LIVING WITH DYSPHAGIA some aspects of the experiential meaning of handicap, adaptedness and confirmation

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ABSTRACT

This thesis is based on three studies (patients n=19, pensioners n=796, students n=1295). The data collection was made by means of interviews and questionnaires. An action-theoretical approach was used as framework for interpretation of data. The purpose of the thesis was to describe individuals' experiences of living with, mainly, oesophageal dysphagia. The description is to a large extent orientated to the domains of handicap, confirmation and adaptedness. Central to this purpose is the contribution of conceptual formation by development of scales concerning handicap and adaptedness and an inquiry aiming at a typology of confirmation.

The results showed that all patients with longstanding dysphagia regarded dysphagia as a handicap. This experience was due to the disabilities connected with the eating situation and to the fact that dysphagia restricted other aspects of life such as capacity to work, exercise and leisure time. Reduced self-esteem and feelings of shame and guilt because of dysphagia were common as well as denial and concealment of dysphagia. Anxiety at meals and other chest symptoms than dysphagia were common in patients and dysphagic pensioners. The higher the goals of eating, the greater the subjective severity of dysphagia. Ten percent of students had dysphagia. Living with dysphagia demanded several coping strategies. Most of the students reported mild complaints and felt adapted to their dysphagia. The higher the goals of eating, the more subjective maladaptedness of dysphagia. Subjective maladaptedness was associated with environmental conditions and need for emotional and informational support. There was concordance between students' beliefs in the causes of their dysphagia and corresponding coping strategies.

Confirmation was redefined as having the components "sympathy", "allowing action", "understanding" and "competence". The patients' and the dysphagic pensioners' experiences of the physician's confirmation were closely connected with their reports of help and improvement in their swallowing ability. Feelings of disconfirmation were common with patients, pensioners and students. Lack of "sympathy", "allowing climate" and "understanding" were common in the patients' spontaneous remarks about their consultation. Patients and pensioners with final oesophageal diagnoses often received other preliminary diagnoses than those of oesophageal origin. The main symptom, dysphagia, was often not addressed to the physician as their first symptom. Chest symptoms other than dysphagia were common. Patient characteristics, for example, sex, age, severity of dysphagia and personality variables did not influence their possibilities to be confirmed by the physician. The scale of handicap (DGH Handicap Scale), the scale of adaptedness (ABCD Adaptedness Scale) and the typology of confirmation (SAUC Confirmation Model) were shown to be useful tools for the specific organization of data.

Key words: oesophageal disorders, action theory, motivation, interview, disability, handicap rating, adaptedness rating, coping, confirmation

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