Patient-reported Outcome in Psoriatic Arthritis: A Comparison of Web-based Versus Paper-completed Questionnaires

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ABSTRACT. ***Objective.*** Patients followed in observational cohorts often complete patient-reported outcomes on paper questionnaires. With advances in technology, Web-based (WB) formats have been developed. The aims of our study were to determine whether WB and paper-based questionnaires (PB) completed by patients followed in the psoriatic arthritis (PsA) clinic are comparable; whether there is a patient preference for one method or the other; and whether any preference is related to patient characteristics.

Methods. Consecutive patients followed at the PsA clinic completed the Health Assessment Questionnaire, Medical Outcomes Study Short Form-36, fatigue scale, Dermatology Life Quality Index, Bath Ankylosing Spondylitis Disease Activity Index, Bath Ankylosing Spondylitis Functional Index, Ankylosing Spondylitis Quality of Life Instrument, and EQ-5D both on paper (PB) and on computer by Internet (WB). Patients were also asked to complete questionnaires regarding their preference for one method or the other. Descriptive statistics and interclass correlation coefficients (ICC) were calculated.

Results. Of 110 patients who agreed to participate, 67 (57.3%) successfully completed both PB and WB questionnaires. These patients did not differ from those who did not complete the questionnaires. WB and PB questionnaires took the same length of time to complete, with 20% of the patients complaining of more pain following completion of the questionnaires, more so with the PB. There was excellent agreement between the PB and WB (ICC 0.89–0.97) for all questionnaires.

Conclusion. The PB and WB versions of 10 standardized self-administered questionnaires in patients with PsA were comparable. The WB format was well accepted by PsA outpatients. Patients may thus be offered a choice of format as well as the choice to complete the questionnaires either in the clinic or remotely by Internet. (First Release Nov 1 2011; J Rheumatol 2011;38:2619–24; doi:10.3899/jrheum.110165)

Key Indexing Terms:
PSORIATIC ARTHRITIS
COMPUTER QUESTIONNAIRES
PATIENT REPORTED OUTCOMES
PAPER QUESTIONNAIRE

With recent technological advances, we are rapidly progressing toward a computer-based society in many fields; the field of clinical research is no exception. A longitudinal observational cohort study of patients with psoriatic arthritis (PsA) was initiated at the University of Toronto in 1978[1]. Patients have been followed prospectively according to a standard protocol, which is entered on a computer database. Since 1993 more than 400 patients with PsA have completed paper questionnaires yearly. In 2008 the database was transferred to a Web-based platform and all data have been uploaded to this Web-based database. The goal for the program is to adopt a computer-facilitated Web-based method of data collection for patient-reported outcomes.

Computerized questionnaires offer numerous advantages over the traditional paper method. Paper handling is minimized, thus reducing storage costs and the environmental burden. There is increased efficiency by reducing the need for data entry technicians. The flexibility of computer software is also beneficial because it can automatically check and offer reminders for omitted items, thus increasing rates of questionnaire completion[2,3,4]. Studies have shown respondents prefer computerized questionnaires over paper versions[4,5,6,7,8,9]. Regardless of the potential advantages, it is important to determine whether computerized and paper versions of patient-reported measures are comparable in PsA before such technology is implemented. This is relevant

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Supported by a grant from the Krembil Foundation and The Arthritis Society National Research Initiative to the Spondyloarthritis Research Consortium of Canada (SPARCC). H. MacKenzie was supported by a Summer Student Scholarship from the Canadian Arthritis Network. V. Chandran is supported by a Canadian Institutes of Health Research–Clinical Research Initiative Fellowship and by the Krembil Foundation.

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Accepted for publication August 5, 2011.

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not only to the University of Toronto's PsA program, but also to a wide range of clinical research programs internationally. Most studies have not found the questionnaire format to have a significant effect on subjects' responses[3,4,6,8,10,11,12,13,14]. McCoy, *et al* showed reduced test-retest reliability for paper-and-pencil versus Web-based formats compared with that for 2 paper-and-pencil administrations[15]. Liefeld evaluated 3 formats: paper questionnaire, computer questionnaire, and verbal interview. The greatest difference in responses was found between the computer and paper questionnaires[16].

The literature assessing the comparability of data collected by paper and computerized questionnaires is unclear and there is little research focusing on patients with PsA. The aims of our study were (1) to evaluate the reproducibility of Web-based (WB) and paper-based (PB) versions of 10 self=administered quality-of-life and functional status questionnaires in PsA; (2) to investigate whether subjects demonstrated a relative preference for questionnaire format; and (3) to determine whether format preference was correlated with subjects' demographic, disease, or computer usage characteristics.

MATERIALS AND METHODS

Subjects. Consecutive outpatients visiting the PsA clinic at the Toronto Western Hospital were contacted by telephone the week prior to their appointment for consent to participate in the study. The research assistant approached those patients who had not been reached by telephone at the time of their clinic visit for participation in the study. Patients without a confirmed diagnosis of PsA were excluded. Participation in the study was voluntary and the subjects received no compensation.

Questionnaires. A set of 10 standardized instruments measuring quality of life and functional status were used. In addition, 2 new questionnaires were developed: the Computer Use Questionnaire and the Format Preference Questionnaire.

The Health Assessment Questionnaire (HAQ) is composed of the Disability Index and the Pain Scale. The Disability Index evaluates 8 categories: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities. Within each category, patients report the level of difficulty associated with 2–3 activities over the past week. Each item is scored on a scale of 0–3, higher scores reflecting greater difficulty. The Pain Scale assesses the severity of arthritis-related pain over the past week using a visual analog scale (VAS) of 0 to 100, with a higher score denoting more severe pain[17].

The Short Form-36 Health Survey (SF-36) asks 36 questions and produces scores along 8 scales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. The scale scores are combined to calculate summary measures of physical health and mental health[18].

The following 4 questionnaires were used for the assessment of spinal disease: the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), the Bath Ankylosing Spondylitis Functional Index (BASFI), the Bath Ankylosing Spondylitis Global Score (BAS-G), and the Ankylosing Spondylitis Quality of Life Instrument (ASQoL). All questions are answered using a VAS of 0–10. The BASDAI asks 6 questions regarding the major symptoms of AS: fatigue, spinal pain, joint pain/swelling, enthesitis, morning stiffness duration, and morning stiffness severity[19]. The 10-question BASFI measures the degree of functional limitation[20]. The BAS-G uses 2 questions to assess the effect of disease on well-being[21]. The ASQoL consists of 18 items that assess quality of life[22]. Higher scores indicate increased disease severity.

The modified Fatigue Severity Scale (mFSS) is a 9-item instrument assessing the effect of fatigue on daily activities. Each item is scored on a scale of 0 to 10, a higher score indicating more severe fatigue[23].

The Functional Assessment of Chronic Illness Therapy (FACIT) Fatigue Scale uses 13 items to assess health-related quality of life specific to individuals with chronic disease. Responses are scored on a 4-point scale for a maximum score of 52. Higher scores indicate less severe fatigue[24].

The Dermatology Life Quality Index (DLQI) consists of 10 questions. Each question is scored individually on a scale of 0–3. Individual scores are summed to produce a total ranging from 0 to 30. Higher scores reflect a greater influence on quality of life[25].

The EQ-5D descriptive system measures health-related quality of life along 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Within each dimension, respondents describe the level of difficulty they are experiencing that day using a 3-point scale: no problems, some/moderate problems, or extreme problems. Each domain is scored 0–1, with 1 representing a perfect state. The EQ VAS uses a vertical 20-cm VAS to quantitatively measure health status[26].

A 9-item Computer Use Questionnaire determined the frequency of computer and Internet use and whether the patient had access to a computer with high-speed Internet at home or elsewhere. A Format Preference Questionnaire consisted of 10 questions, 6 of which address the WB format and 4 the PB format. This questionnaire compares the 2 formats in terms of ease of use, time to completion, degree of worsening of joint pain, and patient preference.

Database. The online database was created by Datazoom Solutions Incorporated (Mississauga, ON, Canada; www.datazoomsolutions.com). Each subject was assigned a unique username and password. Those subjects completing the WB questionnaires in the clinic did so using Internet Explorer at a Dell desktop computer in a semiprivate cubicle in the clinic waiting area.

Computer versus paper questionnaires. The PB and WB versions of the 10 standardized questionnaires were nearly identical. The questions that appeared on the computer screen were worded in exactly the same way as those on paper with the same punctuation and the same words in bold type. All the questions within a single questionnaire appeared on the computer screen together and could be viewed sequentially by scrolling up and down. When completing the WB questionnaires, not only could subjects answer the questions in any order but they also could change their answers as many times as needed. No answers were required but, to encourage completeness, the computer displayed a list of unanswered items before allowing the subject to proceed with the next questionnaire.

The WB questions were displayed as radio buttons (Figure 1A) and check boxes. Subjects used the mouse to click within the circle or square, respectively. There were also VAS questions that appeared as a horizontal or vertical line (Figure 1G). Subjects used the mouse to click along the line to select their answer. In contrast, the PB questions were answered using a pen or pencil to circle the number or place an "X" within the box. Subjects used their pen or pencil to place a mark along the horizontal or vertical line to answer the VAS questions.

Procedure. The Computer Use Questionnaire was administered verbally over the telephone or in the clinic to both participants and nonparticipants. Subjects with access to a computer at home or elsewhere and who were willing to complete the questionnaires from that location formed the "take-home" arm of the study. The remaining subjects completed the questionnaires in the clinic and formed the "in-clinic" arm.

Each subject completed the 10 questionnaires using the PB and WB formats in a randomized order. The 2 formats were separated in time by a period of 1 h in order to reduce the effect of memory on the subjects' responses. This was clearly achieved for those who completed the questionnaires in the clinic. Although we cannot guarantee that the patients did that at home, those were their instructions, and patients tended to follow the instructions.

Before beginning the questionnaires, all subjects received a brief infor-

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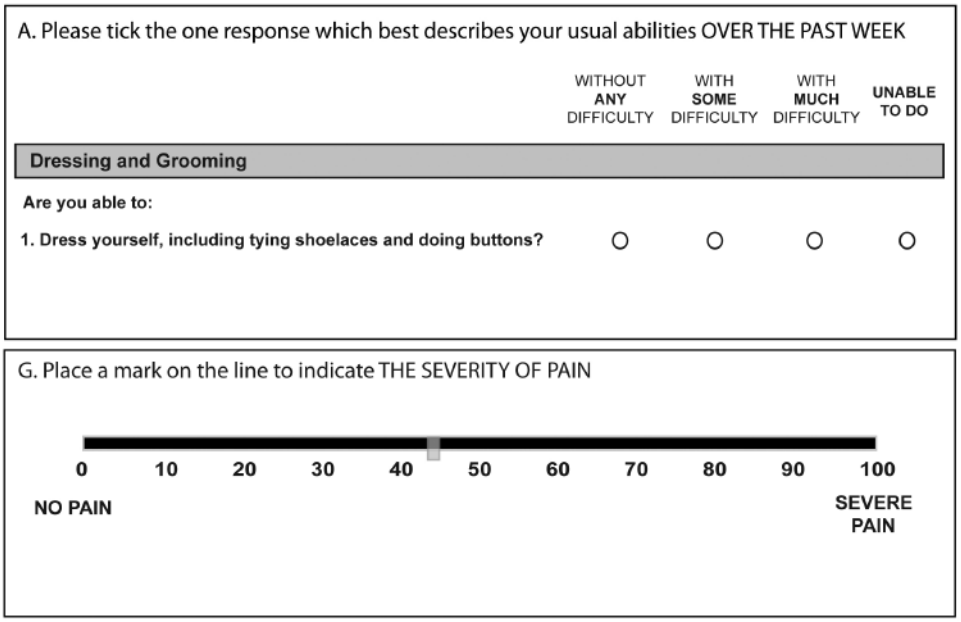

Figure 1. An illustration of WB radio button-type (A) and visual analog scale-type questions (G).

mation session as well as a paper copy of the Patient Online Guide, which provided visual screen-by-screen instructions on how to navigate the WB questionnaires. Subjects in the "take-home" arm of the study were encouraged to contact the research assistant by telephone or e-mail with any additional questions. The research assistant was present to support those subjects completing the questionnaires in the clinic.

After completing both sets of questionnaires, all subjects completed the PB Satisfaction and Preference Questionnaire. Subjects completing the questionnaires from home were provided with a stamped addressed envelope in which to mail back the 10 PB questionnaires as well as the Satisfaction and Preference Questionnaire.

Data analysis. Statistical analysis was carried out using SAS Statistics software. Intraclass correlation coefficients (ICC) with 95% CI were calculated to measure the reproducibility of the PB and WB questionnaire formats. Since the ICC is the ratio of the variability between the 2 methods over the total variability in the data, it allows assessment of the similarity in response to the methods.

RESULTS

Patient acceptance. Of the 138 patients who were approached about the study, 28 (20.3%) refused to participate. The most common reasons why patients did not want to participate included the following: computer inexperience (n = 7), dislike for questionnaires (n = 7), no computer access from home and no time at the appointment (n = 6), inability to attend scheduled appointment (n = 4), and high disease severity (n = 2). Nonparticipants were less likely to have prior computer and Internet use than participants ($p = 0.002$).

Of the 110 patients who agreed to participate, 47 (42.7%) did not complete the questionnaires. Sixty-three subjects (57.3%) successfully completed both the PB and WB questionnaires. The majority of subjects were familiar with computers, although there were 5 who had not used a computer (Table 1). After completing both versions, 54 (85.7%) of the 63 subjects reported that the questionnaires were easy to complete on the computer, and only 9 required additional assistance using the computer. Although 47 did not complete the study, there were no significant differences in demographic and disease characteristics between those who completed and those who did not, except for a younger age at onset of psoriasis in the noncompleters (Table 1).

Compared to before they started, 13 (20.6%) subjects reported increased joint pain after questionnaire completion. Of these, 6 reported the same degree of increase regardless of format, 5 reported a greater increase after completing the PB questionnaires, and 1 reported a greater increase after completing the WB questionnaires.

There was little difference between the PB and WB questionnaires in terms of how long subjects took to complete them. The mean time to completion was 25.0 min for the WB questionnaires (range 5 to 80 min). For the PB questionnaires, the mean time to completion was 24.2 min (range 5 to 60 min). Subjective reports indicated that 21 (34%) of the 63 subjects who completed both questionnaires felt the PB questionnaires took too long, compared to 7 who felt the WB questionnaires took too long.

Of 110 patients who participated in the study, 27 (42.9%) subjects preferred the WB format, 12 (19.0%) the PB, and 21 (33.3%) had no preference. Those patients who preferred the PB format were less likely to have had prior computer and Internet experience.

Reproducibility. The ICC between PB and WB formats were high for all questionnaires (Table 2). The ICC ranged from 0.89 (SF-36 mental component summary scale) to 0.97 (HAQ, BASDAI, ASQoL). For all questionnaires, there was

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Table 1. Characteristics of participants who completed and did not complete questionnaires.

Characteristic	Completers Median (min, max) or Frequency (%)	Noncompleters Median (min, max) or Frequency (%)	p
No. patients	63 (57.3)	47 (42.7)	
Age, yrs	53 (28, 82)	52 (16, 75)	0.22
Sex			
Female	29 (46.0)	20 (42.6)	0.72
Male	34 (54.0)	27 (57.4)	
Education			
High school	15 (23.8)	7 (14.9)	0.18
College	15 (23.8)	16 (34.0)	
University	32 (50.8)	19 (40.4)	
Employment			
Employed	35 (55.6)	32 (68.1)	0.14
Retired	11 (17.5)	6 (12.8)	
Homemaker	2 (3.2)	2 (4.3)	
Student	1 (1.6)	1 (2.1)	
Disabled	9 (14.3)	6 (12.8)	
Sick leave	1 (1.6)		
Looking for work	2 (3.2)		
Other	1 (1.6)		
Age at onset, yrs			
Psoriasis	29 (5, 68)	22 (5, 66)	0.06
PsA	40 (10, 79)	34 (13, 66)	0.15
Disease duration, yrs			
Psoriasis	20 (1, 48)	29 (5, 60)	0.27
PsA	10.6 (1, 41)	13 (0, 43)	0.45
No. active joints	2 (0, 36)	2 (0, 26)	0.60
No. damaged joints	2 (0, 42)	2 (0, 50)	0.46
Functional class*			
1	29 (46.0)	19 (40.4)	0.56
2	25 (39.7)	21 (44.7)	
3	9 (14.3)	6 (12.8)	

* ACR functional class: Grade 1: All activities without pain or handicap. Grade 2: Adequate for most ADL but some discomfort or limitation. Grade 3: ADL limited to self-care and/or a few daily activities. Grade 4: Little or no self-care or confined to a bed or wheel chair. PsA: psoriatic arthritis; ADL: activities of daily living.

little difference between the PB and WB versions in terms of the subjects' responses.

Comparing agreement between the instruments based on whether they were done in the clinic or at home, there was no difference for all but the DLQI and the BASDAI. ICC in the clinic (n = 16) versus the take-home (n = 42) were 0.87 (95% CI 0.68, 0.95) and 0.98 (95% CI 0.96, 0.99) for DLQI and 0.89 (95% CI 0.73, 0.96) and 0.99 (95% CI 0.98, 1.00) for the BASDAI, respectively.

The order of administration of the PB and WB questionnaires did not influence the results. There was no effect of age on the results, regardless of whether age was used as a continuous or categorical variable.

DISCUSSION

We were able to show that a computer-facilitated Web-based method of data collection is comparable to the traditional paper-based method. In our population of outpatients with PsA, the scores obtained by PB and WB questionnaires were nearly identical. There was no order effect and no difference in agreement regardless of whether the questionnaires were completed in the clinic or at home. There was no age effect. The new format was well accepted by subjects, who reported that the WB method was easy to complete, less likely to aggravate their joint pain, and less time-consuming than the PB questionnaires. Overall, 45% of subjects preferred the WB format, whereas only 20% preferred the PB.

Our results were in concordance with other studies done in specialized rheumatology clinics that showed computerized questionnaires to be comparable to paper versions[26,27,28,29,30]. Similarly, these studies also found computerized questionnaires were easy to complete[26,27,30,31], were preferred by patients[26,27,28,30,31], and took no longer than paper versions[27,29].

Although only 57% of the patients who agreed to participate ultimately completed the 2 forms of the questionnaires, there were no differences in the disease characteristics between those who completed the questionnaires and those who did not. Thus, the information collected is generalizable to the remaining patients. However, it may be that only a limited number of questionnaires should be administered to patients in order to have their collaboration. Some patients complained of having more pain after completion of the questionnaires, but the majority found more discomfort completing the paper questionnaires. Only 1 patient complained of more pain completing the questionnaires on a computer. This is likely due to mechanical rather than inflammatory considerations.

Limitations of our study include the fact that not all patients who consented were able to complete the study. However, patients who completed the questionnaires did not differ from those who did not. While in our study design there was an opportunity for a research assistant to help patients complete the forms, this may not be available in clinical practice. This study is particularly relevant to research settings for clinical trials or longitudinal observational cohorts.

Our data indicate that PB and WB versions of 10 standardized self-administered questionnaires in patients with PsA were comparable. Further, the new WB format was well accepted by outpatients with PsA. In the future, it will be feasible to use the 2 formats — PB and WB — interchangeably. Patients may thus be offered a choice of format as well as the choice to complete the questionnaires either in the clinic or remotely by Internet.

ACKNOWLEDGMENT

The authors acknowledge the contribution of Catherine T. Schentag to the study.

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Table 2. Questionnaire summary scores.

Questionnaire	Sample Size	ICC (95% CI)	Difference Between WB and PB Scores
SF-36 PCS (0–100)*	56	0.96 (0.93, 0.98)	–0.48 (–2.6, 1.4)
SF-36 MCS (0–100)*	56	0.89 (0.82, 0.93)	0 (–1.4, 1.3)
HAQ (0–3)**	62	0.97 (0.95, 0.98)	0 (0, 0)
FSS (0–10)**	62	0.95 (0.92, 0.97)	0 (–0.5, 0.3)
FACIT (0–52)*	61	0.96 (0.93, 0.98)	0 (–2, 1)
EQ-5D (–0.59 to +1.0)*	62	0.93 (0.89, 0.96)	0 (0, 0)
BAS-G (0–10)**	63	0.95 (0.92, 0.97)	0 (–0.5, 0)
BASDAI (0–10)**	63	0.97 (0.95, 0.98)	0 (–0.3, 0.3)
BASFI (0–10)**	61	0.95 (0.912, 0.97)	0 (–0.2, 0.2)
ASQoL (0–18)**	61	0.97 (0.95, 0.98)	0 (0, 1)
DLQI (0–30)**	60	0.96 (0.93, 0.97)	1 (0, 1)

* Higher scores indicate a better state (or fewer symptoms). ** Higher scores indicate a worse state (or more symptoms). ICC: intraclass correlation coefficient; WB: Web-based; PB: paper-based; SF-36: Short Form-36 Health Survey; PCS: physical component summary scale; MCS: mental component summary scale; HAQ: Health Assessment Questionnaire; FSS: Fatigue Severity Scale; FACIT: Functional Assessment of Chronic Illness therapy Fatigue Scale; BSA-G: Bath Ankylosing Spondylitis Global Score; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; BASFI: Bath Ankylosing Spondylitis Functional Index; ASQoL: Ankylosing Spondylitis Quality of Life Instrument; DLQOI: Dermatology Life Quality Index.

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