

## Waiting for surgery; living a life on hold—a continuous struggle against a faceless system

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Received 16 March 2004; received in revised form 17 August 2004; accepted 7 September 2004

### Abstract

This interpretive-phenomenological study examined the lived experience of being on the waiting list for arthroplastic surgery of the knee or hip. Interviews reveal that respondents experience suffering in different ways: illness-, caring- and life-suffering. Suffering leads to a struggle in order to have their caring needs met and the struggle is often fruitless—against a faceless enemy—“the system”. No one is there to answer their plea or the frustration they experience. This in combination with their present life situation may lead to a disrupted self-image. Finding or creating meaning in suffering appears to be a crucial issue in the struggling process. Respondents who are able to preserve or create meaning in life are able to reformulate their life-world and live a full life, in spite of severe pain and disability.

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*Keywords:* Osteoarthritis; Interpretive phenomenology; Pain; Suffering

### 1. Background

Osteoarthritis (OA) is a major cause of disability, limitations of activity and distress in the older population worldwide (Brandt and Slemenda, 1988; Hochberg, 1984; McCarty, 1989). Approximately 80% of older adults (age >75 years) suffer from OA (Brandt and Slemenda, 1988; Felson et al., 1992). Prior to joint arthroplasty, the individual may have lived through months or years of suffering due to pain and/or

disability, which is the major problem for these people. If we are to obtain a better understanding of their experience, we must, as Copp (1985) reminds us,

“...strain to comprehend what is happening behind the closed eyelids of persons in pain and to gain insight into how they are responding, enduring, coping. Only those know who have a view from the pillow (p. 69).”

Charmaz (1983) addresses this issue referring to the medical view of suffering as solely defined as physical discomfort, which minimizes or ignores the broader significance of those suffering from chronic illness. People with chronic illness experience restricted life

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(due to disability), social isolation, feelings of being discredited and being a burden to others.

According to Lindholm and Eriksson (1993), can suffering be seen as a natural experience of the human being and thereby a dimension of health. In Eriksson's ontological understanding of the patient as "the suffering human being", there are three forms of suffering namely; illness-suffering, caring-suffering and life-suffering. Illness-suffering is caused by the actual symptoms of illness. Caring-suffering consists of pain and inconveniences inflicted by health care through, for example, examinations and surgery, but also by discrediting patients and not believing what they say. Life-suffering is related to what it is to be a person and what happens when one's whole life situation becomes disrupted or threatened by illness (Eriksson, 1997; Lindholm and Eriksson, 1993).

The research that has been conducted on the question of how waiting for arthroplastic surgery affects subjective well-being and perceived health has generally used quantitative methods. Studies conclude that the length of time waiting for surgery has negative consequences for health status (Derrett et al., 1999; Jonsdottir and Baldursdottir, 1998) as well as psychological well-being and social life (Roy and Hunter, 1996). Hajat et al. (2002) suggest that long waiting times are associated with poorer long-term outcome after surgery. The majority of studies have focused on the acceptance of waiting times (Coyte et al., 1994; Ho et al., 1994) and changes in pain, function and health status (Kelly et al., 2001). Only one study has been identified which used qualitative methodology and dealing with waiting for arthroplastic surgery. It focused on patients' views of waiting lists and prioritization for surgery and the conclusion was that the criteria to aid prioritization for arthroplastic surgery need to accommodate the views of patients as well as professionals (Woolhead et al., 2002).

According to Toombs (1992), can phenomenology be used to elucidate the domains of unreflective, taken-for-granted lived experience in order to provide a detailed account of the manner in which we interpret the world of everyday life—the life-world. She further points out that,

"In order to understand the nature of illness and the experience of the patient, it is necessary to focus upon the lived experience of embodiment (p. xiv)."

In Sweden, approximately 18,000 people a year undergo arthroplastic surgery due to OA of the hip and knee joints (Centre for Epidemiology, 1985–2000). On average, they have to wait for 6–24 months before they undergo surgery (Federation of County Councils in Sweden, 2003). Most health care in Sweden is publicly funded and provided by the county councils in the

different regions of the country. There are few alternative private caregivers and the ones that exist are mostly located in the larger cities. In the last 15 years, public health care has been the subject of major financial cutbacks and the resources at hospitals have been reduced. This has resulted in prolonged waiting times for specialized care, such as orthopaedic surgery.

The aim of this study is to explore people's lived experience of being on the waiting list for arthroplastic surgery of the knee or hip and its impact on daily life.

## 2. Method

The method known as interpretive phenomenology (IP), as described by Benner (1994a), was used in this study. IP is developed within a phenomenological framework of reference (Benner and Wrubel, 1989; Heidegger, 1962; Merleau-Ponty, 1962/2002). Using this approach, lived experience was understood as the ways people encounter situations through their embodied intelligence, in relation to their personal concerns and understanding of the situation. Merleau-Ponty (1962/2002) describes phenomenology as the study of essences, and by this offering us an account of space, time and the world as we live it.

Interpreting peoples lived experience includes a methodological feature relating the particular to the universal, part to whole and episode to totality (Van Manen, 1997).

Interpretive inquiry begins from practical, concerned engagement in some kind of breakdown in human affairs (such as having OA). An ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the breakdown and opens up new possibilities for engaging the problem (Benner, 1994a).

A goal of an interpretive account is to understand and find commonalities in everyday skills, practices and embodied experiences. This can be achieved by finding paradigm cases that embody the meanings of everyday practices, and presenting them in a way that they are not destroyed, distorted, decontextualized, trivialized or sentimentalized (Benner, 1994a).

### 2.1. Respondents

The respondents were included in the study in two phases to obtain a broad view of the lived experience of being on the waiting list for surgery. During the first phase, nine patients were admitted consecutively from the admissions list (in January–March 1999) at a hospital in central Sweden. Each of these nine respondents had undergone total knee arthroplasty (TKA) due to OA of the knee, 1 week prior to their interview. Prior to arthroplasty, all of them had been on the waiting list

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