



Karolinska Institutet

Institutionen för Neurobiologi, Vårdvetenskap och Samhälle

Living with haemodialysis close to death – patients' and close relatives' experiences

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ABSTRACT

The overall aim of this thesis is to generate understanding and knowledge about the experiences of patients living with haemodialysis, and their close relatives, near the end of life. In studies I and II we conducted a series of 31 qualitative interviews over a period of 12 months with 8 severely ill patients (aged 66–87) treated with haemodialysis. For study I the text of the interviews was analysed using phenomenological hermeneutics to describe and to elucidate the meanings of being severely ill living with haemodialysis when nearing end of life. For study II the text was analysed using qualitative content analysis to describe inner thoughts and feelings relating to death and dying of these patients.

For studies III and IV, we conducted 14 retrospective qualitative interviews with close relatives of deceased patients treated with haemodialysis about their experiences during end of the patient's life. For paper III the interview text was analysed using phenomenological hermeneutics to describe and elucidate the meanings of being a close relative at the end of life of a severely ill family member treated with maintenance haemodialysis. For paper IV the text was analysed using qualitative content analysis to describe end of life for the patients from the perspective of their close relatives.

The findings of study I suggest that being severely ill and living with haemodialysis near the end of life means living with suffering from a deteriorating body, a high symptom burden, and dependence on advanced medical technology, simultaneously with reconciliation and well-being. The meanings of living with illness and dialysis are intertwined with the meanings of being old.

Study II shows that thoughts and feelings about death and dying are significant and complex for those living with haemodialysis as they approach the end of life. Patients experience a multifaceted presence of death. Their awareness of approaching death may include their repressing of thoughts of death, not as denial, but to allow them to focus on living as fully as possible the time they have left.

Study III shows that close relatives strive to maintain balance and well-being for themselves and for the patient, which we interpreted as their striving to regain balance, and inner equilibrium in their changed and challenged rhythm of life. Study IV shows that after gradual deterioration and increasing care needs, older patients in haemodialysis care with co-morbidities follow three different main paths at the end of life: uncertain anticipation of death; awaiting death after dialysis withdrawal; and sudden but not unexpected death. The ends of their lives are marked by complex symptoms and existential issues related to haemodialysis treatment and withdrawal, and their uncertainty of what to expect at the end of life suggests the need for increased continuity and coordination of whole person care. Both patients and their close relatives are often alone with their existential thoughts.

In their complex lifeworlds, intertwined meanings of living with illness and maintenance of life with haemodialysis treatment near the end of life show that patients live in a borderland of living-dying that is shared by the close relative. Patients and close relatives focus on living when death is close but uncertain, with severe illness and the maintenance of life through advanced technology.

Integrating the philosophy of palliative care (with a focus on symptom relief, team work, communication, relationships, and support of family members) into dialysis care, may support health care professionals in haemodialysis units and other renal contexts, to improve the care of severely ill patients, both earlier in their illness and as they approach the end of their lives.

Keywords: close relative, death, dying, end of life, end-stage renal disease, haemodialysis, palliative care, patient, phenomenological-hermeneutics, qualitative content analysis, retrospective interviews, serial interviews.