***Abstract***

*Background: The purpose of this research was to understand the experience of parenting a child receiving dexamethasone during maintenance chemotherapy for acute lymphoblastic leukaemia (ALL). Previous research has shown that dexamethasone’s high level of toxicity causes many physical, behavioural and emotional side effects, which reduce quality of life during ALL treatment. Less is known about the experience of parenting a child receiving dexamethasone, and the impact on the parent-child relationship. Methods: In-depth semi-structured interviews were conducted with twelve parents and data was analysed using Interpretative Phenomenological Analysis. Results: Four superordinate themes emerged: “a child on steroids is not your child”: the behavioural and emotional changes in the child and their relationships; “you have to do what you have to do”: adapting parenting to manage dexamethasone; “it breaks your heart… it’s a horrible medicine”: the emotional impact of parenting a child on dexamethasone; and, “it’s the worst week ever”: finding ways to cope with the challenges of dexamethasone. Discussion: A preparatory intervention for parents beginning the dexamethasone journey focussed on likely challenges, managing boundary setting and discipline, and their own emotional struggles, could be beneficial. Research into the impact on siblings could further understanding of the systemic influence of dexamethasone and help develop further interventions.*

Key words: Dexamethasone, Parenting, Acute Lymphoblastic Leukaemia (ALL)

**Introduction**

Acute Lymphoblastic Leukaemia (ALL) is the most common childhood cancer (, Barrington-Trimis, Cockburn et al., 2017). With advances in treatment, five-year survival rates have increased rapidly over the past 50 years but with improved survival rates come increased toxicity and intensity (McCubbin et al., 2002). An integral component of chemotherapy for ALL is corticosteroid administration (McNeer & Nachman, 2010). During maintenance chemotherapy, dexamethasone is typically administered for five days out of every 28 (pulses), and is administered orally by parents at home.

ALL requires a long and demanding treatment regime, which means that the child and their family experience significant disruption to their lives (Patterson et al., 2004; van Schoors, De Mol et al., 2019). Children’s quality of life is reduced, and more so when they are receiving dexamethasone (de Vries et al., 2008). Dexamethasone can cause a wide range of physical side effects, including muscle pain, infections, fluid retention and swelling (Keene, 2002), as well as increased appetite resulting in weight gain (Jansen et al., 2009). It can also cause significant behavioural and emotional side-effects, which families have reported to be more difficult to cope with, and parents have described feeling pushed beyond their coping abilities (McGrath & Pitcher, 2002). Despite this, little is known specifically about how parents cope with the challenges of dexamethasone during treatment.

The Stress and Coping model (Lazarus & Folkman, 1984) is commonly used to conceptualise parental coping in research studies (Klassen et al., 2007). The model states that interpersonal, disease-specific, and environmental factors can predispose an individual to difficulties with adjustment; however, this is mediated by their coping style and interpersonal or environmental protective factors (Lazarus & Folkman, 1984). Stress results when the demands of the illness and treatment outweigh the resources (Bradford, 1997). The Family Adjustment and Adaptation Response model (FAAR; Patterson, 1988) is a similar model; however, it focuses on coping as a family system and the importance of the meaning that is ascribed to each event. The Family Transition to Living with Childhood Cancer model (Clarke- Steffen, 1997) suggests that families cope by creating a ‘new normal’ and develop strategies to integrate the cancer into everyday life.

Whilst there is some research into how parents experience the impact that dexamethasone has on their child, it tends to focus on a descriptive account of the side-effects experienced (e.g. McGrath & Pitcher, 2002). Research into the wider impact of dexamethasone on families or of the experience of parenting a child on dexamethasone during the maintenance phase of treatment appears to be in its infancy. One recent study has shown that parents of children with ALL receiving treatment with dexamethasone experience greater distress, poorer sleep and reduced mental quality of life compared with reference values (Rensen, Steur et al., 2020), and another has described the level of motivation and knowledge parents have with regards to administering dexamethasone and 6-mercaptopurine at home, and the impact on family life (Camire-Bernier, Nidelet et al., 2021). Much of the literature discussed above (Fletcher & Clark, 2002; McGrath & Pitcher, 2002; Patterson et al., 2004) suggests that having a child on dexamethasone would exacerbate the stress already present for parents and cause additional challenges for them to contend with. Furthermore, clinical experience is that parents often seek support from health professionals in managing the challenges of dexamethasone and the impact on their family. Therefore, the aim of this study is to understand the experience of parenting a child receiving dexamethasone during the maintenance phase of chemotherapy for ALL. Interpretative Phenomenological Analysis (IPA) will be used to generate an in depth account of this lived experience, as understanding the impact on the whole family system and how parents manage the additional demands of dexamethasone is a little understood area.

**Methods**

**Design**

This was a qualitative study using semi-structured interviews and IPA to understand the experience of parenting a child receiving high-dose dexamethasone as part of maintenance chemotherapy for ALL. IPA was used because it focuses on understanding participants’ lived experiences and how they make sense of those experiences (Smith et al., 2009). IPA was deemed more appropriate than other qualitative methodologies which seek to develop theories of behaviour as in grounded theory (Glasser & Strauss, 1967) or explore the use of language as in discourse analysis (see Gee, 2014).

***Ethical Approval***

This study was approved by the appropriate National Health Service (NHS) Research Ethics Committee, and the Research and Development departments of the two hospitals recruiting participants.

***Participants***

Purposive homogenous sampling was used in line with the principles of IPA, which state that participants should be selected based on their ability to offer insight into the experience in question (Smith et al., 2009). Participants eligible for this study were biological mothers or fathers of children aged between 2- and 11-years old receiving dexamethasone as part of their maintenance chemotherapy for ALL. This age range was chosen because the treatment of infants follows a different protocol (Mitchel et al., 2005), and moving into adolescence, the difficulties associated with dexamethasone change (Mitchel et al., 2005) so parental experiences may differ. Only one parent per family was interviewed to prevent some families being over-represented in the sample. Families were able to choose which parent participated. There was no requirement for a family to have experienced side-effects of the dexamethasone for them to participate, as the research aimed to generate an understanding of what life is like during dexamethasone pulses from a range of perspectives. For ethical reasons parents of children with a poor prognosis (i.e. they were expected to live less than six months) or if the child had any history of relapse were excluded as it was hypothesised that this would also impact on the experience of treatment. The study aimed to recruit between 6 and 12 participants, in line with the numbers required to allow an in depth analysis of the experience of participants.

***Recruitment***

Paediatric Oncologists at two children’s hospitals identified families that met the eligibility criteria. A letter was sent explaining the study with an information sheet and a form for them to return to the researcher giving their permission to be contacted with no obligation to participate. The principal researcher telephoned the parents to provide the opportunity for them to ask any questions, confirm their eligibility, and arrange interviews.

***Procedure***

The first twelve parents to respond to the study invite were interviewed following providing written informed consent. All interviews were conducted by the principal researcher (AD). Ten participants chose to be interviewed at home and two at the hospital. Participants completed a demographic questionnaire and the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). This is a 14 item self-report measure, with higher total scores indicative of more severe anxious or depressive symptoms. Anxiety and depression are scored separately with scores below 7 indicating non-cases, scores of 8–10 suggesting mild difficulties, 11 -14 moderate, and 15-21 indicating severe symptoms.

The interviews ranged in length from 45 to 90 minutes (mean 66 minutes). The interviews were audio recorded to allow verbatim transcription.

The interview schedule was developed based on relevant literature and

the authors’ clinical experience. A parent user group (parents of children who have or have had cancer) provided feedback on the schedule, which resulted in additional prompts being added because they highlighted areas that had not been included, such as attendance at school. A pilot interview was completed to identify any difficulties with the interview process or the schedule. No changes were required following this and the pilot interview was included in the analysis. The schedule was used as a reference; however, the participants were able to guide the direction of the interview in order to cover what was important to them in line with IPA methodology (Smith et al., 2009).

***Data Analysis***

Each transcript was read and annotated with summaries and preliminary interpretations. The transcript was then re-read to identify emergent themes, which were then organised into clusters. Finally, the themes from the individual transcripts were grouped into subordinate themes and ordered into superordinate themes. The researchers carefully considered the meaning behind the data, and its relevance to existing literature.

In order to adhere to Yardley’s (2000) quality criteria for qualitative research a range of credibility checks were utilised, including independent coding of sections and discussions between authors until consensus was achieved. An audit of the development of themes was also performed by an independent researcher.

**Results**

**Demographic Information:**

Twelve parents (eleven mothers and one father) of twelve children participated. The age range was 30 – 51 years (mean 41 years). All of the parents were white; ten participants were British, one was Portuguese and one was Turkish. Four parents described their religion as Church of England, two parents were Muslim, four said they were not religious and two did not provide a response. Ten of the participants were from two-parent families, and eight had other children living at home. Ten of the participants were working outside of the home, and two were full-time parents. Three of the participants had HADS scores in the mild range for anxiety, and one in the moderate range. For depression, one participant scored in the mild range and two in the moderate range. The age range of the child was 3.5 to 11 years (mean 6 years), and the age range at diagnosis was 2 – 9.5 years (mean 5 years). Eight of the children were male, and four were female.

**Themes:**

Four superordinate themes emerged, and each theme is presented below with illustrative quotes from participants to convey the essence of their experiences.

**1. *“A child on steroids is not your child”*: the behavioural and emotional changes in the child and their relationships**

This theme captures parents’ experiences of the temporary dexamethasone-induced change in their child and the subsequent impact of this on the child’s familial relationships. Parents described how dexamethasone changed many aspects of their child, behaviourally and emotionally, with subsequent effects felt on relations between the child and parent, and the child and their sibling/s.

**1a. Your child becomes somebody else.** Changes were noted by all parents. Parents described tantrums, aggression and arguments over minor situations. When parents described their child on dexamethasone it was like a ticking time bomb with families waiting for the explosion. A number of parents described their child as withdrawing or isolating themselves at times, *“it’s like she’s lost”*. Parents also reported increased emotionality: *“she has a meltdown… because she has to get the aggression or the frustration out of her system”.* Parents described emotions as if they were physically bursting out from their child, and viewed them as directly caused by dexamethasone, rather than the emotions being the child’s response to their experience of it.

**1b. Temporary effect on the parent-child relationship.** Parents described changes in their interactions with their child during the pulses, and some believed their relationship was temporarily affected. It was difficult for parents to maintain typical interactions, *“it’s very hard to keep being as kind of positive and loving as you can be”*, *“that’s the only time that we do kind of fall out really”*. The child’s reactions were perceived as erratic and emotionally intense, which could impact on both parent-child and sibling relationships. Parents found these changes very emotionally challenging, *“she came out with words like ‘I hate you’ and all that and it breaks your little heart”*. The dexamethasone has a powerful influence within the relationship and changes the role of the parent. Parents at times resented the demands placed on them, but some tried to externalise the source of resentment from the child in order to not allow the negative emotion to have a lasting impact on the relationship.

**1c. Siblings relationships become more difficult.** Some parents perceived the emotional and behavioural changes brought about by dexamethasone to lead to altered sibling interactions, for example, *“silly little things that he would normally argue with his brother about, he will get incredibly upset and burst into tears”.* The volatility of the child’s mood led to more fractious sibling relationships during the pulses. Additionally, parents believed that the volatility of the children’s mood caused siblings to want time away from them because it created an unpleasant environment in the home and was upsetting for siblings. Parents perceived siblings to not always understand the changes in the child, and said they were not able to ignore undesirable behaviours as parents tried to do.

**2. *“You have to do what you have to do”*: adapting parenting to manage dexamethasone**

The behavioural and emotional changes in the children and changing family relationships increased the demands on parents forcing most parents to adjust their parenting.

**2a. The struggle between maintaining boundaries and making allowances for dexamethasone.** Parents experienced a dilemma between preserving previous rules and adopting a new flexibility to accommodate the side-effects of dexamethasone. Parents experienced a tension between wanting to be sympathetic towards their child because of their attribution of the behaviour directly to the dexamethasone *(“knowing that it’s the dex really”*), while maintaining expectations regarding standards of behaviour so that their child understands *“what’s right and wrong”*. Parents described initially relaxing rules and discipline following diagnosis, but when boundaries were reintroduced they experienced negative consequences. Parents explained that if they tried usual discipline strategies, *“all hell would break loose…he would shout for an hour, slam doors, scream, which he was never like before”*. Such reactions engendered anxiety in the parents and resulted in them changing their own behaviour towards their child. Further evidence of parents’ dilemma between rules and flexibility was illustrated by their fears that relaxing boundaries during the pulses might reinforce undesirable behaviour in their child at other times. William stated that his son’s tantrums had increased outside of the pulses and wondered *“whether that’s because we’ve allowed it more because of the dex… so now he feels like he can get away with doing it”*.

**2b. Managing having more than one child.** Parents described the additional demands on parenting with more than one child in the family: *“when you’ve got other children around, you have to see it all through because otherwise you end up with a house full of children thinking they can run around and rule the roost”*. Parents were aware of the siblings’ feelings in the differential treatment and amount of attention they received from their parents, and some experienced guilt because of this: *“I hate it you know. It makes me feel awful because I know that if you’re basing it purely, evidence based on the way I treat her and treat Heather, um yes I let Heather get away with certain things”*. Parents were

 aware of the need to try to find strategies that minimised the impact on the wider family.

**2c. Negotiation of parenting roles.** All parents discussed the two parents’ involvement in different aspects of the child’s care. Paternal involvement varied, but in all cases mothers were the primary care-givers. Some mothers reported that fathers did not fully understand the effect of dexamethasone and felt the way fathers tried to manage difficult situations was *“throwing fuel at a fire”*. Some mothers began to resent the uneven split of parenting, whilst some believed they had successfully negotiated the parenting roles.

**2d. Wanting guidance whilst knowing all children on dexamethasone are different.** Throughout this theme there is a conflict between wanting to be given information about what to expect and strategies to manage specific behaviours, whilst knowing that all children respond differently. This demonstrates the difficult nature of dexamethasone and the challenging job of parenting a child on it. Parents reported that receiving information about dexamethasone was helpful. However, some did not feel adequately prepared, having been warned about the *“grumpy pills”* or their child becoming *“a devil child”*, but not about the variation in how dexamethasone can affect children, such as becoming very withdrawn, and how to manage the range of side-effects. Some parents thought that they were *“inventing”* things that others were probably also doing and that more sharing of strategies between parents, or a dexamethasone specific skills-based course for parents, would be beneficial.

**2e. Positive developments in parenting.** Through the challenges of parenting a child on dexamethasone, half the parents identified positive changes or improvements in themselves as parents. They talked about increased patience and a sense of resilience, *“it’s made me stronger”*. Parents were forced into developing their parenting style in order to meet their child’s needs: *“you learn more than anything how to be a patient person, because you have to be very, very patient, understanding and very caring and very passionate, rather than distant and making rules parent”*.

**3. *“It breaks your heart… it’s a horrible medicine”*: the emotional impact of parenting a child on dexamethasone**

This superordinate theme captures the emotional impact of the side-effects, challenges and disruption to family-life caused by dexamethasone. The changing child, family relationships and adaptations to family life took its toll on parents.

**3a. Feeling helpless and judged as a parent.** Parents experienced despair when they

 were unable to manage their child’s challenging behaviour or console them when distressed, *“there’s nothing I can do”*. Parents questioned *“am I doing enough?”* and had thoughts like *“I’m not able to look after him”*. The testing nature of a child on dexamethasone could be overwhelming for parents, causing them to feel negatively about themselves because *“you feel like you’re failing as a parent”*. Parents also felt conscious of, or assumed that others were judging them, *“I’ve found people around us looking as if we can’t discipline our child”*. None of the parents reported receiving any criticism of their parenting. It appeared they were projecting their concerns and worries about their parenting onto others. For example, Janet disliked her daughter gaining weight and then assumed that others would be viewing her negatively for it: *“I thought people would blame me and look at me as a bad mother for letting her get fat, when they didn’t know why she was getting fat”*.

**3b. The constant demands of dexamethasone on parents.** As parents became increasingly tired from the relentlessness of the dexamethasone their perceptions of coping ability decreased. *“The relentlessness of the time and, and the um demands that are put on you can become almost intolerable at times, where you need a break”*. This led to feelings of exhaustion and wondering how they were going to keep going.

**3c. Dreading the dexamethasone pulses.** Most of the parents had strong feelings about dexamethasone, and began to feel dread at the thought of the pulses: *“I just dread the day that he starts and it’ll be the first bit of medication that I inform his sister, or him, that he’s going to be having because with the chemo you’ll get sick, you’ll get tired or your hair might fall out, but with the dex it’s the only one that’ll make you emotionally change.”*

**3d. Heartbreak and sadness.** Perhaps the strongest emotional impact came in the sadness parents felt watching their child change. This was described as *“heart-breaking”*, watching their child be so uncomfortable, upset and frustrated: *“for me as a parent is a very emotional and I feel very sad… I can cry for my son, and then I cry for whole world as well”*. For some parents, the side-effects served as a monthly reminder of the cancer, *“that’s when you realise every week, that’s the week you know he’s got you know…”*.

**4. *“It’s the worst week ever”*: finding ways to cope with the challenges of dexamethasone**

This final superordinate theme represents how parents cope with the challenge of parenting a child on dexamethasone. Parents reported a number of different coping strategies they utilised, including cognitive, personality, social and practical factors.

**4a. Helpful appraisals.** Cognitively, parents’ appraisals of the short term nature of the pulses helped them cope with the challenging side-effects. Parents found it helpful to remind themselves that *“it’s just for a week”*. Attributing behaviour to the dexamethasone rather than the child was echoed throughout many of the themes demonstrating how valuable it was to families. Understanding that their child’s behaviour was due to the dexamethasone helped parents to not take it personally when their child was rejecting or aggressive towards them. Furthermore, remembering the reason for the dexamethasone and feeling grateful for the treatment also assisted with coping: *“It’s upsetting… but it’s doing a job”.*

**4b. Coping by just getting on with it.** This theme reflects the attitude of *“we just*

*have to grit our teeth and crack on with it”*. Parents often believed that there was no choice in

whether their child had dexamethasone or not so the aim was *“to keep your happy mask on and get on with it”*. Parents found it helpful to adopt a determined attitude towards the dexamethasone pulses, and focus solely on managing the child: “*you would have to just forget about yourself for a week, the rest of the family, the friends, the house, the washing, everything… and just concentrate and focus on your little one”*. A number of parents believed that as much normality should be maintained as possible, which was their way to *“just get on with it”*. Whilst all parents recognised that dexamethasone had the potential to cause significant disruption to family life, there were different levels of acceptance of this, with the minority of parents refusing to allow their life to be dictated by dexamethasone.

**4c. Feeling supported facilitates coping.** Parents described feeling supported as helpful in enhancing their coping ability, for example knowing they could ask hospital staff questions or receiving input from a Clinical Psychologist. Supportive employers were perceived as very helpful, compared with parents who described work as an extra challenge to manage. Some parents talked about being able to talk or laugh about the things their child had said or done with their spouse in order to cope with the potential upset. This helped parents to not take things personally and to distance themselves from the emotion. It also facilitated the feeling of support and it being a shared experience, which helped to reduce the perceived burden. This lack of sharing available to single parents for emotional coping exacerbated the feeling of having to cope with it by themselves.

**Discussion**

This study provides a rich account of the lived experience of parenting a child receiving dexamethasone for maintenance treatment of ALL. Whereas previous research has described the many side-effects of dexamethasone and the significant impact of these for the child (e.g. Jansen et al., 2009; Keene, 2002; McGrath & Pitcher, 2002; Mitchell et al., 2005), this study highlights its systemic impact, including the child’s familial relationships and the impact on family life. This research has also shown the additional challenges that dexamethasone created for parents in addition to those already present in parenting a child with cancer. Seeing the impact of dexamethasone had a strong emotional impact on parents, increasing the burden of treatment. Parents felt that parenting styles needed to be adapted, creating many dilemmas which they would like further support with. This study also confirmed findings from previous research; the side-effects reported in this study were mainly in line with previous research (e.g. McGrath & Pitcher, 2002), and the side effects associated with dexamethasone use deepened the burden of ALL treatment.

A number of findings not previously explored in the literature have been highlighted in this study, including the impact on sibling and parent-child relationships. Parents perceived the siblings to not always understand the changes in the child, and said they were not able to ignore undesirable behaviours as parents tried to do. This led to more fractious sibling relationships during the dexamethasone pulses. To the authors’ knowledge, this is the first study to identify the impact of dexamethasone on children’s sibling relationships. These are particularly important findings because during childhood, siblings spend more time together than with any other family member (Sanders, 2004), and these relationships play a central role in social development (Furman & Buhrmester, 1985). The quality of sibling relationships in childhood can have a long lasting impact on adjustment and mental health (Sanders, 2004; Waldinger et al., 2007). This suggests that the disruption to the sibling relationship that dexamethasone can cause could have a lasting impact on both of the children’s development and wellbeing into adulthood, in addition to the impact of a sibling having a cancer diagnosis (Cheung, Acquati et al., 2020). Furthermore, parent-child interaction has long been seen as critical to ongoing development and family functioning (e.g. Alderfer et al., 2009; Tilery, Willard et al, 2020). Therefore, aiming to minimise disruption to both the sibling and parent-child relationship when children require high-dose dexamethasone is crucial.

This study has also highlighted the impact on parenting strategies, and the emotional burden on the parent. A specific challenge for parents is that the parenting style they have developed is typically not the most appropriate for their child when receiving dexamethasone. A number of parents thought they needed professional advice on managing the behavioural and emotional difficulties that their child displayed despite learning and developing strategies themselves. Parenting self-efficacy, the extent to which a parent believes they can competently fulfil their role (Teti & Gelfand, 1991), typically develops over the first two years of being a parent and then remains relatively stable (Weave et al., 2008). The dexamethasone caused a disruption to this stability and caused parents to question their previously robust parenting strategies. Most parents did not feel confident in their parenting during the dexamethasone pulses. This was further complicated by concern about the impact it would have on their other children. This is a new finding that has not been explored in previous research.

Half of the parents identified positive developments in their parenting, but this did not protect them from self-doubt and feelings of inadequacy. This is in line with research showing that distress and positive psychological outcomes can co-exist for parents of children with cancer (Yonemoto et al., 2012). The emotional impact of dexamethasone was striking, leading to sadness in the parent, along with providing a reminder that the child has cancer. A number of helpful coping strategies were highlighted, along with furthering understanding of how living with a child on dexamethasone fits with pre-existing models of coping. Parents’ appraisal of dexamethasone impacted on their coping. All of the parents externalised negative behaviours, attributing them to the dexamethasone rather than their child. Externalisation helps separate the person and the problem (Carey & Russell, 2002). It is possible that viewing the behaviour as external to their child was helpful in maintaining a sense of their child’s identity outside of some of the more challenging behavioural presentations.

Relating the themes to existing literature on coping offers some helpful insights into how families cope with dexamethasone and might be helpful in developing interventions to support families in the future. Models of coping (e.g. Lazarus & Folkma, 1984; Patterson, 1998) state that successful adjustment comes when the individual’s or family’s resources are greater than the stressors. This study shows that family life whilst on dexamethasone is often tested, with parents perceiving at times that the stress associated with dexamethasone use during ALL treatment is a major test of the parent’s resource. In accordance with Lazarus and Folkman’s (1984) model of coping, the themes in this study show interpersonal and disease-specific risk factors / stressors. The interpersonal stressors that were highlighted included disruptions in the parent-child relationships, sibling-child relationships and, for some, conflict within the parents’ relationship. The main disease-specific stressors identified were the practical and emotional demands of managing the side-effects of dexamethasone, and the reminder of cancer that it served as when many other aspects of life had stabilised following the initial treatment phase. The combination of stressors puts parents at risk of the demands outweighing their resources leading to adjustment difficulties. The link between the risk factors and adjustment is mediated by coping (Lazarus & Folkman, 1984), and this research offers some insights into how this relationship is moderated, such as through externalising the side effects, reframing the changes that need to be made to family life, and cognitive re-appraisal of the dexamethasone as helping with the treatment. Identifying families in need of support with developing their coping resources is critical to supporting long term adjustment. The importance of the cognitive factors identified in the research is further highlighted by placing the experiences within the FAAR model (Patterson, 1998). This highlights two important resources: appraisal style and families drawing strength from each other, which are illustrated within this study. Parents experienced certain appraisals to be helpful, namely externalising negative behaviours and emotions displayed by the child, remembering that the dexamethasone pulse is transient, and maintaining awareness of the important role of the dexamethasone in keeping their child in remission. The results of this study also highlighted the need for effective communication between parents and the increased burden that single parents can experience. The increased care-giving needs needed to be negotiated between parents; those who successfully managed this felt more supported and able to cope with the challenges. This gives support to the FAAR model and suggests it could be helpful for thinking about building the resources of parents.

For some families, the impact of dexamethasone served as a reminder of the cancer at a time when children had been able to return to normality in many aspects of their life. This demonstrated the difficulty of establishing a “new normal” to cope with childhood cancer when dexamethasone is a part of maintenance chemotherapy. Parents could not integrate dexamethasone into everyday life as purported by the Family Transition to Living with Childhood Cancer model (Clarke- Steffen, 1997) partly because they said they were unable to get used to something that changed their child. This suggests that whilst this model has been found to be helpful for some cancer types, this may not be a helpful model for professionals to use with the families of children receiving dexamethasone pulses.

**Nursing and Clinical Implications**

Using the Lazarus and Folkman (1984) model of coping as a framework for understanding the data from this study suggests the need to increase parents coping resources to mitigate some of the negative experiences families report. A number of potentially useful clinical applications, at different time-points, have been identified in terms of fostering resources to support parental coping. Prior to the maintenance phase of treatment, it will be important to increase parents’ feelings of being prepared. During the maintenance phase, regular monitoring of coping and distress is indicated. Preparedness can be facilitated by discussing the side effects of dexamethasone again as families approach the maintenance phase, including the range of different effects and sharing ideas for managing the challenges that these present. This might give parents a greater sense of control over the situation and reduce feelings of helplessness. Parents expressed a desire for specific advice on how to adapt their pre-existing parenting strategies to manage the challenges of dexamethasone within their family system. Parents could benefit from assistance with developing clear expectations about behaviour for the days when their child is on dexamethasone, and the days when they are not. This would allow parents the flexibility and leniency to accommodate the impact of dexamethasone whilst providing clear rules for the child. This containment is likely to be beneficial for the children, their parents and their siblings. Parents reported different appraisals and strategies that were helpful, such as externalisation. This could be taught to all parents whose child is to be treated with dexamethasone as a resource-light intervention to limit interpersonal risk factors. The emotional intensity of parenting a child on dexamethasone was captured in this study. Parents may benefit from preparation for possible rejecting behaviour from their child or the negative emotions they might have towards their child during dexamethasone pulses, as highlighted in this study. Increasing staff awareness of the wide ranging effects of dexamethasone on the family system and how to respond to these will be helpful, for example, normalising these experiences for parents may help limit the development of guilt or low self-esteem.

Throughout the child’s maintenance treatment, it will be valuable for professionals working with the child and family to regularly check in about the impact of dexamethasone to enable the provision of timely input when required. It may be necessary for psychologists to work with other health professionals that have more frequent contact with families, for example, nurses, support workers and play specialists, to help them identify families at risk of coping or adjustment difficulties. These families may require individually-tailored interventions to develop coping strategies and resources. Parents discussed feeling judged by others and it is possible that access to peer support during this time would be valuable.

In line with the FARR model, cognitive appraisals and communication between parents was important. The mothers were the primary caregivers in all of the families interviewed and some mothers reported that the fathers had less understanding of the side-effects of dexamethasone and how to manage them. If fathers are unable to attend meetings or interventions due to work commitments or childcare provision for other children, professionals should explore with mothers how they can support the fathers to understand the impact of dexamethasone and develop strategies for managing the behaviour (and vice versa in families where fathers are the primary care-givers). Staff training to increase the identification of parents having difficulty co-parenting or within their own relationship who might benefit from referral to psychology will also be important.

Dexamethasone has been identified to impact on the whole family. A systemic consultation (or family therapy) may be of benefit for some families. This may help families to identify unhelpful patterns in their behaviour and find more adaptive ways of interacting.

**Methodological Considerations**

This study has added many insights about the experience of parenting a child on dexamethasone to the current body of knowledge. However, there are some limitations that need to be considered. Due to the chosen methodology, the sample was relatively small and homogenous, which limits generalisability, and fathers are underrepresented in the sample. The value of IPA, however, is generating an in-depth understanding of a select group’s experience and this cannot be achieved with a large heterogeneous sample.

As a self-selecting sample was used, it could be argued that those who chose to participate may have had a different experience to those who chose not to. However, IPA dictates that participants should be selected based on their ability to inform the researcher about the experience in question, thus random sampling methods are not appropriate (Smith et al., 2009).

**Future Research**

This study has highlighted the systemic influence of dexamethasone, but focussed on understanding it from the parents’ perspective. More research is needed to better understand the impact on the children themselves and their siblings. It may be that a support package for siblings could be developed to prevent or reduce the negative impact on them, improve the sibling relationship, and reduce some of the burden on parents.

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**Disclaimers**

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