



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



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ABSTRACT

This study explores important considerations from a patient perspective in decisions regarding centralisation of specialised health care services. The analysis is performed in the framework of the Swedish National Board of Health and Welfare's ongoing work to evaluate and, if appropriate, centralise low volume, highly specialised, health services defined as National Specialised Medical Care. In addition to a literature review, a survey directed to members of patient associations and semi-structured interviews with patient association representatives and health care decision makers were conducted. The results showed that from a patient perspective, quality of care in terms of treatment outcomes is the most important factor in decisions regarding centralisation of low volume, highly specialised health care. The study also indicates that additional factors such as continuity of treatment and a well-functioning care pathway are highly important for patients. However, some of these factors may be dependent on the implementation process and predicting how they will evolve in case of centralisation will be difficult. Patient engagement and patient association involvement in the centralisation process is likely to be a key component in attaining patient focused care and ensuring patient satisfaction with the centralisation decisions.

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1. 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 health care (while the discussion has mainly focused on surgery, the correlation is likely to also be present in other areas, e.g. internal medicine) [1–4]. The relationship between volume and clinical outcome is probably not just as simple as

‘practice makes perfect’, but also about larger volumes creating an opportunity to build well-functioning structures and define appropriate procedures involving different specialities. 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.

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

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perspective of the patient is sometimes 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].

Improvement in medical outcomes is a compelling argument for centralisation of specialised, low volume health care services, particularly for surgical procedures where the volume/outcome relationship is supported by a wealth of empirical evidence [1–4]. However, many volume/outcome studies are cross-sectional and not properly adjusted for case mix, limiting the usefulness of the results for decision-making. These cross-sectional studies do not give reliable information about the outcome if a given health care unit would increase its volumes. Furthermore, studies are often restricted to use mortality rate as their only outcome measure, which by itself is not a comprehensive measure of health care quality [2,4]. Also, in many studies the threshold number of performed procedures per year needed to achieve acceptable medical outcomes (in terms of mortality) is actually shown to be very low [4]. These aspects make the results difficult to use as references for health care decision-makers, and are why the perspectives generally adhered to in centralisation decisions often seem to be that of either the payer or the provider.

It has been suggested that increased patient involvement and consideration of the patient perspective in health care planning and decision-making have a positive impact on the medical outcome and may increase satisfaction of both patients and health care professionals [9]. Yet, remarkably little has been written about the patient perspective in relation to centralisation decisions and available research has mainly focused on the patient trade-off between clinical outcome and travel time [10,11]. However, the wider issue of patient-reported preferences in relation health care has been studied to some extent. A systematic literature review demonstrated that central factors determining patients' choice of health care provider include accessibility, staff competence, continuity, waiting time, and clinical outcomes [12].

Centralisation of specialised health care services is a topic of current interest in several European countries. In the United Kingdom, the National Health Service has recently launched a new model for commissioning specialised services, moving away from regional commissioning to a single national approach to both commissioning and contracting. The new system will focus on a range of rare conditions and low volume treatments ranging from medical genetics, kidney disorders, and uncommon cancers to complex cardiac interventions, burn care, and some specialised services for children [5].

Also in Sweden, work is currently ongoing to evaluate and, if appropriate, centralise low volume, highly specialised, health services defined as National Specialised Medical Care (NSMC) [6]. Similar work is ongoing in a separate process in cancer care, where specialised cancer care is concentrated to regional or national centres [13], but this paper will focus on the NSMC.

Sweden has 20 county councils independently delivering health care. The population in the counties vary between 150 000 to more than 2 million [14]. The scope of

NSMC is to centralise specialised health services to only one or two county councils servicing the entire country, in order to ensure high-quality care and financial efficiency. Since 2007, the National Board of Health and Welfare (NBHW) has been assigned by the Ministry of Health and Social affairs to decide which specialised health care services in Sweden should be designated as NSMC and to decide which county councils will be responsible for providing the health service [6]. So far, the NBHW has evaluated 19 interventions for eligibility as NSMC and out of these 13 have been designated. Predominately surgical procedures have been designated as NSMC, including paediatric heart surgery, craniofacial surgery, and lung, liver and heart transplants [15]. In 2013 the NBHW conducted an internal evaluation of the ongoing work with NSCM. Despite being acknowledged as highly important by the assessors, the patient perspective in the decision-making processes was put outside the scope for the evaluation [16].

The aim of the current study was to explore factors that are perceived as important for patients in relation to decisions around centralisation of specialised health care services in Sweden. Furthermore, a secondary aim was to understand how the patient perspective is considered in centralisation decision-making processes in Sweden, using the NSMC as a case.

2. Materials and 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 addition to a structured literature review, both qualitative and quantitative methods were applied for triangulation purposes. The qualitative component included semi-structured interviews with stakeholders selected for having experience from or insight into the ongoing work with the NSMC and represented different perspectives. The quantitative component included a survey conducted among members of patient associations affected by the decisions made by the committee for the NSMC.

2.1. Literature review

A structured literature review was performed to identify factors previously suggested to be of importance from a patient perspective in relation to work with, and decisions regarding, centralisation or other forms of allocation of health care. Considering the limited number of publications in this research field, the search strategy was designed to also capture studies covering patient-reported preferences in relation to the wider issue of choices in health care. The review was carried out in Medline and Embase in December 2012, and was later updated in January 2013. The search resulted in 72 publications in total and returned one literature review of particular interest, which reported factors of importance for patient choice of health care [12]. This literature review was used in the development of the patient survey and discussion guide used during the interviews.

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