Everyday life experiences in families with a child with kidney disease

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Author contributions:
Hanne Agerskov: Principal project leader, design of the study, data collection, data analysis, draft, revision and final approval of the manuscript

Helle Charlotte Thiesson: Design of the study, critical revision and final approval of the manuscript

Birthe D. Pedersen: Design of the study, data analysis and critical revision and final approval of the manuscript.

Introduction

This paper explores how individual family members experience everyday life when the family includes a child with end stage kidney disease (ESKD). From a nursing perspective, it is important to gain knowledge about individual family members’ experiences to better understand the impact of the long-term ESKD conditions and dynamics in families.

ESKD is characterised as an often slow-progressing renal injury with irreversible functional deterioration. Congenital malformation and hereditary nephropathies are the main causes of ESKD in children. As in adults, ESKD in children results in comorbid conditions and is associated with risk factors, such cardiovascular diseases (Wong et al., 2012). Nevertheless, ESKD in children is a complex medical and psychosocial disease with factors that differ from adults including poor growth, neurocognitive impairment, bladder dysfunction and special need for nutrition. Some children have ESKD as part of a syndrome (Kaspar et al., 2016).

Literature review

Even though renal replacement therapy is possible, children with severe renal failure have a 30-fold higher risk of mortality, compared with their age-matched population (Wong et al., 2012, Chong et al., 2017). Children undergoing haemodialysis have poor self-esteem and experiences of losing their identity, body integrity, control and independence (Tjaden et al., 2012). Future prospects regarding schooling and further education are poor if they are in need of dialysis – which is time consuming and often produces side effects. Significantly reduced quality of life is found among children with
ESKD (Francis et al., 2018), and in health-related quality of life at all stages of chronic kidney disease (CKD) (Moreira et al., 2015, Splinter et al., 2018).

The illness of a child on haemodialysis has a long-term impact on a variety of psychosocial areas, including the parents’ relationship, social lives and mental well-being. Uncertainty about disease progression and lack of confidence in providing care for the child is described among parents (Tong et al., 2008, Tong et al., 2010). Parents experience difficulties in managing care, and they have a need for more information about the disease, support in handing care, and in managing financial issues (Geense et al., 2017). One study investigated fathers’ perspectives of having a child with ESKD, and found that they had an integral role in family care and that they coped in isolation, with little support (Nicholas, 2017).

Parents are a central part of a child’s life; however, the disease may have an impact on the emotional and social well-being of all family members. Little is known about how individual family members experience and cope with these conditions, or about interactions and dynamics within the family. In the literature, the perspectives of children with ESKD and siblings have been particularly overlooked. It is fundamental to collect their testimonies and not only parents' testimonies of family life. Therefore, the objective was to investigate everyday life experiences from the perspectives of members of a family with a child with ESKD.

**Methods**

The study took a phenomenological-hermeneutic approach inspired by Ricoeur’s theory of narrative and interpretation (Ricoeur, 1976, Pedersen, 1999). In this study, involvement of not only the parents but also the child with ESKD and siblings was a central issue in order to obtain new and important knowledge about everyday life and dynamic within the family.

**Participants**

The participants were recruited from a university hospital in Denmark. The inclusion criteria:
- Parents of children with ESKD under the age of 18 years
- Children with ESKD levels 4 and 5, > 6 years of age
- Siblings > 6 years of age

Eight families were informed orally and in writing and invited to participate. One family declined participation. This family was a mother living alone with the child having a busy period at work. In total, seven parents, five children with ESKD and five siblings accepted participation and signed informed consent forms. Table 1 presents participant characteristics. Part-time* refers to parents who were either fully or partly economically reimbursed by their employers.

Table 1

Data collection

Individual interviews were conducted in the families’ homes by first author (Kvale and Brinkmann, 2014). Open-ended questions were asked and an effort was made to cover personal issues around daily life. Questions included: Please, tell me about daily life in your family? All interviews were recorded and transcribed verbatim by first author. The interviews lasted from 7-65 minutes.

Data analysis

The data were analysed and interpreted using Ricoeur’s theory of narrative and interpretation (Ricoeur, 1976, Pedersen, 1999), on three levels: naïve reading, structural analysis, critical interpretation and discussion.

In the naïve reading, the transcriptions were read several times as a coherent text with an open. The intention was to let the text speak, to gain an overall understanding of what the text was about. This provided an understanding which, according to Ricoeur, you gain by looking/listening to how the text affects you. At this level, an interconnected understanding of the experiences of being a member of a family with a child with ESKD emerged. While reading and re-reading the text material, immediate impressions were written down and a first identification of semantic content was identified.
The structural analysis was carried out to achieve a deeper understanding by identifying quotations in the text (‘what is said’) that illuminated the meaning. Subsequently, the units of meaning were questioned (‘what the text speaks about’). At this stage, the analysis took place in a process that could be seen as a movement from what is said (units of meaning) to what is being talked about (units of significance) with the emergence of key themes, subthemes and patterns. The key themes were validated in relation to the naïve reading, the units of meaning and the units of significance.

The intention was for the units of meaning to emerge from the text (Ricoeur, 1976, Pedersen, 1999). Thus, the analysis and interpretation was a dialectical process, moving back and forth between parts and whole, and between understanding and explanation, as illustrated in figure 1.

**Figure 1**

In the critical interpretation and discussion, the findings were further interpreted and discussed in relation to theory and other research results. Furthermore, a discussion of the study’s implications for practice and its importance in relation to international research was carried out. The findings were discussed in the research team.

**Ethical approval**

The project was reported to the Danish Data Protection Agency (ID-number 16/12249).

**Findings**

During the naïve reading, it became apparent that routines and frameworks in everyday life were considered significant by all members of the family. There seemed to be various marks of the disease on everyday life, including concern for the child’s special needs. Through the structural analysis, two themes emerged:

*The significance of dealing with the disease in everyday life* and *The disease leaves a number of marks.*

These themes are interpreted below.
The significance of dealing with the disease in everyday life

The disease was part of everyday life and the family’s shared life. When it was stable, the disease fell into the background. A mother said: “He does not go around constantly sick. We had to answer questions from the kindergarten: ‘Is he healthy and well?’ And there I wrote ‘Yes’. So, as well as being chronically ill, he is also healthy and well” (M6). It was important that the child was seen in the same way as other children. There was a sense of vulnerability when the disease overshadowed the child’s personal qualities and opportunities.

Nevertheless, the child received particular attention because s/he was more vulnerable. A father said: “Of course, you accommodate him a little more, and can be the cautious one: ‘Just take care now, when you do that’” (F7). When it came to situations where the child was more exposed, the disease came to the fore, and the family members looking after the child showed concern and attention.

Discussing the disease with the health professionals was important for both parents and the older children: “That way, we find out that her scores have increased. Last time, they were back to normal again. So it’s something we’ve learned to live with” (F5). Anxiety would arise when there were fluctuations in blood test results; however, the experience that the child’s well-being and growth were included in the clinical assessment was important, when living with the unpredictability of the disease.

It was necessary to create a framework for the family’s everyday life that could support the child’s special needs: “We share our leave of absence – my husband and I – so that we alternate when we go to work” (M1). Leave of absence was a solution that provided a significant structure in everyday life, where the family experienced coherence and security. But it could be a challenge to be granted leave with financial compensation: “All the practicalities with the municipality (regarding approved leave), it is ‘an uphill struggle’, on top of having a sick child” (M6). It was a gruelling task to be granted leave, which made the parents feel vulnerable and frustrated. For the child, it was important to know that it was possible to come home if the need arose: “I can be picked up when I am tired and that’s good because it means I have more energy” (C3). Having consideration for some of the discomfort the disease caused meant that there was some surplus energy.
to be social and to fulfil one’s schooling. Thus, the family lived a shared everyday life, and created a balance that took into account the special needs related to the disease.

**The disease leaves a number of marks**

The disease led the way in everyday life, because the treatment had to be monitored carefully. It was a situation that affected everyone in the family: “*I can get pissed off because there is a lot of medicine that I have to take and I also have blood tests*” (C5).

For siblings, situations around taking medicine could be experienced as conflict-ridden: “*We must consider the fact that he HAS TO take his pills, and if he doesn’t, then Dad gets cross*” (S2). As the child grew older, the parents found that the child became critical of the disease and could neglect to take their medicine: “*(...) getting her to understand the importance of taking the medicine. I sense that at times she thinks it’s annoying to have the disease*” (F5).

The parents were concerned about the high scores and the progression of the disease, if the child did not take the medicine. Siblings, in particular, experienced such conflict-ridden situations as unpleasant. Therefore, it was important that the chronically ill child was involved and felt responsible for taking care of his/her treatment.

Treatment could mean that there was a need for special considerations during the child’s everyday life: “*It is annoying that I have to pee at least five times (in school), and it goes really badly because I forget to do it. I also have to drink a lot, and I forget that too*” (C7). In the parents, lack of help and support for the child in school or kindergarten caused concern: “*You send a boy to school with seven kinds of diuretic and heart medicine () I get so angry. She (the teacher) cannot understand how important it is to pee*” (M7). When the child was alone with the responsibility for important toilet visits and fluid intake, this led to feelings of powerlessness. It was important that adults in the child’s daily environment supported the treatment.

The child’s growth and well-being constituted important markers of effective treatment, and concerns were aroused when the child would not eat. A mother expressed: “*The fact that she has begun to have the feeding tube has eased some of our concerns. So, we should not force her to eat now*” (M6). Conflicts at meal-times affected the whole
family, and for the parents, the child’s well-being was a big responsibility. So, even though the tube feeding had to be administered at night, it was the best solution in families with children who did not have an appetite.

Admissions led to changes in everyday life for everyone in the family. One sibling stated “I had a very hard time when she went into hospital, because then mum and dad were very taken up with her, and I felt they forgot me” (S3). Upon admission, the disease came to the fore and changed everyday life. It caused concern and extra support was needed by both children and adults; however, over time everyday life was re-established.

Fever or other diseases in the ill child often developed quickly and unexpectedly. A mother expressed: “He got fever and a rash within a few hours, and I was just about to panic. But, I know that I can call (the hospital) right away” (M2). That one could contact the hospital and get qualified help engendered a sense of security, as there was experience with how poorly the child could be. This meant that the parents had reservations about foreign travel and unknown health professionals, which could be felt as a lack by other children in the family: “There are many people who are travelling. But we can’t, and it has often been a problem for her (one of the healthy siblings)” (M3). Not choosing holidays abroad caused a dilemma. Although it would put the vulnerable state of the sick child at risk, there was also a desire to be a family with holiday opportunities like others.

**Discussion**

The study revealed that it was significant to all family members that everyday life and caretaking of the child was structured around reserves of energy. The well-being of the child was an indicator of the well-being of all the family members. The illness demanded special awareness and various care and treatment interventions. Parents’ dependence on other adults around the child caused frustration. Hospitalisation caused anxiety, especially for siblings. The search for normalcy was important and coping with the conditions around the disease could be challenging.

There were a number of signs of the impact of the disease on the family’s everyday life. When the disease was stable, it was important to move the disease into the background.
Tjalden et al. (2012) found that children on dialysis experienced social isolation and felt different from others; however, some were able to routinise dialysis in their daily lives. In our study, family members were, however, aware that the child was more exposed, resulting in a need for a special awareness.

It was considered important to all family members that the child adhered to taking medication. Lack of adherence to situations around medical interventions could be followed by conflicts and fear of disease progression. We found that, especially siblings, suffered emotionally during these conflicts. Cousino et al. (2013) found that chronic illness in childhood had a number of familial impacts in relation to poor adherence. Swallow et al. (2010) found that ensuring that the child took her/his medication was described as a great achievement by parents, and in our study the parents considered it important to let the older children be involved in medical treatment.

Significant needs during the child’s day included the need for other adults to be involved, and it caused frustration when the child’s needs were not met. Geense et al. (2017) found that parents requested disease-related information for teachers, so that teachers could offer practical support to their child. In our study, the parents and the child reflected on how to manage the situation and they felt powerless when the request for support was repeatedly neglected.

Parents and older children had a genuine interest in following the progress of the disease, through blood sample results and consultations with health professionals. One study found that, as children matured, they wanted information to be communicated in ways they could understand (Gutman et al., 2018). In our study, the treatment had to be monitored carefully and an increase in plasma creatinine or proteinuria could be followed by situations that affected everyone in the family. However, changes in blood and urine laboratory values were something they coped with through experiences gained from earlier periods that had been followed by a return to a normalised everyday life.

To manage everyday life involved a task of balancing parents’ work schedules to meet both the child’s care needs, and the needs of the other children in the family. For some families it was, therefore, considered important to get leave from work to avoid caregiver burden. Medway et al. (2015) found that a high frequency of hospital visits and long
distance to the hospital had an impact on employment and family dynamics. In our study, to be economically compensated and being rejected caused frustration among parents. One study found how young people with ESKD developed problem-focused coping and emotion-focused coping to manage challenging situations in daily life (Muhammad et al., 2016). In our study, one way to cope with school was the possibility to be picked up before the end of the school day as an alternative to being off school on long-term sick leave. To ensure the well-being of all family members, official leave of absence was therefore a significant help when striving to achieve a balance in daily life and in maintaining positive family dynamics.

The study showed how the disease left a number of marks on the family’s everyday life. The findings furthermore show how family members were individually affected. From a system theoretical perspective (Bertalanffy 1968), the family represents a system where members mutually affect each other, and where events cause reactions from family members, which then leads to further reactions from other family members.

A unique finding was how siblings experienced limitations in their lives, because they did not have the same opportunities to travel as had their friends. The parents were left in a dilemma between siblings’ feelings of lack, and care-giving activities that caused limitations. We furthermore found that siblings suffered, felt left alone and were in need of support when parents had to accompany their sick sibling to the hospital. To our knowledge, experiences from the perspective of siblings have not previously been investigated. However, studies have found that parents coped in hospitalisation situations, by one parent staying at home to make the situation less disruptive to the other children (Swallow et al., 2011). They furthermore found how some children with ESKD felt guilty for being unable to participate in family activities, and that they believed they deprived their family of freedom. Tong et al. (2010) found that parents had to work hard to maintain relationships and restore those that had been damaged with siblings who felt neglected. In view of systemic thinking, it is important to recognise the importance of multiple perspectives of family members and the study showed that well-being and suffering influence everyone in the family unit.
Limitations of the study

Qualitative research studies are used to understand a phenomenon from the informants’ perspective.

The study included a small number of families (N=7), however 24 interviews were undertaken. In qualitative research, the focus is on the content of the participants’ expression, rather than the number of participants included (Morse 1993, Kvale & Brinkmann 2014).

The interviewer was a professional nurse; however, she was not a part of the clinical staff. Her background knowledge, position and preconceptions enabled her to stay compassionate and focused during the data collection. Furthermore, the chosen method is based on an understanding of research as a systematic and reflective process. Trustworthiness was considered at all stages of the scientific process by a systematic and reflective process with inclusion of individual family members to narrate on their experiences followed by the involvement of fellow researchers in the data analysis and interpretation of the findings.

Implications for clinical practice

In clinical practice, it is essential that health professionals give attention to families’ complex situations. To address possible concerns and/or emotional dilemmas among individual family members, health professionals should focus on the impact of the families’ experiences and needs, the parents’ role and issues around family relationships, in order to support the entire family unit. Conclusion

Living in a family with a child with ESKD has an impact on all family members. Family members feel vulnerable and concerned and are in need of attention and support. Parents consider it important to achieve a balance between their work schedules and caregiving. Unfulfilled attention and support from other adults challenges everyday life and can lead to frustration and feelings of powerlessness. Limitations in everyday life cause a dilemma between meeting the child’s special needs and siblings’ wishes. Thus, the study clearly identifies that the disease leaves a number of marks on the family’s everyday life,
and that the well-being of one family member has an impact on the well-being of the entire family unit.

References


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Table 1; Presentation of participant age, residential setting, and number of children in the family

<table>
<thead>
<tr>
<th>Family number</th>
<th>Parents’ ages</th>
<th>Number of children</th>
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<th>Age of sibling (S)</th>
<th>Residential setting</th>
<th>Working time</th>
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Figure 1: Illustration of structural analysis

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<th>Units of Meaning</th>
<th>Units of Significance</th>
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<td>What the text speaks about</td>
<td>Emergence of key themes</td>
</tr>
<tr>
<td>“We have to always remember that he HAS TO take his pills, and if he doesn’t, then Dad gets cross” (S2).</td>
<td>Everyone in the family experiences that the administration of medication has to be given attention. Situations around taking medication can be conflict-ridden and that causes emotional discomfort</td>
<td>The disease leaves a number of marks</td>
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</tbody>
</table>