fridge ten minutes before he leaves the house. You can't send it in the schoolbag because it can't be out of the fridge that long or if you forget it and leave it in the mother's house (Emma). I find the prescription is an absolute nightmare because I'm always without it and I'm always chasing my tail trying to make sure because they're a special license it's a bit of a disaster… the writing on the form has to be exact. If they do a spelling error it's turned down and I'm like, "My son needs his medication. We don't have time for spelling mistakes,"… Then getting rid of the needles is a nightmare. How that works I don't even know. We have a sharps container and if I want to get rid of it I have to give two weeks' notice. Then, when you bring it down if it's not full enough I'm in trouble and I'm like, "I don't know how I know when it's two weeks away." I have to go down to the clinic and the chemist can exchange it for the needle exchange if [Leo] was on heroine, if he was a drug addict, but he's not a drug addict he's a growth hormone user and for that reason he's not allowed to take them. So you have to go to the clinic and sometimes when you go they don't have a replacement container, which means you're holding the needles separate to your own waste. It's ridiculous. It doesn't make sense… So that's a nightmare and then the labelling has to be exact. So therefore, my thought is the containers should come pre-labelled and I can just fill in the details. She won't take hand written labels, they have to be printed. I don't just have printed labels. Maybe it's just our person is awkward, but why does no one think of these things (Loran). That's the only thing, nobody else will do the injections. We haven't had a night away from [Nancy] really because nobody wants to help us out. They're all a bit icky when it comes to it … My mum would be the person Nancy would stay with every so often, but she doesn't want anything to do with it. She's happy with it all she thinks it's great, but she doesn't want to be the mean granny giving her grandchild an injection. So that's how she feels about it (Nora).
Uncertainty		Attending endocrine follow up appointments	Small things like the three of us were sitting in her office and she said to us, "So what's the problem with [Bill]?" Now, he was six let's say. So in my opinion, definitely old enough that that kind of thing isn't acceptable to say that. I was the one to say, "Maybe husband and Bill could go outside the door for this part or something." So I didn't think she was very sensitive to him and when she sent us the referral letter afterwards, her report letter, she got his name wrong and called him Ben. His name is Bill. Again, I know it's a very small thing, but it's like she didn't bother (Bridget). The first doctor I met, his comment was that, "We have children in here a lot smaller than him." So again, I felt really stupid and I'm bringing my child just because he's a little bit small or whatever… the other doctor I got was very good and he was really-, a completely different experience with him. It just makes such

Table 4 (*continued*)

Concept	Theme (meaning)	Subthemes	Quote
			a difference who you get to deal with. Because with something like this when you're doubting yourself constantly because you're thinking, "Am I just being over the top? I don't want to go and get my kid treatment for something that he doesn't need." (Rose). The consultant is very busy and I always get the impression that she deals with much sicker people than our son and I always get the feeling that she's saying, "You don't know what real sickness is, don't waste my time." She's nice, but I think we're a small problem compared to other things (Bridget).
Uncertainty Normalisation		Vigilance to treatment side effects and positive outcomes.	He just didn't seem well in himself. I know his growth rate had slowed a little bit and I had looked into the dose he should be on based on his weight and I knew he was in the next weight range up when I'd looked into it and he [endocrinologist A] wasn't upping his dose at all and he's doing fine and blah, blah, blah, very dismissive. I felt again I had to push things. I said, "Look, he's in the next weight range. I find he's just not doing great in himself, I find [Ryan] can get quite tired and different things as well." Very dismissively he said, "It just affects growth so, he shouldn't have any other symptoms." which is ridiculous really. If it just affects growth, my logic is then why do we have it as adults? I know it's minimal, but we still have it in adults because it fulfils other functions right (Rose). When he feels unwell, I worry is it something to do with his treatment. It is something we will always do as mothers of children with unusual medical condition (Francis's diary).
Normalisation Uncertainty	"I hadn't been told anything about it" Information Behaviour; looking for normality and certainty	Information needs	I hadn't been told anything about it, it was just being thrown at me, "Consider growth hormone." So I was looking it up on Google, which was a disaster and seeing how movie stars were taking it, like Sylvester Stallone and [Kim's] weight continued to escalate… [endocrinologist] was encouraging me to go for it, but I felt because I didn't know anything about it… [endocrinologist] did ask me afterwards, what was my biggest fear. It was that she'd die if she took it… I was ignorant about it. That was the real reason. I don't think it's explained enough (Kelly). I felt I had no support and I'm confident that he's getting injections and he's growing, but I am really unaware of potential future affects and that worries me. I'm not going to think on it because if I stop the injections he'll stop growing. Do they stop growing? I don't know. If he doesn't get them, does his body now produce growth hormones? I don't know. Do they ever review the stim test? I don't know. When I ask they say, "He'll be taking these until he's 17 or 18." If his body used to produce growth hormones and stopped producing them, why did it stop producing them and is it impossible for it to start producing them again? I don't know (Loran).
Normalisation Stigma Uncertainty		Seeking and sharing information	I haven't met another parent. I suppose there's still probably a bit of a taboo about it (GHT) maybe. I don't know, maybe it's just very uncommon, I have never heard of any other kid that's on it, but then I suppose maybe they are and you just don't hear about it. I think maybe there is a bit of a-, it's not a spoken about thing. It's funny, my mother, when he was diagnosed she was saying, "Am I to tell people or is a secret?" and I was thinking, "Why would it be a secret?" If he was diabetic you'd say, "Oh god, my grandson has just been diagnosed with diabetes." If he was asthmatic. So that was her generation and she was saying, "I hope you don't mind now, but I did say to-." I said, "Tell anybody, I have no issue."(Sandra). Maybe have a meeting for the parents with other parents … because there's nothing like talking to somebody else who's in the same boat as yourself (Kelly).
Normalisation Stigma Uncertainty		Need for support	The physical side of support with using the device, choosing the device, I thought the physical side of it was fantastic and the support regarding the medical side of things but I guess the emotional aspect of it, I felt I was on my own completely (Nora). I feel like the doctors are good at analysing what's wrong with the child and prescribing the medication, but after that it's up to you as a parent, as a caregiver to do the research and know what you're doing and how you're doing it and you have to advocate for your child a lot (Liz). Other parents have sometimes helped us out. We've got the name from [support organisation] other parents who are on growth hormone as well. So that's very useful as well to have a community of growth hormone parents that can help each other out (Louise).

uncertainty surrounding the continuity of their children's healthcare as they enter adulthood and transition to adult services.

Theme 2: "Doubting yourself constantly" constant uncertainty

This theme encompasses the numerous areas of uncertainties that appeared highly significant to mothers. Mothers expressed many doubts around their journey of reaching a definite diagnosis. Their uncertainties continued as they decided to start their children on GHT and thereafter. They also expressed unknowingness around future matters in relation to their children's well-being with or without GHT.

Subthemes

Diagnostic uncertainty

Mothers encountered many uncertainties in their journey to obtain a final diagnosis for their children. Uncertainties in noting a growth problem were apparent with regard to symptom patterns and manifestations. Uncertainties were also present while mothers sought medical attention, especially when their concerns and uncertainties were dismissed or ignored by several healthcare professionals. Discrepancies in professionals' practices and standards for finding a diagnosis also exacerbated mothers' uncertainties.

Treatment uncertainty

Mothers reported being overwhelmed with all the uncertainties related to GHT. They expressed feeling hesitant making the decision to start GHT due to their uncertainties around the possible side effects. They had many doubts about the necessity of starting the treatment especially when lacking a definitive test that would identify the cause of the GHD. Many coped with their uncertainties by relying on trusting the healthcare provider. Most felt reassured when seeing the positive results of the treatment for their children. However, uncertainties about potential side effects continued. Mothers also expressed feeling uncertain about the timing of starting GHT due to the inconsistencies in treatment protocols across different cases and countries. These many uncertainties associated with GHT led to constant feelings of guilt and worry.

Future uncertainty

Many mothers had uncertainties about future matters related to their children. These matters included the length of treatment, discontinuation of treatment due to potential harmful side effects, and transition into healthy adulthood and genetic predisposition to future offspring. The length of treatment and the potentiality of stopping GHT were also noted as areas of uncertainty for mothers.

Theme 3: “But then you just get used to it I suppose” adhering to GHT and lifestyle changes - the new normal

This theme addresses the mothers' adjustment to caring for a child receiving GHT. This involved the management of GHT within the home and external environment, attending endocrine appointments and continuously monitoring the effects of the treatment.

Subthemes

Managing GHT injections

Mother's knew that commencing GHT entailed daily injections yet they described being ‘hit by the reality’ on the first night of administrating a GHT injection at home. Many mothers disliked giving the injection and hated the thought of piercing their children's skin and inflicting pain on their loved one. Expressions such as ‘jabbing’ and ‘stabbing’ were used to describe the process. In addition to the emotional turmoil when managing GHT injections, several also reported experiencing technical challenges.

Mothers found a variety of ways to reduce injection pain by applying anaesthetic cream prior to injecting, using buzzy bee, choosing the smallest gauge needle, adding a needle shield to the injecting device, taking the medication out of the fridge in advance of its administration so it could adapt to the room temperature, and finding the least painful site to inject. Others chose an appropriate timing for administration specific to their children while still adhering to the GHT regimen such as administering when the child was not tired or while sleeping. They found ways to adjust to the regimen as ‘the new normal’, and looked for ways to make the experience easier for both the child and parent.

Lifestyle adjustments

Challenges with balancing treatment management with other aspects of family life were also reported. Mothers expressed how GHT became integrated into the normal bedtime routine such as brushing teeth and reading a story. However, some mothers reported situations where they might need to miss doses, for example, working nightshifts or running out of medication and supplies. Traveling or the child having a sleepover at a friend's house could also affect the routine. In addition, a child's desire to conceal the treatment from others appeared to affect adherence, especially for those who were self-injecting. Having permission from the healthcare providers to miss a dose was also used in certain situations to cope with routine disruption. Often mothers found it difficult to find others to inject GHT when the children were not self-injecting and they wanted to travel or stay out late. In these situations, fathers, siblings, or family members often helped with injecting GHT. Some mothers found it hard to hand over the responsibility of administrating the injection to others.

Leaving the home environment and traveling in a car, boat or plane, created many practical difficulties. Preparation required intentional planning and thinking ahead. Mothers' preparations included remembering to request a traveling letter from the GP, packing all the needed supplies (device, needles and medication cartilages), ordering enough supplies to last the trip, maintaining GHT drug storage instructions while traveling and finally choosing suitable holiday accommodations to suit GHT storage recruitments. Mothers' also described expending time and effort on aspects of GHT management other than administration and storage, for example, organising prescriptions, sorting out the disposing of used needles, ordering supplies, requesting medical financial support and organising trips to follow up appointments that for many meant traveling long distances. Much effort was thus spent mobilising multiple resources to help with the many practical, often administrative aspects of GHT.

Attending endocrine appointments

All mothers mentioned a routine of attending endocrine clinics at least twice a year. Patient and doctor relationship issues were mainly expressed in relation to how sensitive and considerate doctors were to the mothers' and children's needs. Problematic issues included the doctor not being sensitive enough, feeling rushed and not getting enough time at appointments to ask questions and express concerns, and a sense of feeling unworthy of the doctor's time or being less important to the doctor than other patients. Inadequate communication was sometimes another major negative aspect of the patient-doctor relationship. Some doctors were described as having a ‘thoughtless manner’ when it came to addressing concerns around the child's lack of growth while others were more sensitive, thoughtful and actually listened.

Vigilance to treatment side effects and positive outcomes

In addition to constant monitoring of GHT positive outcomes, mothers were constantly vigilant and continuously alert to potential side effects. Mothers did not tend to think of GHT side effects when their children were responding well and were generally healthy. However, they were very quickly reminded of the potential side effects as soon as the child fell sick. They were hypervigilant when their children complained of unusual pain or were not their normal selves.

Theme 4 “I hadn't been told anything about it” information behaviour: looking for normality and certainty

Mothers faced considerable emotional, physical, and practical challenges associated with their children's condition and GHT management. These challenges resulted in a breakdown in the mothers' notions of normality, and the concomitant gap in their knowledge about GHT exacerbated their uncertainty. This uncertainty stimulated information behaviours—including voicing information needs, and seeking and using information as they struggled to understand their lived experiences caring for their children on GHT while re-establishing a sense of being normal. Mothers drew upon information behaviours from their reported stories regarding their experiences from the very beginning and continue to the present for many.

Subthemes

Information needs

Mothers appeared to lack information regarding many aspects related to their children's condition and GHT journey. There were many examples of inadequate and inconsistent information that contributed to the uncertainty the mothers felt. The lack of information affected mothers' ability to manage their children's conditions and GHT effectively, which contributed to their stress and anxiety.

Seeking and sharing information

When mothers received limited information from the healthcare providers, they turned to alternative sources of information. Many searched the internet for information, but often found undesirable information, which replaced their curiosity and sense of uncertainty with disappointment and frustration leading to more stress and worry. Receiving medical information from the healthcare providers (endocrinologist, endocrinology nurse, drug company nurse and pharmacist) was considered the most reliable source of information about GHT. However, most mothers expressed their additional need for experiential knowledge, and to share information with parents in similar situations. Sharing personal GHT experiences with other parents appeared to facilitate emotional and cognitive engagement for many mothers, which resulted in decreasing their uncertainty.

Need for support

Lack of information was linked to a perceived lack of support. Mothers expressed a need for emotional support as knowledge gaps exacerbated feelings of uncertainty and increased their anxieties. Lack of support was closely linked to them feeling alone on the treatment journey. Most sought support from parents living the same shared experience. Being able to compare experiences with parents in similar situations would have helped mothers in terms of making the decision to start GHT, and assess GHT's effectiveness. Similarly, contact with other parents provided a sense of community with parents assisting each other at times of need, providing reassurance, advice and recommendations based on experiences. Finding the support from others who were described as 'being in the same boat', was very helpful.

Discussion

The findings from our study share commonalities with several other studies on GHT (Brod et al., 2017; Kremidas et al., 2013; Marini et al., 2016; Van Dongen & Kaptein, 2012) and with chronic childhood conditions and rare disorders (Cohen, 1993; Genuis & Bronstein, 2017; Germeni, Vallini, Bianchetti, & Schulz, 2018; Kerr & Haas, 2014). Mothers reported delays getting a diagnosis, which is consistent with parents' experiences in other studies (Murray, Dattani, & Clayton, 2016; Saari et al., 2012; Stochholm, Juul, Juel, Naeraa, & Højbjerg, 2006). The growth measuring techniques used by the GP resulted in preventable delay in referral to specialised services and receiving the appropriate medical treatment. Healthcare providers authority was questioned, and many times their decisions were challenged by the mothers as they firmly believed that their children would still be undiagnosed or diagnosed at a much later stage if they had not advocated for their children, which resonates with other studies (Hinton & Kirk, 2017; Thomlinson, 2002).

Growth hormone treatment (GHT) is a controversial treatment as it has been associated with possibly causing cancer when misused (Conrad & Potter, 2004; DiVall & Radovick, 2013; Hintz, 2004; Nicholls et al., 2017). Controversy has been exacerbated by GH use for other biomedical enhancement or non-medically unlicensed reasons such as anti-aging and sports enhancement (Foddy & Savulescu, 2017). The controversial issues surrounding GHT, the novelty and unfamiliarity of the treatment, and the social taboo attached to it all influenced the mothers' sense of uncertainty surrounding GHT for their children. This is a noteworthy finding, which has not been reported before.

The lack of consistency in the recommended guidelines for starting GHT between countries and between cases made mothers question the accuracy of their children's GHT commencement timing. Delay in their children's diagnosis augmented the mothers' uncertainty. The lack of congruency of the treatment's positive outcomes and potential harmful effects also heightened their uncertainty, which accords with Marini et al.'s (2016) findings. Marini et al. (2016) suggested that a lack of reassurance could negatively affect adherence to GHT, which was also noted by Laing (2014). The lack of support and information from healthcare providers noted in this study is consistent with previous studies that information support from healthcare providers can influence uncertainty (Marini et al., 2016; Tiwaree, Kantawng, Wonghongkul, & Lertwatthanawilat, 2016).

Mothers' concerns that GHT may heighten the pre-existing stigma of their children 'being different' because they are short illustrates the uncertainty they attached to the possibility of adverse psychological effects from GHT. This notion of medicalisation of short stature contributing to psychosocial problems has been reported elsewhere (Conrad & Potter, 2004; Naiki, Horikawa, & Tanaka, 2013). Furthermore, the lack of support and understanding from others was seen by mothers as hugely associated with the stigma attached to GHT. The requirement mothers felt to justify to others the need for GHT when their children were healthy but small made it hard for mothers to disclose their children's diagnosis and treatment to others. The disclosure of the treatment proved to be even harder as time passed and the positive effects of GHT had been witnessed by others but the child still required GHT. Mothers claimed that since the visible stigma 'short stature' was not there anymore, people did not understand the medical reason for continued treatment and mothers felt the need to justify having their children on GHT.

This interaction uncertainty parallels parental experiences caring for children with chronic conditions such as multiple sclerosis (Hinton & Kirk, 2017). However, this finding in the current study contributes new knowledge and understanding with regards to mothers caring for children receiving GHT. This result is significant as it hindered some mothers from seeking support from family and friends, resulting in feeling of isolation, a dynamic that has been reported about other conditions (Benson, Lambert, Gallagher, Shahwan, & Austin, 2017). Lack of public understanding and knowledge about growth disorders and GHT was also noteworthy as negative public perceptions of GHT made some mothers' adjustment to the treatment that much more difficult.

Lack of choice in picking the GHT device that best suited the mothers' needs reported in studies conducted in Ireland, UK and the Netherlands (Hawkes & O'Connell, 2016; Laing, 2014; Langham & Kirk, 2011; Van Dongen & Kaptein, 2012), and was present as a parental concern in this study. Van Dongen and Kaptein (2012) and Laing (2014) recognised the need for support and participation of parents in the practice of selecting a GHT device. In Ireland there is a wide range of GHT devices (Pfizer (Genotropin), Novo Nordisk (norditropin), Merck (Saizen, easypod), and Zomacton (Zoma-Jet)) to choose from.

Mothers encountered many unanticipated technical and organisational soon after starting GHT. Reducing injection pain and storing and traveling with GHT were all issues for which mothers needed extra support and information as reported elsewhere (Brod et al., 2017; Kremidas et al., 2013; Marini et al., 2016). Lack of or inconsistency in the instructions on how to dispose of used needles caused additional frustration for many mothers. The need to organise and plan to source supplies for GHT from multiple sources added to the burden of treatment. Marini et al. (2016) also mentioned organisational issues, but the current study gives detail to the organisational burden associated with GHT to help target these problematic issues especially in the Irish context. Laing (2014) suggested that longer durations of GHT prescriptions, prescription collection and home delivery, reminders and calendars, in addition to immediate and extended family and social support, could help children and their caregivers to continue with GHT. Although some mothers had sufficient teaching, support, and follow up after the initiation of GHT, many described the support as being stopped at some point. This implies the need for on-going support from the drug company nurse or specialist paediatric endocrine nurse who can provide that support.

Uncertainty regarding the future due to the impact of the condition and GHT could have on the children's ability to be 'normal' in the future were noted. Mothers were concerned about potentially harmful circumstances, as well as their children's ability to attain culturally normative milestones, such as moving out of the family home. These uncertainties and concerns have been noted previously (Hinton & Kirk, 2017; Kerr & Haas, 2014). Mothers' concerns about the successful continuity of GHT when children reached adolescence coming from the mothers was reported before (Laing, 2014; Rosenfeld & Bakker, 2008; Van Dongen & Kaptein, 2012).

Lack of communication between paediatric and adult endocrine services and lack of preparation for transitioning patients is common (Cook, Yuen, Biller, Kemp, & Vance, 2009). Like others with chronic conditions, a high number of patients with GHD drop out of therapy during the transition period. This is due to many factors such as inadequate understanding of the disease process, inadequate knowledge of treatment options, and the patient becoming more independent and requiring interaction with a new set of healthcare providers (Hauffa, Touraine, Urquhart-Kelly, & Koledova, 2017). Hauffa et al. (2017) suggested that education regarding disease management and treatment options should be available from an early age and continue through the transition period. Children in the current study were prepubertal, and their mothers were not prepared in advance for the transition period despite their curiosity, which led to ambiguity and uncertainty. This highlights the importance of discussing with parents from as early stage the possibility of the continuation of GHT into adulthood and the process of transitioning to adult services.

The literature recognises information-seeking and sharing as the central means of making sense of illness and re-establishing perceived normality (Genuis & Bronstein, 2017; Germeni et al., 2018). The lack of sufficient information, social support, and contact with other parents were notable barriers in this study and mothers voiced their need for more relevant information and support from other parents in similar circumstances. Seeking and sharing information from social support networks are common needs amongst parents who care for children with long-term conditions (Smith, Cheater, & Bekker, 2015). This indicates that mothers not only need sufficient information and support from healthcare providers to help them make sense of the disruption of normality (during the diagnostic stage, decision-making to start GHT, and management of GHT and future) but require continuous support and information provision to bridge gaps and assist them in re-establishing their new normal and adapting to it. They also need connections with other families who have similar experiential knowledge or to social support groups through charity organisations. Information about support groups and specialist networks occurred by chance rather than being afforded as an essential part of care delivery both in this study and others (Smith et al., 2015).

Relevance to clinical practice

Healthcare providers need to recognise parents as integral members of the healthcare team and involve them in decisions and information-sharing about GHT treatment. Proactive communication and building a trusting relationship can help reduce uncertainties and enhance their sense of satisfaction. Correct measurement of growth in children to detect growth failure is significant for early referral to paediatric endocrinology services. The healthcare system and providers should aim to reduce unnecessary delays in reaching the diagnosis, as such delays contribute to the late initiation of GHT. Healthcare providers should also acknowledge the stressful impact of the diagnosis and treatment for parents.

It is important to recognise the parental stress induced by adoption of the ‘wait and see’ approach after referral to the paediatric endocrinology services before confirming a diagnosis or commencing the child on GHT. Supporting families with resources and information is also critical. Healthcare providers can significantly help by giving enough support during the decision-making process to commence GHT. They can equip parents with information such as clear guidelines, audio-visual material, and online resources verses written material. The healthcare team needs to give enough time to parents and children at appointments to ask questions. Face-to-face communication is most helpful to reduce initial uncertainties and worries that parents may have. Acknowledging the importance of experiential knowledge in helping parents make an informed decision to commence their children on GHT is significant. Therefore, professionals should provide the contact details of support organisations and connect parents with other families who have children receiving GHT. They should explain to parents the rationale for starting GHT and the suitability of its timing and offer choices regarding a GHT device that suits both child and parents' needs.

Offering continuous practical and emotional support along the treatment journey is important. Education and advice in the management of GHT must be realistic and built on care provided by parents at home. The endocrinology team should promote adherence to GHT and recognise the importance of GHT being integrated with maintaining normalcy in the family life. By recognising and acknowledging the difficulties parents face in the organisational aspects of managing GHT, the endocrinology team can assist in developing a better coordinated approach between their office, the local pharmacy and the GHT drug company. This coordinated approach can minimise the level of the burden associated with maintaining GHT supplies and reduce the multiple points of contact for parents. As noted earlier, uncertainties can increase at any point during the GHT regimen. By anticipating the uncertainties associated with GHT and recognising the nature of making sense of the disruption of normality and seeking normality, professionals can help to minimise some of the stress and anxiety experienced by parents and families of children receiving GHT.

Limitations

Findings are limited by the lack of fathers' perspective and the experiences of mothers who participated may differ from those who declined participation. The mothers' experiences with GHT ranged from six months to eight years with most being <3 years. This may indicate that mothers caring for children for >3 years may adapt and need less support and reassurance. However, five of the mothers had long-term experiences with GHT. Sample was limited to Ireland so findings are not generalisable to other countries where healthcare provision may vary. However, many of the findings were similar to other studies across the world. Using interviews to collect retrospective accounts may be prejudiced by recall bias. However, by adding the diary component, mothers had the opportunity to share more thoughts and new events between interview and diary collection.

Conclusion

This is the first study that explored mothers' experiences of caring for children receiving GHT in Ireland. This hermeneutic study delivers an in-depth understanding of the experiences of a small group of mothers. The meaning of their experiences can help healthcare professionals gain a deeper understanding of the maternal and wider family needs when caring for children on GHT to ensure that services include the necessary information and supports.

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CRediT authorship contribution statement

Rasha Alsaigh: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Visualization, Project administration, Funding acquisition. **Imelda Coyne:** Conceptualization, Validation, Supervision, Writing - review & editing, Visualization, Project administration.

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Declaration of competing interest

The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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