Patient perspectives on centralisation of low volume, highly specialised procedures in Sweden

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Introduction

Experience and common sense tells us that a person doing something repeatedly has a greater chance of mastering it compared to someone who only does it a few times. This correlation between volume and outcome is scientifically proven and has been much discussed in healthcare [1-4]. The relationship between volume and clinical outcomes is probably not just as simple as ‘more practice makes perfect’. It can also be due to larger volumes creating an opportunity to build well-functioning structures and define appropriate procedures involving different specialties. Consequently, an important organisational principle is that health care services should be provided at the administrative level associated with the best possible outcome for the patient, with due concern for an efficient resource use.

Improvement in medical outcomes is a compelling argument for centralisation of specialised, low volume health care services. However, as political and economic needs come into play, it is easy to see that different stakeholders, including surgeons, nurses, hospital administrators, politicians, and citizens, sometimes have conflicting objectives in decisions about where to locate health care. At what administrative level different health care services should be provided is therefore a matter of debate in many countries [5,6]. The perspective of the patient is therefore completely lost in this, but also patients may face important trade-offs between access to the most experienced surgeons, vicinity, cost, and continuity of care [7,8].

Centralisation of specialised health care services is a topic of current interest in several European countries, including Sweden. In 2012, the Swedish National Board of Health and Welfare (SNH) published a report on the future development of health care services in Sweden, in which it was concluded that the SNH was of the opinion that a single national system for organ transplantation should be established, and that the SNH was of the opinion that there is a need to develop a national system of organ transplantation with a single organ transplant centre in Sweden [9].

Objectives

The objective of this study was to explore important considerations around factors of importance and anticipated consequences from a patient perspective in decisions regarding centralisation of specialised health care services in Sweden, using the ongoing work with NSMC as a case.

Methods

The ongoing work with the NSMC was used as a case for understanding the factors of importance to patients in decisions regarding centralisation of specialised health care. In a separate survey, the primary health care services and hospitals were included. The survey was conducted in 2013 and the web application was open for about two weeks. The survey included questions regarding respondent demographics, factors influencing patient perspectives in health care, and anticipated positive and negative effects of centralisation of care services on these factors. The results of the survey were then used to inform the development of a centralisation decision model for patients, and the rest of the factors were suggested to be of importance from a patient perspective during the centralisation of care services. A multiple-choice methodology was used to determine the factors of importance and the importance of each factor. The final results of the survey was analyzed by calculating percentages of respondents providing an answer.

Results

A total of 561 persons responded to the survey and the majority were members of either The Swedish Association for Survivors of Accident and Injury (53%) or The Children’s Heart Association (43%). The remaining respondents were either members of Rare Diseases Sweden (3%) or The Swedish Association for Gastrointestinal Disorders (3%). Patients accounted for 57% of the responders, while 43% of the responders reported that they were relatives to an affected patient. The gender distribution among the responders was 70% females and 30% males. An overview of the factors regarded to be of highest and lowest importance by the survey respondents is presented in Figure 1.

Discussion and conclusions

Both the interview and survey results indicate that quality of care and well-functioning care pathways are of highest importance for patients in relation to centralisation of health care services, and that cost and income loss, and geographic location of low performance of low importance. There is a high level of agreement in responses from the patient association members and the health care decision-makers. This suggests that decision makers involved in the work with NSMC in Sweden seem to have a good understanding of what patients value, which is a good starting point for considering the patient perspective when taking and implementing centralisation decisions.

Most of the patient association representatives and health care decision-makers interviewed suggested quality of care and well-functioning care pathways are of high importance from a patient perspective. Continuity of treatment, individualised care-ability, accessibility for contact and information, and involvement in the care process were also regarded to be of high importance. However, income and location were regarded to be of low importance.

Quality of care was the only factor that the majority of patient association members (53%) anticipated would be ‘affected positively’ by centralisation, which in many cases is likely to be true in consequence to the volume/outcome relationship [1-4]. The view of that, many patients in need of specialised care are likely to be satisfied with and have acceptance for centralisation decisions. This is especially true since two factors likely to be affected negatively in consequence of geographic location and costs and income loss - are factors many patients regard as less important [7,8]. However, only 35% believe that centralisation affect well-functioning care pathway positively, which may be more alarming. Many of the factors that the survey respondents suggest are important, such as well-functioning care-pathway, individualised care-ability of treatment, accessibility for contact and information and involvement in the care process, are not sufficiently studied in relation to centralisation. This is also reflected in the survey results, which indicate that responders have different opinions on those factors which would be affected in case of centralisation, which may be harder to predict how those factors will be affected in case of a centralisation decision. Possibly, these evoke after centralisation is highly dependent on the implementation process and if given sufficient attention they may not be affected negatively.

References


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