Feasibility of web-based decision aids in neurological patients

Janine A van Til*, Constance H C Drossaert*, Gerbert J Renzenbrink†, Govert J Snoek†, Evelien Dijkstra*, Anne M Stiggelbout‡ and Maarten J IJzerman*

*Health Technology and Services Research, University of Twente, Enschede; †Centre for Rehabilitation "Het Roessingh", Enschede; ‡Leids Universitair Medical Center, Leiden, The Netherlands

Summary

Decision aids (DAs) may be helpful in improving patients' participation in medical decision-making. We investigated the potential for web-based DAs in a rehabilitation population. Two self-administered DAs focused on the treatment of acquired ankle-foot impairment in stroke and the treatment of arm-hand function in cervical spinal cord injury (SCI). Data collection comprised a telephone interview and a self-reported paper questionnaire. Of the patients who agreed to participate, 39 stroke patients (44%) and 38 patients with SCI (78%) returned a questionnaire. More than 75% of patients expressed a need for more information about the treatment of disease-related impairment. The DAs were highly appreciated by both patient groups. Nearly all patients expressed a positive attitude towards the use of the web-based DAs in general practice. The DAs had a positive effect on the knowledge about the treatment alternatives in the stroke patients ($P = 0.001$), although not in the patients with SCI. The DAs reduced patients' conflict about treatment ($P < 0.05$). The effect of the DAs on patients' desired role in decision-making was limited. Web-based aids are feasible in the rehabilitation population with access to a computer and can improve the knowledge gaps in patients.

Introduction

Providing patients with information about their disease process, treatment options and the expected outcomes of treatment is an important part of improving quality in health care.[1] Legally, it ensures that a patient has good knowledge of the treatment process and outcome before agreeing to treatment. Ethically, it can help patients to become actively involved in the treatment decision-making process.[2–4] Doctors do not always succeed in providing sufficient information to patients.[1,5–7] Decision aids (DAs) are promoted as adjuncts to, or as preparation for, a consultation with the doctor.[8,9] A DA is defined as an intervention designed to help people make choices by providing information on the options and outcomes relevant to a patient's health.[10–12] A DA differs from traditional educational materials because it explicitly describes treatment options, includes qualitative and quantitative information about benefits and risks, and motivates patients to view the information in the light of their own values and preferences.[13] It is known that the use of DAs can result in more realistic expectations of treatment outcome, improve agreement between personal values and choice of treatment, and result in an increased desire to participate in the decision-making process.[14]

In rehabilitation medicine, patient participation in treatment decision-making is highly valued because improving patient autonomy is an important goal.[6–15] Information provision to the patient is a prerequisite for a patient to participate in decision-making.[10] Although DAs can take on several forms, such as a brochure, an audiotape, a leaflet or a video, computer-based aids are preferred because they are convenient, accessible and flexible. The feasibility of these DAs in an older, chronically ill and sometimes cognitively impaired rehabilitation population is unknown. The first aim of the present study was to investigate the need for and general feasibility of DAs in a rehabilitation population. The second aim was to evaluate the feasibility of two web-based DAs. The third aim was to measure the effect of the DAs on patients' knowledge, decisional conflict and preferred role in decision-making.

Correspondence: Dr J A van Til, Health Technology and Services Research, University of Twente, PO Box 217, 7500 AE Enschede, The Netherlands (*Fax: +31 53 480 2159*; *Email: j.a.vantil@utwente.nl*)

 DOI: 10.1258/jtt.2009.001012

Methods

The DAs were self-administered aids. The DAs focused on two relevant matters in rehabilitation medicine, namely the treatment of acquired ankle-foot impairment in stroke and the treatment of arm-hand function in cervical spinal cord injury (SCI). The DAs were developed by two teams, each consisting of a rehabilitation medicine consultant (physiatrist) and two physical or occupational therapists. The teams used existing written information brochures, scientific literature, and personal and patient experiences to draw up a preliminary version of the DA according to standards set in the International Patient Decision Aids Standards.[12] The preliminary versions of the DAs were evaluated by five independent physiatrists and by ten patients. Based on the results of this evaluation, improvements were made with regard to the content and layout of the DAs.

The DAs presented (1) general information about the disease, (2) general information about the treatment options, (3) a qualitative description of the health-related benefits and harms of each option, (4) the process of treatment, (5) the decision under consideration and the importance of personal values and preferences in determining the best treatment, and (6) a value clarification exercise.

The patients with SCI had been selected from the patient records of seven Dutch rehabilitation centres during two previous studies.[16] The stroke patients were selected from the patient records of the local rehabilitation centre. Stroke patients treated between January 2004 and December 2006 were drawn from the database. Only chronic (>1 year) patients were selected for the study.

Patients were informed about the aim of the study in a letter that was sent to their home address and they were subsequently contacted by telephone. Inclusion criteria for the study were (1) acquired ankle-foot (stroke) or arm-hand impairment, (2) access to a computer with an Internet connection and (3) physical ability to complete a paper and pencil questionnaire. After eligibility was confirmed, verbal informed consent was obtained. Ethics permission for the study was not required. A baseline telephone interview was conducted. If the patients completed the interview, the location of the DA was provided to the patients. After one week, a paper and pencil questionnaire was sent. The response in the post-test was 68% for stroke and 83% for SCI patients (Figure 1).

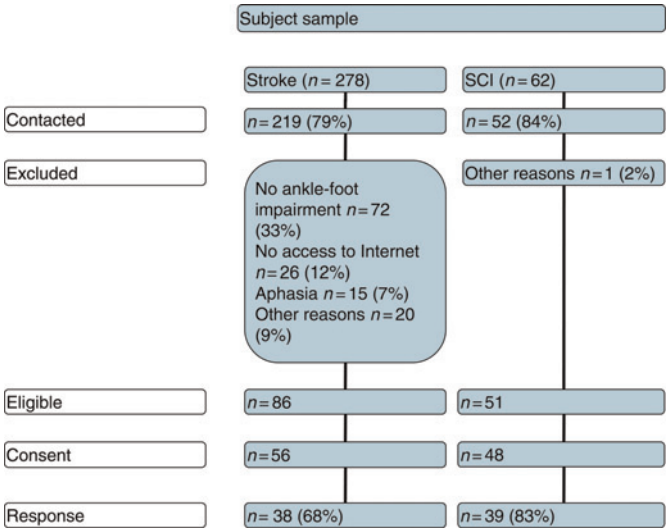

Figure 1 Flow chart for patient inclusion. Contact: number of patients that were contacted by telephone. Excluded: patients excluded based on the inclusion criteria. Eligible: patients eligible for the study. Consent: patients who gave verbal informed consent. Response: patients who returned the paper questionnaire. In contrast to the patients with SCI, those with stroke could not be selected based on the presence of ankle-foot impairment. This explains the larger percentage of excluded patients in the stroke group based on the exclusion criteria

Measures and instruments

At baseline, a patient's demographic characteristics (age, gender, living situation and education) and current use of the Internet were assessed. Information needs were assessed by asking patients whether they had a need for information about the treatment of disease-related impairment and their preferred source of information. To examine the effects of the DAs, the patient's (a) knowledge, (b) decisional conflict about treatment and (c) actual and desired role in the decision-making process were measured. Knowledge was assessed with six true/false statements about the treatment of the disease-related impairment. A knowledge score was calculated by summing the correct answers. Decisional conflict was measured using the Dutch version of the 16-item Decisional Conflict Scale (DCS).[8,17] Only four of the five subscales of the DCS were administered: uncertainty (3 items), uninformed (3 items), unclear values (3 items) and unsupported (3 items). The subscale ineffective choice was omitted because no actual choice for treatment was made in the study. The overall score ranged from 1–5, with 5 indicating higher decisional conflict.

The patients' actual role in treatment decision-making of disease-related impairment and the patients' desired role in a hypothetical future decision-making process were measured with the Control Preference Scale.[18] In this scale, five different vignettes are described that portray a patient's role in treatment decision-making from very active to very passive.

The post-test paper and pencil questionnaire consisted of two parts. First, the feasibility of the disease-specific DAs was determined. The constructs were based on the revised Technology Acceptance Model (TAM).[19] The constructs included the perceived usefulness (6 items; Cronbachs' $\alpha = 0.56$), the perceived user-friendliness (9 items; $\alpha = 0.84$) and the perceived attractiveness (2 items; $\alpha = 0.98$) of the DA, the perceived pleasure derived from using it and the perceived attitude towards the use of the DA in daily practice. Second, (a) knowledge, (b) decisional conflict about treatment and (c) desired role in the decision-making process were measured using the measures described earlier.

Statistical analysis

The effect of the DA on patients' knowledge, decisional conflict and desired role in decision-making was assessed by comparing baseline and post-test scores using Wilcoxon Signed Rank tests. The agreement between the patients' actual and desired role in decision-making was tested using a Wilcoxon Signed Rank test.

Results

Of the patients who agreed to participate, 39 stroke (68%) and 38 SCI (78%) patients returned the completed questionnaire (Figure 1). The average age of the patients with stroke was 56 years, most were males and most lived with a partner (see Table 1). The patients with SCI were on average almost 15 years younger and the majority lived alone.

Feasibility of a web-based decision aid

The majority of stroke and SCI patients expressed a requirement for more information about the treatment of their disease-related impairment. The desired source of information was a web-based information resource in about 40% of stroke patients and in about 50% of SCI patients. These proportions are similar to the baseline experience of patients with the web, as 50% of stroke patients and more than 60% of SCI patients reported using the web every day (Table 1).

Table 1 Demographic characteristics

	Stroke (n = 38)		Spinal cord injury (n = 39)	
	Average	SD	Average	SD
Age (years)	56	12	42	10
	No.	%	No.	%
Males	23	61	29	74
Females	15	40	10	26
Living situation				
With partner	31	82	15	39
Alone	7	18	18	46
Other			6	15
Education				
Low	6	16	5	14
Middle	20	53	24	62
High	12	32	10	26
Information need				
Yes	30	91	30	77
No	3	9	9	23
Desired source of information				
Doctor	11	36	2	6
Written brochure	6	19	12	33
CD/DVD	1	3	3	8
Online	13	42	19	53
Internet use				
Never	1	3	1	3
Occasionally	5	14	1	3
Once a month	2	6	0	0
Once a week	7	19	0	0
A few times a week	3	8	12	32
Every day	18	50	24	63

The percentages are based on valid cases only

Table 2 Scores relating to the feasibility of decision aids

	Stroke		Spinal cord injury	
	Average	SD	Average	SD
Perceived usefulness	3.9	0.6	3.6	0.5
Perceived user-friendliness	3.8	0.5	3.7	0.6
Perceived attractiveness	3.7	0.8	3.4	0.9
Perceived enjoyment	4.0	0.8	3.8	0.8
Attitude	3.8	0.9	3.9	0.5

Scores range from 1 to 5. Higher scores are positive (higher feasibility)

The patients expressed a moderately positive judgment on the usefulness, user-friendliness and attractiveness of the DA. The use of the DA was viewed as pleasurable by the majority of patients in both groups (Table 2). There was a positive attitude towards using the DAs in clinical practice.

Effect of the decision aids

The DAs had a positive effect on knowledge about the treatment alternatives in the stroke patients ($Z = -3.2$; $P = 0.001$) (Table 3). The average scores were about 3, the midpoint of the scale, i.e. decisional conflict with regard to the treatment of disease-related impairment was moderate in both groups of patients. A significant reduction of overall decisional conflict was found in the stroke patients ($Z = -3.2$; $P = 0.001$) and the SCI patients ($Z = -3.9$; $P < 0.0001$). The significant decrease in decisional conflict could be attributed to the subscales of feeling uncertain (stroke, $Z = -2.9$; $P = 0.03$ and SCI, $Z = -2.3$; $P = 0.02$) and feeling uninformed (stroke, $Z = -2.6$; $P = 0.01$ and SCI, $Z = -4.1$; $P < 0.0001$).

No significant effect of the DA on the desired role in the decision process was found (Table 4). A significant difference between actual and preferred role in decision-making ($Z = -2.0$; $P = 0.043$) was found in the stroke patients, with patients preferring a more active role than they experienced.

Discussion

One finding of the present study was that more than 75% of the patients expressed a requirement for more information

Table 3 Scores for knowledge and decision conflict, pre- and post-test

	Stroke		Spinal cord injury	
	Baseline Mean (SD)	Post-test Mean (SD)	Baseline Mean (SD)	Post-test Mean (SD)
Knowledge	1.4 (1.3)	2.3 (1.7)**	5.2 (1.0)	5.4 (0.9)
Decisional conflict scale	3.0 (0.6)	2.7 (0.6)*	2.8 (0.6)	2.5 (0.5)**
Uncertainty	3.3 (0.9)	2.9 (0.8)*	2.9 (0.7)	2.6 (1.0)*
Uninformed	2.9 (0.8)	2.7 (0.7)*	2.9 (0.9)	2.3 (0.7)**
Unclear values	2.9 (0.6)	2.7 (0.6)	2.8 (0.7)	2.7 (0.6)
Unsupported	2.7 (0.8)	2.9 (0.6)	2.3 (0.7)	2.1 (0.7)

*$P < 0.05$; **$P < 0.01$
Lower scores indicate lower decisional conflict and lower knowledge

Table 4 Effect of the decision aids on patients' role preference in decision-making

	Stroke			Spinal cord injury		
	Actual role	Desired role		Actual role	Desired role	
Role preference scale	No. (%)	Baseline No. (%)	Post-test No. (%)	No. (%)	Baseline No. (%)	Post-test No. (%)
Very passive	15 (44)	6 (16)	3 (8)	3 (9)		
Passive	7 (21)	6 (16)	5 (14)	1 (3)	1 (3)	4 (11)
Shared	4 (12)	11 (30)	18 (49)	6 (18)	7 (18)	5 (14)
Active	4 (12)	11 (30)	10 (27)	15 (45)	29 (74)	26 (70)
Very active	4 (12)	3 (8)	1 (3)	8 (24)	2 (5)	2 (5)

The percentages are based on valid cases only

about the treatment of their disease-related impairment. This confirms the information need that was previously identified in rehabilitation patients.[4,6,7,20] The results also indicate that stroke and spinal cord-injured patients have a positive attitude towards the use of web-based DAs in daily practice. The feasibility of the DAs was similar in the two groups.

The DA increased knowledge in the stroke patients. Increased knowledge is the most consistently found effect of DAs.[16,21] In agreement with earlier studies, the DAs reduced the decisional conflict in both groups,[10,22,23] specifically on the subscales of feeling uninformed and feeling uncertain. This indicates that the DAs developed in the present study mostly targeted real knowledge and information gaps in the patients.

In contrast to earlier studies, no significant effect of the DA was found on the patients' role preference in the decision-making process.[14] In the SCI population the majority of the patients stated that they preferred an active role in decision-making. Stroke patients preferred a more passive role both at baseline and after the DA. The less active attitude of the stroke patients might be attributed to their older age[23] or to cognitive limitations as a result of stroke. The literature suggests that although most patients want to be informed about disease, this does not imply they want to be involved in treatment decision-making.[4,24] Noticeably, stroke patients preferred a more active role than they had in the past. This indicates that physiatrists should be receptive towards each individual patient's desire to participate in decision-making in clinical practice.

The present study had some limitations. For example, all patients had terminated their active rehabilitation process. Also, about a quarter of the stroke patients could not be included in the study because of lack of access to a computer. This indicates that if a web-based DA was to be implemented in practice, alternative information access methods would need to be provided. Further research should focus on the feasibility and effect of a DA in patients who are in the process of decision-making about disease management, and compare a web-based aid with other sources of information, preferably in a randomized design. In conclusion, web-based aids are feasible in the rehabilitation population with access to a computer and can improve the knowledge gaps in patients. In our study, the DAs did not influence the patients' desire to participate in decision-making.

Acknowledgements: This research was supported by The Netherlands Organization for Health Research and Development ZonMw (grant number 143.50.026).

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