



*Living with experiences and memories from
being in intensive care - A lifeworld perspective*

Sissel Lisa Storli



*Avhandling for graden philosophiae doctor (PhD)
i
helsevitenskap*

*Avdeling for sykepleie og helsefag, Institutt for klinisk medisin,
Det medisinske fakultet, Universitetet i Tromsø*

2007

ABSTRACT

Patients' experiences from intensive care during critical illness represent a field of research that has become internationally prominent. Research shows that many patients experience phenomena that do not appear to belong to a commonly shared reality. They recount having been other places than in a hospital bed on the intensive care ward and often in threatening or emotionally intense situations. Traditionally such experiences have been interpreted in a disease perspective and have been denoted as delusional or unreal. Research also shows that patients in the aftermath of intensive care can develop post-traumatic stress symptoms, and the latter is placed in context with a high degree of delusional perceptions relating to the patient's experiences and recollections. On the basis of this, various follow-up offers are in development. One of the aims is to provide information to the patient on what actually occurred so that he/she is able to comprehend that the "delusional" did not occur.

The overall objectives in this study were to gain insight into patients' world of experience while under intensive care and to elucidate the meaning and significance in people's lives of experiences and memories associated with the treatment process. The study was developed proceeding from an inquisitiveness concerning how time spent on the intensive care ward affects patients over a period of years, but also motivated by certain doubts concerning established explanatory models of the "delusional", a doubt that was nourished by conversations with patients during a career of clinical practice over the period of many years. As an approach to an investigation of the aspects of meaning and significance of human experience, a lifeworld perspective is applied and the study is conducted within a hermeneutic-phenomenological framework. The study consists of two parts. In the one, former patients were interviewed 10 years after intensive care treatment (=10). In the other, patients were followed through intensive care treatment via observations/conversations and then interviewed after their release from the hospital (n=10). The dissertation comprises five papers (I-V).

The study shows that what may appear to be "delusional" is in fact *filled with meaning* - meaning that can be discerned if the patient is given the opportunity to scrutinize his/her experiences (II-III). Experiences can be seen as expressions of the fact that we as human beings exist in the world as *lived body in lived time, lived space* and in *lived human relation*. The patient is susceptible to *sensation and mood* (ambience). In this sense, the phenomenon of having been "elsewhere" can be understood as an expression of basic human phenomena, and not necessarily as a result of pathological brain processes (III). A struggle within the individual for survival is manifested. In this struggle there is a *strength* inherent in the individual that can be reinforced by the confirmation that one has *something and someone to live for* (III-IV). Critical illness and intensive care treatment leave durable traces in people's lives. Memories may remain clear even ten years afterwards such as memories entailing bodily sensations and strong emotions (IV). But memories were not necessarily clear in the consciousness. Memories residing in the body at a pre-reflective level and which could be awakened without being triggered by will or conscious thought comprised an important segment of the memory spectrum. Complaints such as "tightening" of the chest and feelings of anxiety were largely associated with such memories, but also with recurrent "remembered images" from frightening situations that had provoked intense emotions. Some of the informants were still striving years later to understand chaotic memories and reactions. Living with experiences and memories is interpreted as a *journey in quest of meaning* (IV). Follow-up offers (I) consisting of patient diaries and conversations were elucidated as potential sources of meaning (V). Coming back to the intensive care unit, being allowed to relive the ambience of the room, appeared to be significant in a quest for meaning. It is via *feeling the room* that experiences and memories can be integrated in life in a *true* way (II-V). The study shows that in aiming at helping the patient on his/her journey of life, the main objective of follow-up should not be to make the patient realize that the "delusions" are delusional, but rather to provide an opportunity for discovery of meaning in experiences and memories, a discovery which bears with it the positive potential that patients can understand new contexts in their own lives.

Key words: Delusion, Follow-up, Hermeneutic-phenomenological, Intensive care, Lifeworld, Lived experience, Meaning, Memories, Patient diaries, Patients' experiences, Phenomenology

LISTE OVER ARTIKLER

Denne avhandlingen er basert på følgende artikler som det vil refereres til i teksten med henvisning til deres romertall:

- I Storli SL, Lind R, Viotti I. (2003). Using diaries in intensive care: a method for following up patients. *Connect: The world of Critical care Nursing*, 2(4), 103-108
- II Storli SL, Asplund K, Heggen K, Bengtsson J, Engelsrud G. (2004). Intensivpasientens erfaringer. En problematisering av minnekategorisering i forskning og klinikk. *Norsk Tidsskrift for Sykepleieforskning*, 6(3), 22-37
- III Storli SL, Lindseth A, Asplund K. (2007). "Being somewhere else" – delusion or relevant experience? A phenomenological investigation into the meaning of lived experience from being in intensive care. *International Journal of Qualitative Studies on Health and Well-being*, 2(3), 144-159
- IV Storli SL, Lindseth A, Asplund K. (2008). A journey in quest of meaning: a hermeneutic-phenomenological study on living with memories from intensive care. *Nursing in Critical Care*, 13(2), 86-96
- V Storli SL, Lind R. The meaning of follow-up in intensive care: patients' perspective. *Scandinavian Journal of Caring Sciences*. Accepted Nov 2007.