Going in Dialysis is Time to Live: Family’s Experiences of Everyday Life with Haemodialysis Treatment

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Time is a central concept when attempting to capture how life develops as results of the interaction between the individual and those in his/her immediate environment. Chronic renal disease such as ESRD with chronic haemodialysis not only shortens life but also places everyday life on a thin line survival paramount. The haemodialysis is also a time-consuming treatment that makes it necessary to carefully plan of everyday life and involves next of kin to a large degree. The aim of this study was to explore the content of time in everyday life as experienced by the next of kin of haemodialysis patients. This study used explorative and descriptive design with a content analysis approach. The interviews, which were conducted in the informants’ homes, lasted 20-60 minutes and were audio-taped and transcribed verbatim in order to not to lose any information. Twenty next of kin were selected purposive with the criterion of having at least one year of experience as a next of kin of a patient on haemodialysis. The content of time in everyday life can be described as follows: fragmented time, vacuous time and uninterrupted time. Conclusion which illustrate how time is minimised and life space contracted for next of kin and their family. They were aware of the prognosis of renal disease and the fact that haemodialysis is life-sustaining treatment, which forced them to live for the moment. It is important to gain insight into how time influences the next of kin’s experiences of everyday life and how this knowledge can be communicated in the nursing science.
Introduction

Everyday life can be complex when next of kin of haemodialysis patients are preoccupied with taking care of patient and his/her health, which the difficulties and requirements needed. The experience of time varies during the life span due to the changes that continually take place in the life of every human being (Novotny, 1994). Time is a central concept when attempting to capture how life develops as a result of the interaction between the individual and those in his/her immediate environment (Jepsson, 2001). As human relationships can last a life time, they are affected by the past, the present and the future. Next of kin are part of the individual’s closest circle, and the care and attention they exhibit when a family member becomes ill is influenced by their common past and can help them to look to the future (Waerness, 2000). Consequently, experiences over time are valuable for next of kin and can provide the details of individual identity and group relations in everyday life. When a life-threatening disease strikes, life changes not only for the person affected but also for those in their environment who are emotionally and socially close to them. Chronic and serious diseases are a reminder of human vulnerability and, in cases where the course and prognosis of the condition are uncertain, lead to a sense of uncertainty in everyday life (Charmanz, 1997).

Chronic renal disease often requires haemodialysis, which is a time-consuming treatment that necessitates careful planning of everyday life and involves next of kin to a very large degree (White & Grenyer, 1999). The patients require dialysis three to four days per week for three to four hours on each occasion. As the treatment is both time-consuming and tiring for the patient, his/her next of kin and social life are very much affected (Hagren, 2001). Furthermore, the next of kin have to adapt their lives to the haemodialysis treatment schedule. A person’s time can be severely restricted when his/her life is devoted to the needs of another. Feelings of insufficiency and strain may surface when everyday life is experienced as restricted, and personal space is perceived to be contracting (Davies, 1996; Ziegert & Fridlund, 2001). It is therefore important to investigate next of kin’s experience of time in connection with the care of haemodialysis patients. The aim of this study was to explore the content of time in everyday life as experienced by the next of kin of haemodialysis patients.

Time experiences

Time is defined as a numerical measure of change involving movement in both action and thought, which distinguishes between the past, the present and the future (Aristotle, 1941). Novotny (1994) describes time in terms of the human being’s social environment and the changes that take place during the life span. Time is divided into personal time or perceived time, which varies from individual to individual throughout life, and time as defined a social institution, as a symbolic means of orientation, which is visible and measurable in units. The perception of time in adulthood has been described as private time and public time. According to Ingthorsson (2002), the present becomes frozen in the absence of knowledge about the future or when life is focused on living from day to day. An image of the future is necessary for the present. Davies (1989) states that perceived time is the most important time in the everyday life of the individual. Human beings need time for reflection, which is afforded by self-perceived time. The sense of having unlimited or sufficient time generates feelings of happiness and a zest for life. When the day is planned in detail and the diary overflowing, everyday life can be disrupted, giving rise to a sense of meaninglessness. Jönsson (1999) describes time as an important part of life, due to its central role in the existence of each individual. Time is described as a visible band around the life of each human being. McInerney (1993) regards the experience of time as a conception of scarcity, due to the fact that an enormous number of events take place simultaneously, which can influence a person’s
everyday life. However, time can also be perceived as endless, when the individual finds tranquility in everyday life, which happens when he/she experiences nature and feels as if time is standing still. Craig (2000) highlights the fact that major changes in everyday life lead to a loss of a sense of time. Time is reflected by the measurable time, speed and rhythm. Each individual has his/her own body clock and individual rhythm. The time measured by the clock often dominates life, as the individual reacts to measurable time as opposed to perceived time. Nevertheless, both the biological and the cognitive rhythm are central. Novotny (1994) emphasises the importance of questions dealing with perceived time when attempting to capture experiences of everyday life, due to the fact that perceived time and everyday experiences are strongly linked. An individual’s thoughts are also guided by his/her rhythm, which can make it difficult to reflect with people who have a different rhythm. However, in close relationships with family members, an understanding of each other’s rhythms is developed, which means that time is a central concept for capturing the interaction between an individual and the people in his/her immediate environment.

Study design
This study used a qualitative, descriptive design with a content analysis approach. Qualitative content analysis is a tool for drawing validated conclusions of verbal, visual or written data in order to describe and evaluate a specific subject (Berg, 2004). Qualitative content analysis closely adheres to the original material and does not paraphrase the reality (Polit and Beck, 2004). The participants were based on consisted of 38 eligible patients on haemodialysis who lived in a county in south-western Sweden (270 000 inhabitants) (SRAU, 2004). The participants were selected by purposive sampling with the inclusion criterion of having at least one year of experience as a next of kin of a patient on haemodialysis. Twenty next of kin fulfilled this criterion and agreed to take part in the study, thus forming the sample.
Table 1. Characteristics of next of kin to haemodialysis patients (N = 20)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (range) years</td>
<td>58 (31-80)</td>
</tr>
<tr>
<td>Type of Dialysis</td>
<td></td>
</tr>
<tr>
<td>Hospital haemodialysis</td>
<td>20</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Relationship to the patient</td>
<td></td>
</tr>
<tr>
<td>Wife (Spouses)</td>
<td>11</td>
</tr>
<tr>
<td>Husband (Spouses)</td>
<td>2</td>
</tr>
<tr>
<td>Adult children</td>
<td>5</td>
</tr>
<tr>
<td>Mother</td>
<td>1</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
</tr>
<tr>
<td>Next of kin’ experiences of dialysis years</td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td>12</td>
</tr>
<tr>
<td>3-5</td>
<td>5</td>
</tr>
<tr>
<td>6-15</td>
<td>3</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>4</td>
</tr>
<tr>
<td>High school</td>
<td>13</td>
</tr>
<tr>
<td>University/post graduate</td>
<td>3</td>
</tr>
<tr>
<td>Spatial closeness</td>
<td></td>
</tr>
<tr>
<td>Living with patient</td>
<td>13</td>
</tr>
<tr>
<td>Living close to patient</td>
<td>6</td>
</tr>
<tr>
<td>Living far away from patient</td>
<td>1</td>
</tr>
</tbody>
</table>

The study was approved by the operations managers at the selected county hospital in southwestern Sweden as well as the Ethics Committee, Lund University, Sweden. The interviews were conducted over a four-month period in 2004. The participants were fully informed about the voluntary nature of participation, how their data would be treated and the procedures that would be used to ensure confidentiality. Informed written consent was obtained from all participants. Further, they were informed that they could withdraw their participation anytime. The main researcher then introduced herself and explained the purpose of the study to the next of kin. Codes were used to identify the participants. The transcripts, audio-tapes and consent forms were stored in a locked cabinet. The ethical issues were reflected on and harm
minimised, through following the guiding ethical principles of the World Medical Association’s Helsinki Declaration 1964 (The Swedish Medical Research Council, 2000).

**Data collection**

The main focus of the interviews was the next of kin’s experience of time in their everyday lives when caring for a family member who is on haemodialysis. The research questions concerned the everyday life of the next of kin and how they viewed their own time in relation to caring for the patient, with focus on the past, present and future. The first interview questions were broadly formulated “Can you describe your everyday life?”, “What has been your experience of time since your family member started haemodialysis treatment?”, and “How do you view your everyday life in terms of the past, the present and the future?” Follow-up questions could be “What do you do on an ordinary day?” and “What is your experience of your time that you have to yourself?” The interviews, which were conducted by the main researcher in the next-of-kin’s home, lasted 30 to 60 minutes, were audio-taped and transcribed verbatim.

Data were analysed according to the principles of content analysis (Berg, 2004). The following steps were chosen:
1. Impression. The analysis started when the transcripts were read and compared to the audio-taped interviews in order to check the accuracy of the text and to gain a first impression of the transcribed interview texts.
2. Coding. While reading the transcripts of each interview, notes were made in the margin indicating the subjects dealt with in the interview and the emerging ideas. The entire text was then read through once again, and text units that corresponded to the aim were coded.
3. Inductive process. In this step the text units were condensed in order to filter out irrelevant information. An inductive process was initiated by the main researcher becoming deeply absorbed in the written material with the aim of identifying dimensions or themes that appeared meaningful in relation to how the information was presented.
4. Reduction. The condensed texts were read and coded into broad categories in a so-called category list. The analysis continued with another reading of the texts to identify different nuances in the broad categories, which were then reduced to new, more nuanced ones.
5. Validation process. In this step, new categories were formed based on the aim. The texts were read through in order to verify that quotations and categories were in agreement. All 440 quotations were extracted from the transcripts and documented under the respective category. All quotations were discussed and processed in order to reduce and highlight the meaning-carrying quotations. When the researchers (KZ, EL) had reached agreement, the validation was completed by selecting quotations for the results that corresponded to the description of each category.
6. Writing process. The texts were re-read in order to link the original material to the category descriptions. Thereafter the main researcher selected the most important information from each category together with the quotation that expressed it, after which the meaningful information about the respective category was identified.

**Findings**

Analysis of data from the interviews revealed experiences of time in the everyday lives of the next-of-kin of haemodialysis patients. Their experiences are reflected in the concepts fragmented time, vacuous time and uninterrupted time. The next of kin described how their own time drastically reduced when they prioritised the patient’s health problem first.
**Fragmented time**

Fragmented time contained descriptions of restricted and divided time in the next of kin’s everyday life, due to being constantly on hand to help the patient, thus limiting the time for his/her own activities. Fragmented time also meant less freedom, as daily life was divided in order to accommodate the patient’s treatment times. This resulted in reduced mobility and difficulties going away, having fun or spending time together with other people. Next of kin’s time was governed by the patient’s schedule, which left them no opportunities to do what they wanted or to shape their day based on their own ideas. Furthermore, time restrictions brought with them increased responsibility for the patient’s health and for the home, for contact with the healthcare services and the local authority as well as for making applications for aids of assistance. “My hubby’s disease is very restricting and affects all social aspects of life. Nothing but musts, everything hinges on the dialysis”.

Next of kin were hindered in their everyday life by a multitude of tasks which were concentrated on the patient, such as assisting with personal hygiene, administering medication, shopping, cooking, cleaning and transport. Their everyday life was full of obligations, and time to consider themselves or opportunities to get away from it all was limited. Time was devoted to the patient’s needs, and there was no possibility of handing over responsibility to somebody else: “Well, my day became quite different. I can’t stay away from home more than an hour at any one time, as there is nobody else here”.

Fragmented time dominated the everyday life of the next of kin, as their whole attention was focused on the patient’s disease, health and haemodialysis treatment, which meant that they had no time to themselves. They planned their time to coincide with the patient’s daily activities in order to give priority to his/her needs. The restricted time mainly consisted of time focused on the patient at the expense of their own unbroken time. Next of kin adapted their day to the fixed times of the patient’s haemodialysis treatment, with the result that their daily life was fully planned, which gave rise to the feeling that their energies were divided.

**Vacuous time**

Vacuous time comprised descriptions of the present as vacuous, empty and without a future of one’s own, as the patient’s haemodialysis treatment prevented the planning of long-term goals. Next of kin were aware of the prognosis of the disease and of the uncertainty associated with each day, due to the life-sustaining nature of the treatment and the inherent risk of complications. Vacuous time was also linked to the knowledge that the disease could lead to death, which strengthened the next of kin’s ties to the patient. They dared not stop thinking about the patient, which constituted a hindrance in their everyday life, as the present made it impossible to plan for the future. The feeling that time was vacuous restricted the next of kin’s daily life, as they dared not plan ahead, since the patient was their main focus. “Well, it somehow feels as if I don’t have a future. Of course you sometimes wonder what will happen to her, if she will be given a kidney transplant and able to return to a normal life”.

The patient’s disease was the focus of the next of kin’s everyday life, which they adjusted in order to cope with the development of the disease, thus restricting their possibilities of envisaging the future in a long-term perspective. Aspects that could inspire them with hope for the future were limited. Daily life was experienced as empty and vacuous, as their time was focused on the fully planned existence of the patient and dominated by restrictions related to the treatment. Previous wishes to travel or undertake enjoyable activities together with the patient had to be abandoned due to uncertainty about the health of the latter. “We had planned to travel but one has to take each day as it comes. That’s what I do anyway. Her future is my future”.

The strict division of time contributed to the vulnerability of the next of kin, as they had a feeling that time was running out for the patient, which resulted in an emotional void due to
uncertainty about a different future. The fact that there was no hope of an improvement in the patient’s health prevented the next of kin from undertaking major changes in their daily lives. The emptiness of their existence played a central role. Furthermore, they made no plans for the future, as their thoughts were concentrated on the here and now. Next of kin were uncertain about their own future. Time was measured from day to day and they lived in the present.

**Uninterrupted time**

Uninterrupted time comprised descriptions of the next of kin’s private time, when they could devote time to themselves, their own activities and needs and feel free. There was also time for experiences that gave them the urge to do things and the energy to create happiness in their daily lives. Their time was filled with everything from experiencing nature, travel and cultural activities to socialising. “I have to see my friends fairly regularly, otherwise it becomes tedious”.

Uninterrupted time had the potential to provide renewed strength, when next of kin could undertake something special that they enjoyed. They described how cultural activities or spending time in the countryside gave them a feeling of time as connected and uninterrupted. “I like sitting at the computer and working with image processing. Then I have time to myself, which I enjoy very much”. The next of kin’s experiences of uninterrupted time were related to uneventful days or when they enjoyed themselves. They also experienced time as uninterrupted when they did not have to keep an eye on the clock and the time was their own. During periods of uninterrupted time, the next of kin could rest and recoup energy to cope with the strain of their daily lives. “I think Friday is quite a good day as being on my own, perhaps because you have the whole weekend ahead of you. There is no dialysis on weekends”. For the next of kin, uninterrupted time implied having time to themselves, which they spent on various pastimes that they found enjoyable or relaxing. Uninterrupted time also created an opportunity for reflection and occurred during calm days, on which there was no dialysis, when the next of kin could feel free. Uninterrupted time thus had the potential to be beneficial, as they could relax from the supporting of the patient.

**Discussion**

The existential knowledge that one cannot live forever constantly in focus, which can create insecurity in everyday life and the feeling that time is running out, especially as haemodialysis take up so much of it. The role of next of kin changes when they become involved in the care, which in turn can lead to a change of lifestyle and restrictions in everyday life and the life cycle.

A qualitative descriptive and explorative design with a content analysis approach was used to capture experiences content of time in the everyday lives of next of kin of haemodialysis patients. This method was considered suitable for the present study due to its naturalistic approach without paraphrasing reality (Berg, 2004; Polit and Beck, 2004). In order to ensure the quality of the findings and methods used in this study, trustworthiness will be discussed in terms of the following criteria: credibility, transferability, confirmability and dependability (Polit and Beck, 2004) Credibility was ensured by the use of a reliable method and the fact that the interviews were in line with the aim of the study. Furthermore, the data analysis was carried out in accordance with the clearly defined steps described above in order to generate reasonable results. Although the results cannot be generalised or transferred in a statistical context, they are in a qualitative sense transferable to similar samples in a similar clinical context. The participants were purposively selected, and the inclusion criterion was one year’s experience of being a next of kin of a haemodialysis patient, sufficient times enough collecting thoughts and experiences of being a next of kin of haemodialysis patients.
Surprisingly, the education level was relatively high, indicating the possible failure of this analysis to capture the experiences of less well-educated people. On the other hand, as it is well known that well-educated people are better at verbalising their experiences, it is possible that the next of kin contributed further knowledge. Confirmability refers to the objectivity of the data and implies balancing the researcher’s knowledge with the content emerging from the data. The study was conducted by means of qualitative analysis, a tool for drawing validated conclusions based on verbal data and aimed at describing and evaluating a specific subject. The selection criterion, use of a tape recorder, verbatim transcripts of interviews and the steps of content analysis further guarantee the dependability of the results. To increase reliability of the analysis, the researchers (KZ, EL) had reached agreement and assessed all text responses independently, and level of agreement was assessed.

The results showed time in the everyday lives of next-of-kin of haemodialysis patients as fragmented time, vacuous time and uninterrupted time. Next of kin described fragmented time as their daily existence being split and restricted by their responsibility for the patient’s health and haemodialysis treatment. Ekvall et al.’s study (2004) reveals that the next of kin’s responsibility for the patient’s care in the home can comprise several different caring interventions, such as nursing tasks, which include keeping in contact with the nurse and physician responsible for the patient, assisting the sick person with everyday activities and being available to provide help in the home. The study also revealed that next of kin of severely ill patients assume increasingly greater responsibility for nursing interventions in the home, which can leave them little time for themselves. Fragmented time occurred when next of kin were involved with the patient, both physically and mentally, resulting in a lack of time for themselves. Nieboer et al. (1998) describe how spousal caregivers’ free time is drastically reduced when they prioritise the patient’s needs, thus allowing themselves no opportunity for relaxation and activities of their own. There is also an increased risk of depression when the demands and duties in the home become greater and the opportunity for relaxation is accordingly fail. In the present study, the majority of quotations described fragmented time, which may indicate that next of kin of haemodialysis patients were exposed to a health risk due to their time being divided and restricted (Table 2). When time was constantly restricted and divided, they were at risk of being afflicted by tiredness, which phenomenon has also been described by Ekstedt and Fagerberg (2005), who focused on experiences of time in involved people stricken by tiredness.

The second category described vacuous time as empty and useless, which also weakened the next of kin’s belief in the future. They were aware of the prognosis of renal disease and the fact that haemodialysis is a life-sustaining treatment, which forced them to live for the moment. They also had to live with uncertainty, as they were aware that haemodialysis can fail and they were unable to plan for the future. This uncertainty prevents next of kin from planning activities that demand a great deal of time, as they feel imprisoned in their everyday existence, which, according to Ingthorsson (2002), results in a focus on the present, which leads to paralysis and lack of goals in their daily lives. Vacuous time was associated with the wish to live one day at a time and in the here and now. This strategy can help the next of kin to cope with the emptiness of their uncertain existence caused by the patient’s disease. In contrast, Pelletier-Hibbert and Sihi (2001) underline the importance of next of kin living from day to day and in the present, which can reduce their level of uncertainty about the future. According to Calvin (2004), haemodialysis patients are aware of the life-threatening nature of their renal disease and that they cannot survive without haemodialysis. The patient shares this knowledge with his/her next of kin, which can create insecurity in everyday life and the feeling that time is running out. Benzein et al. (2004) argue that open communication in the form of discussions between health care professionals and next of kin can strengthen the feelings and beliefs of family members who are responsible for the patient’s care in the home.
The next of kin are also resource mainly because of the latter’s belief that one should take care of one’s own family. However, they point out the risk that the next of kin will not have sufficient strength to cope if their belief in the future is extinguished. Vacuous time was present in next of kin’s daily lives and, in order to understand their feeling of emptiness and believe in their own future, they needed to be continuously informed about the patient’s health during conversations with health care professionals.

In the uninterrupted time category, next of kin of haemodialysis patients described their own time as beneficial. Time was experienced as uninterrupted or infinite when they could relax and engage in activities of their own. McNerney (1993) holds that uninterrupted time is when an individual experiences a feeling of tranquillity in his/her everyday life, which can arise from nature or other pleasurable activities. The content of the uninterrupted time category described the next of kin’s wishes and needs to escape from their everyday life in order to gain the energy necessary to cope with the strains of caring for the patient in the home. This is in line with Kuuppelomaki et al.’s (2004) study, where family carers needed repeated positive experiences, a break from everyday life and to follow their own intuition when choosing activities to afford them relaxation. The family carers also reported that uninterrupted time was when they escaped from their daily routines and had an opportunity to pursue activities other than their daily chores. Renal disease and its treatment in most cases play a central role in the everyday lives of next of kin, due to their uncertainty about the patient’s symptoms, which can also influence the family’s rhythm and give rise to their experience of time being affected (Charmanz, 1997). In the nursing process, the next of kin’s opportunities for uninterrupted time can be identified by means of the assessment conversation, when they are asked about their psychosocial situation. Renal care professionals should also be able to create such opportunities when planning the patient’s care. The everyday life of next of kin is shaped by various experiences and perceptions in the interaction with other people during a long period, which can be related to Rollands’s theory (1998) about the role of the individual in his/her own everyday life. The patient’s closest relations are family members who are normally available 24 hours a day, which is consistent with the findings of the present study. When next of kin of haemodialysis patients play an important role in the patient’s life, and when they assume responsibility for their joint existence and its smooth functioning, their personal life becomes minimised and their common life space also contracts (Waerness, 2000).

Conclusions and implications

The experiences of content of time in everyday life among next-of-kin of haemodialysis patients demonstrated that time for themselves was minimised and that the common life space contracted. The results identified three categories: fragmented time, vacuous time and uninterrupted time. Next of kin’s everyday life was characterised by fragmented time, due to their responsibility for the patient’s health and care in the home, while uninterrupted time, which provided relaxation and recovery, rarely reduced. Vacuous time generated emptiness and uncertainty regarding plans for the future as well as leading to the narrowing of their common everyday life. It is important to gain insight into how experiences of time influence the next of kin’s everyday life and how this knowledge be communicated in the nursing process. Attention should be focused on time in the nurse’s assessment of the next of kin’s everyday life, so that the nursing care plan can take account of the time required for the patient’s care, and whether or not next of kin have sufficient time for relaxation and recovery. There is a need for further research that focuses on a generalisation of the findings by means of the development of instruments that can contribute to improved assessment of the ability of next of kin to care for the patient in the home and whether or not time can be made available in order to promote their well-being.

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References


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