



Assessing Patient Participation in Health Policy Decision-Making in Cyprus

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Abstract

Although the importance of patient participation in the design and evaluation of health programs and services is well-documented, there is scarcity of research with regard to patient association (PA) participation in health policy decision-making processes. To this end, the present study aimed to validate further a previously developed instrument as well as to investigate the degree of PA participation in health policy decision-making in Cyprus. A convenient sample of 114 patients-members of patients associations took part in the study. Participants were recruited from an umbrella organization, the Pancyprian Federation of Patient Associations and Friends (PFFPA). PA participation in health policy decision-making was assessed with the Health Democracy Index (HDI), an original 8-item tool. To explore its psychometric properties, Cronbach α was computed as regards to its internal consistency, while its convergent validity was tested against a self-rated question enquiring about the degree of PA participation in health policy decision-making. The findings revealed that the HDI has good internal consistency and convergent validity. Furthermore, PAs were found to participate more in consultations in health-related organizations and the Ministry of Health (MoH) as well as in reforms or crucial decisions in health policy. Lower levels were documented with regard to participation in hospital boards, ethics committees in clinical trials and health technology assessment (HTA) procedures. Overall, PA participation levels were found to be lower than the mid-point of the scale. Targeted interventions aiming to facilitate patients' involvement in health policy decision-making processes and to increase its impact are greatly needed in Cyprus.

Keywords: Patient Participation, Health Policy, Decision-Making

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Introduction

Patient involvement is critical in health and healthcare. It has been shown that patient dissatisfaction is strongly linked to lack of information and poor knowledge of clinical shared-decision-making.¹ Patients should collaborate with their physician to better understand aspects of their disease, so as to actively participate in treatment decisions and provide their informed consent to any treatment plan.^{2,3} In recent years, a number of initiatives and interventions have been implemented worldwide in order to encourage and support patients to take a more active role in protecting their health.⁴ These interventions have focused on fostering patient empowerment, enhancing health literacy and supporting self-management in chronic health conditions.⁵⁻⁷ Well-informed and active patients may facilitate decision-making about treatment, contribute to reduced likelihood for medical errors and are in low risk for relapse and poor health outcomes.⁶⁻⁸ Concomitantly, research evidence suggests that patient participation is a fundamental component for designing effective and sustainable healthcare systems.^{9,10} Researchers advocate patients involvement in health policy decision-making as equal partners in order to ensure that population health needs are incorporated in the policy agenda, as well as that the services delivered and policies implemented are addressing these needs effectively.¹¹⁻¹³ Increased patient involvement is associated with improved quality and safety of healthcare services, higher cost-effectiveness and better

health outcomes.^{12,14} In this reasoning, patient involvement is indispensable in the development and implementation of health policies.^{13,15,16}

In this context, many governmental and non-governmental organizations across Europe have carried out campaigns aiming to raise patient awareness with regard to participating in health policy decision-making.¹⁶ Moreover, relevant laws and regulations, mostly at local or federal levels, have been formulated in most European countries in order to facilitate patients' interaction with health authorities and thus to contribute effectively in health policy decision-making.^{15,17-20} Evidence has indicated that although efforts aimed to improve patient participation have been intensified, only few of these initiatives have been evaluated.²¹ As a result of this, a lot of resources are spent without the anticipated impact. Assessing patient involvement in different stages of health policy decision-making processes could shed light on barriers preventing individuals from having a more active role in the development of programs and policies impacting on their health.^{4,22} Furthermore, it may guide future interventions geared towards targeting these obstacles and, thus, upgrade the role of patients as equal partners.^{7,17}

According to researchers and health policy-makers the position of patients can be bolstered if they are grouped together.²³ In this reasoning, patient associations (PAs) can be indispensable in facilitating democracy, promoting patients' interests, and influencing health policies.²⁴ Nonetheless,

research on their role in impacting policy decision-making processes is scarce and it is largely based on qualitative methods.²⁵⁻²⁷ In an endeavour to fill this gap, a brief tool for measuring PA participation in health policy decision-making processes was developed and validated in a random sample of members of PAs in Greece.²⁸ In particular, the development of the index followed the steps of defining and reviewing the construct, item drafting and reviewing as well as pilot testing of its psychometric properties (reliability: internal consistency, test-retest reliability and validity: construct validity and convergent validity). Evidence indicated that the tool has good psychometric properties.²⁸

In this context, the present study aimed to validate further the particular index as well as to explore the degree of PAs participation in health policy decision-making in Cyprus.

Methods

Sample and Procedure

A convenient sample of 114 patients – members of PAs (22 men and 92 women) participated in the present study. Participants were recruited from the umbrella patient organization “Pancyprian Federation of Patient Associations and Friends” (PFPA), the national coalition of PAs in the country. The PFPA consists of several PAs, which cover a diversity of chronic health conditions, while there are certain PAs which are not disease-specific. Therefore, to be eligible for participation, patients had to be members of a PA of the PFPA, to be fluent in Greek language and to be older than 18 years old.

All members of the PFPA were invited to participate in the study. Initial recruitment was carried out via email. An invitation for participation was sent to all PAs that belonged to the PFPA and each PA forwarded the email invitation to its members. An online, self-reported questionnaire was used for data collection. Once an individual had agreed to participate and signed the written informed consent, the board members of the PFPA forwarded the web-link accordingly. The web-page did not ask for participants' personal information and as a result of this, their anonymity were ensured.

Instrument

The questionnaire was comprised of two parts, a socio-demographic section and the Health Democracy Index (HDI).²⁸ The HDI is an original scale consisting of 8 items, enquiring about PAs' participation in health policy decision processes at the organizational design and governance level as well as at the policy-making level²⁹: reforms, panels at the MoH, panels in other prominent health-related organizations, hospital boards, ethics committees in clinical trials, health technology assessment (HTA) procedures and the national parliament. For each item, 7 response options were provided: (i) it is not a legal requirement and it never happens, (ii) it is not a legal requirement and it rarely happens, (iii) it is not a legal requirement but it often happens, (iv) it is a legal requirement and it never happens, (v) it is a legal requirement and it often happens, (vi) it is a legal requirement and it happens very often, and (vii) it is a legal requirement and it always happens. In addition, there is one question enquiring about the frequency whereby a substantial change in a health policy decision was evoked as a result of PAs' involvement in

the process. For this item, ratings were made on a 7-point scale reflecting a frequency dimension: never – very rarely – rarely – sometimes – often – very often. Consistent with these, higher composite scores indicate higher degree of PA participation in health policy decision-making processes.

As already stated, for the development of the index, the subsequent steps were followed: (i) definition of the construct, (ii) review of the construct definition, (iii) item drafting, (iv) item review, (v) pilot testing of its psychometric properties (reliability: internal consistency, test-retest reliability and validity: construct validity and convergent validity). In particular, after the construct PAs participation in health policy processes was defined, its definition was reviewed by a panel of 34 stakeholders in the field: patients-members of PAs (n=10), representatives of PAs (n=10), health policy-makers (n=5), healthcare providers (n=5) and researchers (n=5). The panel was selected on the grounds of their knowledge and experience on the topic and, thus, purposive sampling was employed.

Item drafting occurred after drawing up a list of potential items on the grounds of existing international literature. Furthermore, a focus group of 12 patients-members of PAs was also conducted. Patients involved in the activities of PAs were invited to take part in a focus group centred on aspects of PA participation in health policy processes. This process resulted in the inclusion of 10 items in the scale. The panel of experts who reviewed the definition of the construct was further invited to review and comment on the derived items. As a result of this, the 10 items were reduced into 8. Moreover, the panel commented on the need to weight items, as participation in these different facets of health policy were not of equal importance. By adopting a Delphi methodology weights were assigned to each item of the index. In this rationale, the construct and face validity of the HDI was substantiated to some extent.

Moreover, in a random sample of 414 patients-members of PAs in Greece, the psychometric properties of the index were examined. The index displayed high internal consistency (Cronbach $\alpha=0.851$) and test-retest reliability ($\rho=0.873$). Exploratory factor analysis revealed that the construct is unidimensional; while confirmatory factor analysis indicated an adequate fit of the one-factor model (root mean square error of approximation [RMSEA]=0.079, comparative fit index [CFI]=0.976 and goodness-of-fit [GFI]=0.972). As regards convergent validity, the HDI composite score was found to be highly and positively correlated with one question tapping self-rated degree of PA participation in health policy processes ($\rho=0.734$, $P<.0001$).²⁸

Congruent with the pilot study in Greece, the questionnaire of the present study also included one question asking participants to rate their PAs' degree of participation in health policy decision processes. Ratings on the particular item were made on a 6-point scale ranging from absent to very high. The question was incorporated in order to explore the convergent validity of HDI, as there is no other scale to measure PA participation in health policy decision-making.²

Statistical Analysis

Continuous variables are presented with mean and standard deviation (SD) or with median and interquartile range (IQR).

Qualitative variables are presented with absolute and relative frequencies. The internal consistency of the questionnaire was analyzed with Cronbach's α . Reliability equal to or greater than 0.70 was considered acceptable. An exploratory factor analysis was used in order to evaluate construct validity of the questionnaire and to determine whether the scale could be considered as a measure of a single construct. Principal component analysis (PCA) was chosen as extraction method using varimax rotation. The cut-off point for factor loadings was 0.40 and for eigenvalues it was 1.00. Spearman correlation coefficients were computed to explore the intercorrelations of the HDI items and their association with the degree of participation of their organization in health policy decision-making. It was supposed that the aforementioned correlations would be significant and would further confirm the validity of the index. Correlation coefficient between 0.10 and 0.30 are considered low, between 0.31 and 0.50 moderate and over 0.50 high. *P* values reported are two-tailed. Statistical significant level was set at .05 and analysis was conducted using SPSS 19.0.

Results

Sample Characteristics

Sample consisted of 114 participants (22 men and 92 women) with mean age 44.5 years ($SD = 12.34$ years). Sample characteristics are presented in Table 1. Most of the subjects were Cypriot (76.32%), while 15.79% were Greek. Seventy-two percent had high educational level and most of participants were married (64.03%). The mean duration of disease was 10.72 years ($SD = 10.00$ years).

Psychometric Properties of the Index (Reliability, Construct Validity, and Convergent Validity)

Table 2 presents intercorrelations of the HDI items. All items were highly and positively correlated. The highest correlation was found between the questions "Does your patient organization take part in boards of hospitals?" and "Does your patient organization take part in Ethics Committees for clinical trials" and between "Does your patient organization take part in HTA procedures?" and "Does your patient organization take part in Ethics Committees for clinical trials." Additionally, very high was the correlation between the question "Does your patient organization take part in reforms or crucial decisions in health policy?" and the questions "Does your patient organization take part in workshops or panels held at the MoH?" and "Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?"

A PCA with a varimax rotation was conducted. In the final model all items were entered into the factor analysis and one factor was revealed with eigenvalue more than one that accounted for 68% of the total variance. Factor loadings ranged from 0.75 to 0.87. Internal consistency reliability for the HDI was accepted with Cronbach's alpha equal to 0.91. Table 3 shows correlation coefficients of the HDI items with the self-rated degree of PA participation in health policy decision-making (convergent validity). All HDI items were positively and significantly correlated with the particular question. The highest correlations were found with the items "Does your patient organization take part in reforms or crucial

Table 1. Sample Characteristics

	n (%)
Age, mean (SD)	44.5 (12.34)
Gender	
Men	22 (19.30)
Women	92 (80.70)
Marital status	
Married/civil partnership	73 (64.03)
Co-habiting	5 (4.38)
Widowed	3 (2.63)
Divorced	5 (4.38)
Single/non co-habiting partner	28 (24.58)
Nationality	
Cypriot	87 (76.32)
Greek	18 (15.79)
Both	9 (7.89)
Educational level	
None	1 (0.88)
Secondary school education	20 (17.54)
Vocational qualification	11 (9.65)
Higher diploma or degree	50 (43.86)
Postgraduate degree	32 (28.07)
Duration of disease, mean (SD)	10.72 (10.00)
Position in the organization	
Participant	18 (18.37)
Non-voting active member	30 (30.61)
Voting member	26 (26.53)
President or other board member	24 (24.49)
Years of membership, mean (SD)	6.47 (5.81)

Abbreviation: SD, standard deviation.

decisions in health policy?," "How often do you observe a substantial change in the content of a health policy decision as a result of interference from a patient organization? (yours or another's)" and "Does your patient organization take part in workshops or panels held at the MoH?" Similarly, a strong and positive correlation was also found between the particular question and the scale score ($r = 0.815$, $P < .001$)

Degree of Patient Associations Participation in Health Policy Decision-Making

Summary statistics for the HDI items are shown in Table 4. The lower median value was 1 and was found for the questions "Does your patient organization take part in boards of hospitals?," "Does your patient organization take part in Ethics Committees for clinical trials?" and "Does your patient organization take part in HTA procedures?" while the highest median value was 4 and it was found for the question "Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?"

Discussion

The present study builds upon previous work, conducted on a random sample of patients with chronic illnesses-members of PAs in Greece.²⁸ In particular, a self-reported instrument to evaluate the degree of PA participation in various facets of health policy from patients' perspective (HDI) was developed and validated. In the present study, the psychometric properties of the index were further substantiated by demonstrating good internal consistency and good convergent validity in a convenient sample of patients-members of PAs in Cyprus.

Table 2. Intercorrelations of the HDI items

	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8
Does your patient organization take part in reforms or crucial decisions in health policy?	0.83	0.80	0.58	0.63	0.64	0.63	0.64
Does your patient organization take part in workshops or panels held at the MoH?		0.79	0.67	0.65	0.65	0.68	0.62
Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?		0.60	0.60	0.60	0.60	0.62	0.65
Does your patient organization take part in boards of hospitals?				0.90	0.84	0.70	0.60
Does your patient organization take part in Ethics Committees for clinical trials?					0.88	0.70	0.62
Does your patient organization take part in HTA procedures?						0.72	0.67
Does your patient organization take part in the national parliament during decision-making for important health policies/issues?							0.77

Abbreviations: HDI, Health Democracy Index; MoH, Ministry of Health; HTA, health technology assessment.

Note: all correlations were significant at $P < .001$.

Table 3. Correlation Coefficients of the HDI Items and Total Score With the Self-rated Degree of PA Participation in Health Policy Decision-Making

	Degree of Participation of Their Organization in Health Policy Decision-Making
Does your patient organization take part in reforms or crucial decisions in health policy?	0.81
Does your patient organization take part in workshops or panels held at the MoH?	0.71
Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?	0.66
Does your patient organization take part in boards of hospitals?	0.50
Does your patient organization take part in Ethics Committees for clinical trials?	0.52
Does your patient organization take part in HTA procedures?	0.54
Does your patient organization take part in the national parliament during decision-making for important health policies/issues?	0.67
How often do you observe a substantial change in the content of a health policy decision as a result of interference from a patient organization? (yours or another's)	0.72
HDI total score	0.81

Abbreviations: HDI, Health Democracy Index; MoH, Ministry of Health; PA, patient association; HTA, health technology assessment.

Note: all correlations were significant at $P < .001$.

Table 4. Summary Statistics for the HDI Items

	Mean (SD)	Median (IQR)
Does your patient organization take part in reforms or crucial decisions in health policy?	3.54 (1.61)	3.53 (2-5)
Does your patient organization take part in workshops or panels held at the MoH?	3.31 (1.72)	3 (2-5)
Does your patient organization take part in workshops or panels in other important organizations, pertinent to health?	3.71 (1.61)	4 (2-5)
Does your patient organization take part in boards of hospitals?	2.10 (1.59)	1 (1-3)
Does your patient organization take part in Ethics Committees for clinical trials?	2.10 (1.59)	1 (1-2)
Does your patient organization take part in HTA procedures?	2.24 (1.63)	1 (1-3)
Does your patient organization take part in the national parliament during decision-making for important health policies/issues?	2.70 (1.64)	2 (1-4)
How often do you observe a substantial change in the content of a health policy decision as a result of interference from a patient organization? (yours or another's)	3.33 (1.44)	3 (2-4)
HDI total score	23.04 (10.00)	20.00 (15.00-29.00)

Abbreviations: HDI, Health Democracy Index; MoH, Ministry of Health; HTA, health technology assessment.

Moreover, the present study revealed that the higher participation levels were documented with regard to PA participation in workshops or panels in important health-related organizations, in the MoH and in reforms or crucial decisions in health policy. Lower degree was documented with respect to participation in hospital boards, Ethics committees for clinical trials and HTA procedures. Moreover, the HDI composite score was below the mid-point (median = 20, mid-point = 28). Consistent with this, PAs do not participate substantially in health policy decision-making in Cyprus. A possible explanation for this finding is that PAs may lack the necessary resources, tools or skills that would enable them to participate in decision-making processes, while advocating effectively the health needs of their members. This is in line

with previous studies, suggesting that targeted interventions to support patient organizations in advocacy strategies are necessary to improve the impact of patient participation in health policies.^{30,31} As a response to this requirement, many countries have adopted a “bottom-up” approach as a capacity building strategy in order to facilitate the involvement of patient groups in health decision-making.^{16,21} In several European countries, in conjunction with federal and regional health councils and targeted interventions, participatory decision-making processes have been integrated in law formulation, so as to facilitate patient groups to freely express their opinion and to participate equally in health policy decision-making.^{2,8,16,20,21,31} Results of the present study should be interpreted in light

of the following limitations. Even though participants were recruited from the organizations-members of the PFFA, which is an umbrella organization representing Cypriot patients at national and international level, we cannot claim that the sample was representative of the patient population in Cyprus. In addition, as patients with various chronic diseases were included into the sample, the sample size restricted us from exploring a potential influence of type of disease on PA participation. Future research should head towards this direction. Moreover, the HDI does not shed light on the barriers PAs experience, which hinder their effective involvement in procedures pertaining to health policy decision-making. For example, a growing body of research indicates that low health literacy; lack of training on advocacy and lobbying issues and poor knowledge of the health system, its operations and processes, all contribute to hampering PA participation in health policy decision-making.^{2,21,32,33} Since patient involvement in health policy decision-making is a necessary premise to improve the quality and performance of health systems and services as well as the health outcomes of the population, it is important to explore the barriers patients and patient organizations tackle throughout this process. In this way, we will be able to develop appropriate and adequate interventions and policies that would foster their participation in a sufficient and effective manner.

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Ethical issues

Not applicable.

Competing interests

Authors declare that they have no competing interests.

Authors' contributions

KS: conceptualization, design, data analysis, preparation of manuscript, editing. EA: design, preparation of manuscript, editing. LEP: design, comments on first and second draft, revising. CT: supervision of the data collection, elaboration, and data analysis. GS: comments on first draft, editing. MT: overall coordination, supervision of the data collection, comments on first draft. All authors contributed to the interpretation of the data and have read and approved the final manuscript.

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