The LYMPHO-RAC study: analyzing out-of-pocket payments of primary lymphedema patients in France

Background and rationale: Primary Lymphedema is a form of lymphedema which is not directly attributable to another medical condition. It develops as a result of many complications and depending upon age of onset the most common are congenital lymphedema, lymphedema praecox and lymphedema tarda (Mendola 2013, Quéré 2002). According to Orphanet, the prevalence of all of these primary lymphedemas is around 1 to 5/10 000 (www.orpha.net). It is a chronic disabling condition responsible for serious infectious complications and functional disability profoundly altering the quality of life of patients. Its treatment management needs a multidisciplinary care and it’s based on the use of specific medical devices (HAS 2010 Quéré 2014), but many of these treatments are partial or not reimbursed by social security and health insurance. The out-of-pocket costs can be substantial for a patient; the partial coverage for treatment and supplies creates barriers for the patient including delays in treatment initiation and completion.

Relevance: The analysis of out-of-pocket costs represents a major challenge for assessing the efficiency and the equity of access to healthcare system based on needs and not on ability to pay. It could be a factor threatening the access. In 2013, the average annual load remains in the general population (thus including persons not seeking care) was 200 € (Franc 2013) The right to health protection, respect for dignity and equity are enshrined in the Public Health Code, (Law of 4 March 2002) on patients' rights and the quality of the system health.

Objective: To quantify and to analyse out-of-pocket payments of patients with primary lymphoedema in France.

Methods: Observational prospective and multicenter study from 150 patients in 17 centers. Data costs of treatment before and after reimbursement by social security and health insurance.