Responsiveness of the Effective Consumer Scale (EC-17)

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ABSTRACT. Objective. The Effective Consumer Scale (EC-17) comprises 17 items measuring the main skills and behaviors people need to effectively manage their healthcare. We tested the responsiveness of the EC-17. Methods. Participants, in 2 waves of a 6-week Arthritis Self-Management Program (ASMP) from Arthritis Ireland, received a questionnaire at the first and last week of the weekly ASMP. The questionnaire included the EC-17 and 10 other measures for arthritis. Deficits, mean change, and standard deviations were calculated at baseline and Week 6. The EC-17 scores were compared to the Arthritis Self-Efficacy (ASE) and Patient Activation Measure (PAM) scales. Results were presented at OMERACT 9.

Results. There is some overlap between the EC-17 and the ASE and PAM; however, most items of greatest deficit in the EC-17 are not covered by those scales. In 327 participants representing both intervention waves (2006 and 2007), the EC-17 was more efficient than the ASE but less efficient than the PAM for detecting improvements after the ASMP, and was moderately correlated with the PAM. Conclusion. The EC-17 appears to measure different skills and attributes than the ASE and PAM. Discussions with participants at OMERACT 9 agreed that it is worthwhile to measure the skills and attributes of an effective consumer, and supported the development of an intervention (such as proposed online decision aids) that would include education in the categories in the EC-17. (J Rheumatol

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ARTHRITIS PSYCHOMETRICS CONSUMER PARTICIPATION INSTRUMENT

QUESTIONNAIRES DECISION-MAKING

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INTRODUCTION

There are a number of self-management interventions to empower and help people with arthritis improve their own health^{1,2}. To evaluate the effectiveness of these interventions, it is important to develop not just clinical outcome measures, but quantifiable assessments of how well individuals with arthritic diseases manage their health and healthcare. The OMERACT initiative (Outcome Measures in Rheumatology) has given priority to establishing valid and reliable outcome measures that are important to patients. People with arthritis are invited to participate in yearly OMERACT meetings and in setting priorities. The measurement of how patients effectively engage in the management of their chronic disease was identified as a priority area in 2005.

The Effective Consumer Scale (EC-17) was developed to assess patients' perception of their skills and behaviors that are important for effectively managing, participating in, or leading their healthcare^{3,4}. Following a literature review, semistructured interviews were conducted with people with arthritis diseases and their networks (e.g., family, healthcare providers, etc.) to identify a set of skills and behaviors that people need to manage their health effectively. These interviews were supplemented by consultations with key stakeholders, including patient and professional organizations and research experts. A pilot project assessed the psychometric properties of the scale, and Classical and Item Response Theory Analyses reduced the scale from 48 to 17 items⁴. The

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scale is unidimensional but covers 5 subdomains: (a) use of health information, (b) clarifying personal priorities, (c) communicating with others, (d) negotiating roles and taking control, and (e) deciding and taking action.

The purpose of this study was to explore the construct validity and responsiveness of the EC-17. Specifically, we aimed to: (1) Assess the proportion of people with arthritis with deficits on each item (skill or behavior) of the EC-17; (2) Measure the responsiveness for aspects of the EC-17 that are predicted to change after exposure to this program; (3) Compare EC-17 results with the Self-Efficacy Scale and the Patient Activation Measure and test construct validity (in particular, convergent validity); and (4) Propose an intervention designed to address remaining deficits deemed important for effective consumers in the management of their chronic condition.

MATERIALS AND METHODS

Participants. Eligible participants who had a diagnosis of arthritis, such as rheumatoid arthritis and osteoarthritis, were recruited to participate in the Arthritis Self-Management Program (ASMP) provided by Arthritis Ireland. Arthritis Ireland is a consumer organization that aims to achieve positive changes in the provision of and access to services; provide information and education for people with arthritis; and improve the quality of life of people with arthritis through empowerment and support (www.arthritisireland.ie). Participants were recruited through the Arthritis Ireland branch network and membership, rheumatology clinics, and primary care practices, and by their own health professionals. In September 2006, Arthritis Ireland began offering the ASMP. Two cohorts completed the program: one starting September 2006 and the other February 2007. This article incorporates results from both cohorts of patients.

Intervention. The ASMP is a series of 6 weekly 2.5-hour sessions to help people manage their arthritis, deal with pain and other symptoms of arthritis, and compare how they currently manage their arthritis with how they will manage it after completing the program. Specific sessions include: (a) information and exercises for pain management, (b) relaxation, (c) exercise, (d) diet, (e) relationships with health professionals, and (f) building confidence⁵. The ASMP was licensed for use by Arthritis Ireland, and is provided by trained volunteers, who often had arthritis themselves. Systematic reviews of the effectiveness of this program consistently find that it provides small to moderate benefits to people with arthritis diseases⁶⁻⁸.

Outcome measures. To evaluate the effects of the ASMP, each participant received a Personal Self-Management Questionnaire to complete during the first and last session of the 6-week program. The questionnaire included 11 validated and commonly used scales to measure pain, function, fatigue, well-being, healthy behaviors, self-efficacy, and health service use. The EC-17 was included in the questionnaire at baseline and at 6 weeks. The Self-Efficacy Scale was included at baseline and 6 weeks during the first cohort and the Patient Activation Measure (PAM) was included at baseline and at 6 weeks during the second cohort.

The Effective Consumer Scale. The EC-17, developed by a team from the University of Ottawa and University of Queensland^{9,10}, comprises 17 items covering 5 areas. Participants rank statements about knowledge, attitudes, and behaviors, on a scale of how often the statements are true for them. Each item is scored from 0 ("never") to 4 ("always"), and a total score is calculated by adding item scores and converting to a scale out of 100. If more than one item is missing on a subscale, that subscale is not scored; if more than 3 items are missing on the total scale, the scale is not scored. In general, the higher the score, the more effective the consumer's knowledge, attitudes, and behavior. Content and face validity, and reliability have been previously established⁴. Arthritis Self-Efficacy Scale (ASE)

was used to measure how confident an individual feels dealing with and managing symptoms of the disease (such as pain), functional limitations, and emotional issues ¹¹. For each item, individuals rate his or her confidence level ranging from 0 (very uncertain) to 10 (very certain). Average scores are determined separately for 3 subscales: Pain, Function, and Other symptoms. The ASE is well validated ¹¹.

Patient Activation Measure. The 13-item Patient Activation Measure (PAM) for chronic disease was used to assess patient knowledge, skills, and confidence in self-management of the disease⁹. The scale includes items such as making lifestyle changes, knowing medications and treatment options, and taking responsibility for care. Participants rank statements from 1 (strongly disagree) to 4 (strongly agree). A raw score is calculated and translated to an overall Patient Activation level. This scale has strong psychometric properties⁹.

Analysis. The EC-17 was compared to the ASE and PAM scales to determine which skills and behaviors were included and excluded in each scale. Next, the proportion of people who reported a deficit, defined as a score of 2 or lower, on each item of the EC-17 was calculated and compared using the baseline and 6-week data from the 2 cohorts.

Mean change scores and standard deviations were calculated at baseline and Week 6 for the 2006 and 2007 cohorts separately for the EC-17, as well as for the PAM and ASE scales. The change was also presented as a proportional change relative to the baseline score, using the formula:

Proportional change =
$$(M_a - M_b)/M_b * 100$$

where M_a is mean after and M_b is mean at baseline (or before).

An effect size statistic, the standardized response mean (SRM), which provides information about the magnitude of the change, was calculated for the EC-17 and comparison scales using the formula:

$$SRM = (M_a - M_b)/SD (M_a - M_b)$$

where SD ($\rm M_a-M_b$) is the standard deviation of the mean change from baseline (before) and after. A value of 0.20 to 0.49 has been proposed as representing small responsiveness, 0.50 to 0.79 for medium, and 0.80 or greater for large responsiveness ¹².

To test convergent validity, the items on the EC-17 and the ASE and PAM scales were first subjectively compared. Pearson correlations between EC-17 and the ASE and PAM scales were then calculated at 6 weeks. Convergence of measures was considered moderate at 0.4.

RESULTS

A total of 502 participants started the program in 2006 and 2007: 168 in September 2006, and 334 in February 2007. Data at baseline and 6 weeks were available for 327 (65%) participants; 164 in September 2006 and 163 in February 2007. Of these participants, most were female, over 50 years of age, and diagnosed with osteoarthritis or rheumatoid arthritis (Table 1).

Deficits for the individual items of the EC-17 at baseline and at 6 weeks for the 2 cohorts are shown in Table 2. From the analyses of individual items, 73% agreed that they were able to understand their health information. However, between 32% and 62% of participants had deficits at baseline for other items, with 40% or more of the participants experiencing deficits for 9 items. The deficits were notable for items related to negotiating their role in their healthcare, taking control of their health (e.g., 62% did not feel a sense of control over their disease), and making decisions and taking action (e.g., 49% did not feel they could negotiate with the healthcare system about what to do to manage their disease). From baseline to 6 weeks, fewer patients indicated deficits. Nevertheless,

Table 1. Baseline characteristics of participants attending the Arthritis Ireland Self-Management Program.

Cohort	Age > 50 yrs, %	Female, %	Osteoarthritis, %	Rheumatoid Arthritis, %	Fibromyalgia, %	Multiple, %	Other, %			
September 200	06 (n = 164)									
Baseline	77	80	43	36	7	7	7			
6 weeks	77	81	43	38	6	6	7			
February 2007 (n = 163)										
Baseline	79	78	46	30	6	8	10			
6 weeks	78	78	41	34	5	10	11			

40% or more of participants still had deficits for 2 items (sense of control and negotiating the health system), and 30% or more of participants still had deficits for 8 items after being exposed to the intervention. Overall, deficits persisted for the items related to negotiation, control, and acting on decisions.

The 3 scales (EC-17, ASE, PAM), presented in Table 3, show areas of similarity and differences. Overall, the more comprehensive EC-17 covers skills and behaviors not covered by the other 2 scales. The greatest overlap was found for items such as setting realistic goals and taking action. However, most skills and behaviors of greatest deficit, before and after the ASMP, are not covered by the other 2 scales (see items marked with an asterisk in Table 3). Agreements between the measures at Week 6 are presented as Pearson correlations in Table 4. Low correlations were found between the EC-17 and all subscales of the ASE. A moderate correlation (which was significant at p < 0.01) was found between the EC-17 and PAM scales.

Quantitative comparisons, including absolute and proportion-

al changes from baseline to 6 weeks, are presented for the EC-17, ASE, and PAM in Table 4. The mean changes on the EC-17 scale were consistent between the 2 cohorts. SRM are presented in Table 4. Small effect sizes were found for the EC-17 and the PAM, but no responsiveness for the Function subscale of the ASE, and moderate responsiveness for the Pain and Other symptoms subscales of the ASE. The EC-17 was more efficient than the Function subscale of the ASE, but less efficient than the Pain and Other symptoms subscales of the ASE and the PAM scale for detecting improvements after the ASMP.

DISCUSSION

A variety of scales measuring nonclinical symptoms were used to evaluate participant status before and after an ASMP as provided by Arthritis Ireland.

The principal reason for including EC-17, ASE, and PAM in this evaluation was to further test the properties and responsiveness of the recently developed EC-17. Although sample

Table 2. Percentage of people scoring a deficit for each item of the EC-17 (v.1) at baseline and 6 weeks. The items reflect an earlier version of the EC-17 scale, which was revised during OMERACT 9 for greater clarity and ease of use.

		Baseline			6 Weeks		
Effective Consumer Scale Items	n	N	Deficit, %	n	N	Deficit, %	
How I use health information							
a. I know who can help me judge the quality of the information I receive about my disease	126	275	46	78	210	37	
b. I understand the information I receive about my disease	76	286	27	35	215	16	
c. I know how to adapt general health information to my own situation	92	287	32	38	218	18	
How I clarify my priorities							
d. I can be clear about what is important in my life when I make decisions about my disease		278	32	56	212	26	
e. I can weight the pros and cons of a decision about my disease	104	283	37	60	215	28	
f. I can set realistic goals about the management of my disease	116	279	42	62	212	29	
How I communicate with others							
g. I can express my concerns well to healthcare providers	109	293	37	58	214	27	
h. I know how to ask good questions about my health and my disease	113	287	39	70	214	33	
i. I have built an open and trusting relationship, based on mutual respect, with my healthcare providers	103	279	37	58	209	28	
How I negotiate my role and take control							
j. I am able to play the role I want to in my healthcare team	108	261	41	76	201	38	
k. I know who to work with to meet my health needs	112	267	42	72	206	35	
I. I can be assertive to get what I need to meet my health needs (for example, information and treatments)	118	274	43	81	210	39	
m. I feel a sense of control over my disease	170	275	62	101	208	49	
How I decide and take action							
n. I feel confident in making decisions about my health	121	282	43	60	211	28	
o. I can negotiate with others about what we need to do to manage my disease		274	43	66	211	31	
p. I can negotiate with the healthcare system about what to do to manage my disease		260	49	87	206	42	
q. I can organize my life to act on decisions about how to manage my disease	117	273	43	59	213	28	

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Effective Consumer Scale 17	Arthritis Self-efficacy	Patient Activation Measure
a. I know who can help me judge the quality of the information I receive about my disease*		
b. I understand the information I receive about my disease		I understand the nature and causes of my health condition(s). I know what each of my prescribed medications does. Percentage with deficits at baseline. Percentage with deficits at end of study
c. I know how to adapt general health information to my own situationd. I can be clear about what is important in my life		I know the different medical treatment options available for my health condition(s).
when I make decisions about my disease e. I can weigh the pros and cons of a decision about		
my disease f. I can set realistic goals about the management of my disease	How certain are you that you can make a small-to-moderate reduction in your arthritis pain by using methods other than taking extra medication? How certain are you that you can make a large reduction in your arthritis pain by using methods other than taking extra medication	
g. I can express my concerns well to healthcare providers h. I know how to ask good questions about my health and my disease*		I am confident I can tell a doctor concerns I have even when he or she does not ask.
i. I have built an open and trusting relationship, based on mutual respect, with my healthcare providers		
j. I am able to play the role I want to in my healthcare team*		Taking an active role in my own healthcare is the most important factor in determining my health and ability to function.
k. I know who to work with to meet my health needs*l. I can be assertive to get what I need to meet my		
health needs (for example, information and treatments)*		
m. I feel a sense of control over my disease*	How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?	When all is said and done, I am the person who is responsible for managing my health condition(s).
n. I feel confident in making decisions about my health o. I can negotiate with others about what we need		
to do to manage my disease* p. I can negotiate with the healthcare system about what to do to manage my disease*		
q. I can organize my life to act on decisions about how to manage my disease		I am confident I can figure out solutions when new situations or problems arise with my health condition(s). I have been able to maintain the lifestyle changes for my health condition(s) that I have made. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition(s).

^{* 30%} or more of participants experienced deficits for this item after completing the ASMP.

sizes were small, this evaluation provides preliminary and useful information about the EC-17.

As described in earlier publications of the scale^{3,4}, the EC-17 scale reflects skills that people with arthritis believe are important to effectively manage, participate in, and lead their healthcare. From the analysis of deficits before and after the

ASMP, it is clear that people taking self-management programs enter these programs with deficits that make it more difficult to be an "effective consumer." These deficits seem to be most notable in patients' interactions with healthcare providers and the healthcare system. Some deficits (particularly related to negotiating roles, feeling a sense of control,

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Table 4. Internal responsiveness for comparison scales at baseline and 6 weeks.

Cohort	n	Baseline, mean (SD)	After, mean (SD)	Change, mean (SD)	Proportional Change, %	SRM	Pearson Correlations
September 2006							
EC-17	88	67 (16)	72 (14)	5 (14.6)	8	0.34	1.00
Self-efficacy — Pain	96	5.4 (1.7)	6.5 (1.7)	1.1 (1.6)	20	0.65	0.25
Self-efficacy — Function	99	6.5 (2.2)	6.8 (2.2)	0.3 (1.4)	4	0.18	0.16
Self-efficacy — Other symptoms	99	5.8 (1.7)	6.6 (1.7)	0.8 (1.5)	14	0.54	0.27
February 2007							
EC-17	92	62 (20)	66 (14)	4 (17)	7	0.25	1.00
Patient Activation Measure	81	54 (14)	60 (13)	5 (13)	10	0.41	0.52

Scale range: EC-17, 0 to 100 (best); Arthritis Self-efficacy, 0 to 10 (best); Patient Activation Measure, 0 to 100 (best). SRM: standardized response mean.

making decisions, and taking action) still persisted after people completed the self-management program. This persistence may not be surprising, since the principal aim of the program is to improve the confidence and ability of participants to control and manage symptoms, and does not claim that participants will gain all the skills measured by the EC-17. These analyses suggest that a standard self-management program, although it addresses some key needs of patients, may not be sufficient to improve people's effectiveness at participating in and leading their healthcare.

We have not been able to find any comprehensive effective program to improve all the skills people with arthritis feel are important to effectively manage their disease. Discussions at the OMERACT 9 Patient Perspective Workshop indicate there is significant interest in the development of an interactive online tool to assist people to become more effective consumers.

Analyses also indicate that the EC-17 responsiveness is adequate when compared with the ASE and PAM. A limitation of this comparison is that, as discussed above, the 3 scales contain unique items that measure different skills and attributes. Overall, it appears that the EC-17 is measuring different and useful attributes of effective consumers. A program tailored specifically to develop these attributes, such as how to negotiate the healthcare system to meet healthcare needs and play the desired role on the healthcare team, would seem to be a useful addition to the range of patient programs available to assist individuals with arthritis.

In conclusion, although not yet tested in a controlled trial, this "before" and "after" study shows that the EC-17 appears to be responsive to change when individuals with arthritis diseases are exposed to interventions designed to enhance their knowledge, skills, and behaviors important for self-management of their chronic condition. More research is required to evaluate its use in the context of interventions more tailored to address patients' skill and behavior deficits deemed necessary for effective consumers. The authors are also actively seeking current or planned randomized controlled trials in which they can test the EC-17, and they welcome any interest in this regard. Further, although current work has been conducted in

patients with arthritis diseases, the scale is likely to be relevant for individuals with other chronic diseases such as asthma, cardiac disease, and diabetes.

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