

INCIDENCE AND PREVALENCE OF LYMPHOEDEMA

Defining incidence and Prevalence

Epidemiology is a term used to describe the study of the causes, distribution and control of disease in populations. In order to better understand the burden of any particular disease or condition on a specific population, it is vital to have good information on how many people are currently suffering from the condition (prevalence) and how many new cases develop over a defined timeframe, usually a year (incidence). This is important as it allows us to compare different populations over time and helps greatly in planning health services.

One of the main difficulties in using this approach to study lymphoedema is that there is currently no agreed definition of lymphoedema and therefore we are not sure how many people suffer from this condition here in Northern Ireland. In evaluating the epidemiology of a condition, it is essential to describe exactly how the disease is defined. An exact and valid definition allows for comparisons between populations. This is further compounded by the fact that lymphoedema is not always recognised at all or on some occasions may be misdiagnosed due to similarities with other conditions.

This difficulty is evident when the worldwide research on the incidence and prevalence of Lymphoedema is taken into account. Only a relatively small number of studies have considered the level of lymphoedema in the population and all highlight the limitations of their literature reviews. Of those studies which have been undertaken, different definitions of lymphoedema and indeed different measurement tools have been used. As a result, there is no strong body of evidence which relates to population incidence or prevalence of lymphoedema, therefore making it very difficult to draw any comparisons or robust conclusions.

Literature summary – population incidence:

A systematic search of the literature revealed a limited number of papers relating to population incidence and prevalence, whilst a few have reviewed population burden (Williams, Logan, Campasi, Stitza), most identify incidence within a particular sub group e.g. those who have developed the condition as a result of cancer treatment.

Only one study (Moffat) was found which reported the incidence of lymphoedema in a local population (SW London). This study found a population prevalence of 1.33 per 1000 for all ages, rising to 5.4 per 1000 in the over 65 age group. The authors also highlighted that the study was likely to underestimate the true burden of the condition. Using these rates, this would equate to 2274 people in Northern Ireland suffering from lymphoedema, with 1258 over 65's having the condition (NISRA June 2004 mid year estimates).

In analysing a subsection of those who were clinically identified as having lymphoedema, 25% had developed the disorder as a result of cancer

treatment. It was interesting to note that 47% developed symptoms within one year with only three developing symptoms 10 years after cancer therapy.

The next section highlights incidence of lymphoedema related to specific causes and considers the impact for Northern Ireland if the rates are applied here.