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Quality of hospital care for neuromuscular disorders from the patients' perspective

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1. Introduction

Neuromuscular disorders (NMD) cover a wide range of conditions as over 600 different types of diseases are known. However, all these diseases have a prevalence below 5 out of 10,000 European Union inhabitants and are therefore categorized as 'rare diseases'. Although patients rely heavily on hospital care for diagnosis, acute care, surgery, and treatment, healthcare professionals in hospitals often have limited knowledge of neuromuscular disorders and little experience with diagnosis and treatment. In order to provide care of highest quality, concentration of care for patients with NMD in expert centres is desirable [1]. The volume of surgery and specialization have previously been studied especially in the field of oncology care [2]. Results indicate that high surgeon volume and specialization are positively associated with improved patient outcome [3–5]. It is presumed that cooperation between experts of neuromuscular teams will lead to a quicker draft of a cost-effective treatment plan. This is important, because diagnostic delay is common [6]. Apart from that, cooperation creates opportunities for scientific research [7].

An estimated 45,000 people in the Netherlands (population of 16.5 million) have a neuromuscular disease. The Dutch Association for Neuromuscular Diseases (VSN) is the most important patient organization for these patients [8]. The VSN is in favour of concentrating care for patients with NMD to one of the seven university hospitals the Netherlands counts. Although the patient organization as well as the government [9] are in favour of concentration of care, it is unclear how individual patients experience care in centres of expertise (university hospitals) as compared to general hospitals. The objective of this study is to measure experiences with hospital care through the eyes of patients with neuromuscular disorders. For that purpose, an instrument for measuring patient experiences has been developed. This instrument is a member of a larger 'family' of patient experience questionnaires, the so-called Consumer Quality Index or CQ-index [10], and is based on American and other examples of questionnaires [11,12].

Our research questions were:

- (1) What is the quality of hospital care according to patients with neuromuscular disorders?
- (2) What are differences in experiences between different components of the hospital care process?
- (3) What are differences in experiences between university and general hospitals?

2. Patients and methods

For a detailed description of the development and validation of a CQ-index instrument, see other publications about these instruments [13–16].

The development of a CQ-index questionnaire for patients with neuromuscular disorders (CQ-index NMD) consisted of a qualitative phase with focus groups in which items for the test version of the questionnaire were generated [17,18], followed by a quantitative phase in which the preliminary instrument was tested in a group of patients according to standardized test protocols [18–20]. This study was conducted in cooperation with the VSN.

2.1. CQ-index NMD hospital care – experience

The CQ-index NMD assessing experiences with hospital care contained 104 questions divided over 6 themes starting with the introduction (1 item), followed by questions about the diagnosis (25 items), medicines (4 items), outpatient department (20 items), admission to hospital (24 items), and cooperation and communication between different healthcare institutions (18 items). For each part of the questionnaire, an item was included about the type of hospital (university or general) where the type of care was received. The final part of the questionnaire contained questions on demographic characteristics. Respondents were asked to report about their experiences with hospital care of the last 2 years. The experience items had different response formats: (1) never, sometimes, usually and always, or (2) not a problem, a small problem, and a big problem, or (3) yes and no. For every theme a global rating from 0 to 10 could be given, with a score of 10 representing the best possible care.

2.2. Data collection

The CQ-index NMD Hospital Care was sent to 700 members of the Dutch Association for Neuromuscular Diseases (VSN). Patients (18 years and older) with a neuromuscular disorder were randomly selected from their membership register. Data were collected between November ('10) and January ('11) according to the mix-mode method of Dillman [21].

2.3. Analysis

Data were analyzed following a manual for the development, measurements and data-analysis of CQ-index questionnaires [18]. Different response formats of the experience questionnaire were converted into a scale of one to four, where the highest score was the most positive answer. We performed principal component analysis with oblique rotation in order to ascertain the underlying structure of the experience questionnaire. Questions with the highest factor load (minimum of >0.3) for a certain scale were included. Next, we performed reliability analysis on the formed scales. A factor with a Cronbach's α greater than 0.70 was considered as reliable. Table 1 shows the results of these analyses. From Table 1 it is clear that the instrument consists of five reliable scales measuring patients' experiences with hospital care for neuromuscular disorders.

3. Results

3.1. Response

At the end of the data collection period, 416 individuals returned the experience questionnaire. After exclusion according to the criteria, the experience data of 386 participants (57.3%) were analyzed.

[Table 1]

[Table 2]

[Table 3]

3.2. General hospital vs. university hospital

The global ratings of the different components of hospital care are presented in Table 2. Overall, participants rate the components of hospital care as adequate with grades between 7.0 and 7.5. However, the cooperation and continuity of care between different healthcare institutions is valued as fairly poor with an average rating of 6.3.

A significant difference in rating of the diagnosis process was found between university and general hospitals. While general hospitals score poorly at this aspect with a 4.8, university hospitals score a 7.7. Patients treated in outpatient departments of a university hospital also rated this component of hospital care significantly better.

The factors measuring five aspects of hospital care are: communication with doctor during period of diagnosis, information services of outpatient department, communication with doctors of outpatient department, communication with nurses during admission to hospital, and cooperation and continuity of care (cf. Table 1). Table 3 displays the average scale scores of these aspects in total and for university and general hospitals in more detail. The scores represent the average score of all items within this scale. Higher scores represent better experiences. Scale scores were high for the communication with the doctors of the outpatient department as well as for the communication with the doctor during the period of diagnosis and nurses during the time of admission to hospital. Patients reported relatively negative experiences with the information services of the outpatient department which were even worse for those who visited a general hospital. The care received in a university hospital was experienced significantly better considering the aspects of communication with both doctors during period of diagnosis and doctors of outpatient department.

4. Discussion

In this study, we gained more insight in the actual experiences according to patients with neuromuscular disorders. We were also able to investigate the difference in perceived quality of care for general and university hospitals. The results show that patients have better experiences with the different components of hospital care when this was received in university hospitals where they have more expertise with diagnosis and treatment of neuromuscular disorders. High quality of care for patients with NMD can be obtained by regionalization and concentration of the care in a few university hospitals with specialized neuromuscular centres. Therefore, collaboration between both university and general hospitals is essential in order to improve the quality of care. Referral of patients with NMD to neuromuscular centres with adequate experience and higher case-volumes will improve both the quality of clinical outcomes, as the perceived quality of care.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.nmd.2012.08.006>

References

- [1] High Level Group on Health Services and Medical Care. Work of the High Level Group on health services and medical care during 2005. Brussels: European Commission, 2005.
- [2] Chowdhury MM, Dagash H, Pierro A. A systematic review of the impact of volume of surgery and specialization on patient outcome. *Br J Surg* 2007;94:145–61.
- [3] Wouters MW, Karim-Kos HE, le Cessie S, et al. Centralization of esophageal cancer surgery: does it improve clinical outcome? *Ann Surg Oncol* 2009;16:1789–98.
- [4] Lemmens VE, Bosscha K, van der Schelling G, et al. Improving outcome for patients with pancreatic cancer through centralization. *Br J Surg* 2011;98:1455–62.
- [5] Nienhuijs SW, Rutten HJ, Luiten EJ, et al. Reduction of in-hospital mortality following regionalisation of pancreatic surgery in the southeast of the Netherlands. *Eur J Surg Oncol* 2010;36:652–6.
- [6] Faurisson F. Survey of the delay of diagnosis for 8 rare diseases in Europe (Eurordiscare2). 2007. http://www.eurordis.org/IMG/pdf/Fact_Sheet_Eurordiscare2.pdf.
- [7] van Engelen BG, van Veenendaal H, van Doorn PA, et al. The Dutch neuromuscular database CRAMP (Computer Registry of All Myopathies and Polyneuropathies): development and preliminary data. *Neuromuscul Disord* 2007;17:33–7.
- [8] Boon W, Broekgaarden R. The role of patient advocacy organisations in neuromuscular disease R&D—The case of the Dutch neuromuscular disease association VSN. *Neuromuscul Disord* 2010;20:148–51.
- [9] de Boer RH, Bruggeman LC, Dekker J, Bontje MJW, Schippers EI. Governmental agreement 2012–2015 (in Dutch). The Hague: Netherlands Ministry of Public Health, Welfare and Sports; 2011.
- [10] Delnoij D, Rademakers J, Groenewegen P. The Dutch consumer quality index: an example of stakeholder involvement in indicator development. *BMC Health Serv Res* 2010;10:88.
- [11] Hargraves JL, Hays RD, Cleary PD. Psychometric properties of the Consumer Assessment of Health Plans Study (CAHPS) 2.0 adult core survey. *Health Serv Res* 2003;38:1509–27.
- [12] Sixma HJ, Kerssens JJ, Campen CV, Peters L. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. *Health Expect* 1998;1:82–95.
- [13] Stubbe JH, Gelsema T, Delnoij DM. The Consumer Quality Index Hip Knee Questionnaire measuring patients' experiences with quality of care after a total hip or knee arthroplasty. *BMC Health Serv Res* 2007;7:60.
- [14] Stubbe JH, Brouwer W, Delnoij DM. Patients' experiences with quality of hospital care: the Consumer Quality Index Cataract Questionnaire. *BMC Ophthalmol* 2007;7:14.
- [15] Zuidgeest M, Sixma H, Rademakers J. Measuring patients' experiences with rheumatic care: the consumer quality index rheumatoid arthritis. *Rheumatol Int* 2009;30:159–67.

- [16] Berendsen AJ, Groeier KH, de Jong GM, et al. Assessment of patient's experiences across the interface between primary and secondary care: Consumer Quality Index Continuum of care. *Patient Educ Couns* 2009;77:123–7.
- [17] Porter M. *A Dictionary of Epidemiology*. New York: Oxford University Press; 2008.
- [18] Sixma H, Delnoij D, Stubbe J, et al. *Manual CQI instruments: an instruction for the development and use of Consumer Quality Index (CQI) questionnaires (in Dutch)*. Utrecht: Centrum Klantervaring Zorg (Dutch Centre for Consumer Experience in Health Care); 2008.
- [19] Sixma H, Delnoij D. Measuring patient experiences in the Netherlands: the case of hospital care. *Eur J Public Health* 2008;18.
- [20] Sixma H, Triemstra M, Delnoij D. The Consumer Quality Index, CQI): background, general characteristics and advantages of a standardized approach to measure user views on quality of care. *Euro J Public Health* 2007;2:33–4.
- [21] Dillman DA. *Mail and internet surveys: the tailored Design Method*. New York: Wiley; 2000.

Tables

Table 1 Reliability and item description of the factors in the questionnaire.

Item	Factor and item description	α
	<i>Factor 1: Communication with doctor during period of diagnosis</i>	0.84
12	Were you able to ask your doctor questions?	
13	Did the doctor explain things in an understandable manner?	
14	Was the doctor (or team of doctors) who diagnosed you skilled in the field of neuromuscular diseases?	
17	During the time of diagnosis, were you able to ask the doctor questions (personally or by telephone)?	
	<i>Factor 2: Information services of outpatient department</i>	0.71
38	Was treatment and advice of different hospital doctors synchronized?	
39	Did the doctors give you information that was contradictory?	
47	Was there a fixed contact person available who you could consult for questions?	
48	Did you receive information about treatment and checkups coming within a year?	
49	Were you able to ask questions when things about coming treatment and checkups were not clear for you?	
	<i>Factor 3: Communication with doctors of outpatient department</i>	0.89
40	Did the doctors take enough time for you?	
41	Did the doctor listen to you carefully?	
42	Did the doctors take you seriously?	
	<i>Factor 4: Communication with nurses during admission to hospital</i>	0.91
68	Did the nurses take into account your capabilities and disabilities during admission to hospital?	
69	Did the nurses have enough time for you?	
70	Did the nurses listen to you carefully?	
71	Did the nurses take advice about your care from you and your family seriously?	
	<i>Factor 5: Cooperation and continuity of care</i>	0.89
85	Did your main care provider think along with you about possible care you might need in the future?	
86	Was your main care provider skilled in the field of neuromuscular diseases?	
88	Did your hospital doctors know where you receive other care?	
89	Did your hospital doctors know of what kind of care you received from other healthcare providers?	
90	When referral was needed, did the doctors refer you on time?	
91	When referral was needed, did the doctors refer you to the appropriate healthcare professionals?	

Table 2 Global ratings of the different components of the hospital care process in university and general hospitals for patients with neuromuscular disorders (grade from 1 to 10).

Component of hospital care	Total	SD	N	University hospital	N	General hospital	N	p-value
Diagnosis	7.0	0.41	35	7.7	24	4.8	9	<0.01
Outpatient department	7.5	0.10	344	7.8	210	6.8	76	<0.001
Admission to hospital	7.3	0.30	50	8.0	22	7.0	23	NS
Cooperation and continuity of care	6.3	0.17	154	6.9	24	7.2	13	NS

Table 3 Experiences of adults with neuromuscular disorders with different aspects of hospital care in university and general hospitals (scored on a scale from 1 to 4).

Factor	Total	SD	N	University hospital	N	General hospital	N	p-value
Communication with doctor during period of diagnosis	3.15	0.15	34	3.34	23	2.44	9	<0.01
Information services of outpatient department	2.37	0.10	47	2.56	26	2.04	17	<0.01
Communication with doctors of outpatient department	3.35	0.05	182	3.47	119	3.01	42	<0.001
Communication with nurses during admission to hospital	3.11	0.12	49	3.21	23	3.03	23	NS
Cooperation and continuity of care between different healthcare institutions	3.00	0.08	104	3.21	20	3.25	13	NS