

Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations

Raisa B. Deber PhD,* Nancy Kraetschmer MSc MBA PhD,† Sara Urowitz MA MSW PhD‡ and Natasha Sharpe PhD MBA§

*Professor, Department of Health Policy, Management and Evaluation, University of Toronto, Toronto, †Project Director, Benefits Evaluation, Canada Health Infoway, Toronto, ‡Associate Scientist, Oncology Education/Survivorship Program, Princess Margaret Hospital, Toronto, Canada and §Board Member, Kensington Health Center, Toronto, Canada

Abstract

Correspondence

Raisa B. Deber
Professor
Department of Health Policy
Management and Evaluation
155 College Street Suite 425
Toronto
ON M5T 3M6
Canada
E-mail: raisa.deber@utoronto.ca

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Background What role do people want to play in treatment decision-making (DM)?

Objective Examine the role patients indicate they would prefer in making treatment decisions across multiple clinical settings in Ontario, Canada.

Design Secondary analysis of a series of survey/interview-based studies measuring preferred role, conducted in 12 different populations.

Setting and participants Respondents were outpatients, largely but not entirely attending outpatient clinics in large teaching hospitals in urban settings in the Province of Ontario, Canada. The subgroups and sample sizes were: breast cancer (202), prostate disease (202), fractures (202), continence (46), orthopaedic (111), rheumatology (56), multiple sclerosis (22), HIV/AIDS (431), infertility (454), benign prostatic hyperplasia (678) and cardiac disease (300), plus 50 healthy nursing students (for scale validation).

Measurements All studies categorized preferred role using the Problem-Solving Decision-Making (PSDM) scale with one or both of the Current Health condition and Chest Pain vignettes.

Results Few respondents preferred an autonomous role (1.2% for the current health condition vignette and 0.7% for the chest pain vignette); most preferred shared DM (77.8% current health condition; 65.1% chest pain) or a passive role (20.3% current health condition; 34.1% chest pain). Familiarity with a clinical condition increases desire for a shared (as opposed to passive) role. Preferences for passive vs. shared roles varied across settings; older and less educated individuals were most likely to prefer passive roles.

Conclusions Despite consumerist rhetoric among some bioethicists, very few respondents wish an autonomous role. Most wish to share DM with their providers.

Background

What role do people want to play in treatment decision-making (DM)? Patient-centered care implies that doctors should respond to their patients' preferences, including their preferences for involvement in making treatment decisions. Yet the nature of such preferences, and how these have changed over time, remains contentious.

On one hand, there has been a major shift in the doctor–patient relationship, from its former emphasis on paternalism, to a new recognition of the importance of an informed, autonomous patient.^{1–12} This presumed shift in the locus of DM from the doctor to the patient has been heavily reinforced by the legal requirement for informed consent.¹³ On the other hand, a growing literature has examined preferred roles in making treatment decisions,^{14–27} as well as how policy might promote more active participation^{28–30} and how to place this within the context of the therapeutic relationship.³¹ This literature suggests that many patients do not seek the level of involvement which the bioethics literature suggests they should wish.

This manuscript adds empirical evidence using secondary analysis from a series of studies, carried out in various clinical settings in Canada, about the role patients would prefer in making treatment decisions.

Defining preferred role: the Problem-Solving Decision-Making scale

In previous research, we suggested that the conceptualization of 'participation' should distinguish between two elements of choice. Recognizing that there is variation in nomenclature across subfields, we employed the term problem-solving (PS) to refer to situations in which there is one correct answer, and for which preferences are irrelevant. For example, results of an X-ray cannot vary to respond to an individual's preference that her arm not be broken. In contrast, the term DM was used to refer to tasks which may indeed require prior PS, but also involve weighing the relative importance of potential outcomes.^{32–35} This distinction

Box 1 Problem-Solving Decision-Making (PSDM) scale

Problem-Solving Decision-Making (PSDM) scale
 The four PS tasks are:
 Who should determine (diagnose) what the likely causes of your symptoms are?
 Who should determine what the treatment options are?
 Who should determine what the risks and benefits for each treatment option are?
 Who should determine how likely each of these risks and benefits are to happen?
 The two DM tasks are:
 Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?
 Given all the information about risks and benefits of the possible treatments, who should decide what treatment option should be selected?
 All six tasks are evaluated on a 5-point Likert scale, where: 1 = the doctor alone; 2 = mostly the doctor; 3 = both equally; 4 = mostly me and 5 = me alone.

between PS and DM is one way of reconciling the recognition that 'only the patient will know how he or she feels' about particular outcomes⁸ with a model of shared DM which allows patients to take responsibility for DM while leaving PS tasks to their providers.

This distinction between PS and DM tasks was used to construct a scale which can assign individuals into one of three categories of preferred role.³⁶ The Problem-Solving Decision-Making (PSDM) scale, which has been validated in other studies,^{33,34} presents a short vignette; respondents are asked 'who should decide' for each of a series of six tasks, written to encompass both PS and DM activities. The scale is shown in the accompanying Box 1.

Mean scores are then computed separately for the PS and DM dimensions for each respondent, and collapsed into one of three classifications: 'hand over' (mean score on that dimension < 3); 'share' (mean score between 3 and 3.99); or 'keep' (mean score ≥ 4). These classified PS and DM scores are then used to place respondents into one of three categories. *Passive* patients wish to hand off both PS and DM. *Shared* patients want to hand off or share PS but share or keep DM. The 'share' category can be further broken down into the following four subcategories: 'leaning passive', 'shared equally',

Table 1 Categorization of preferred roles

Responsibility for DM	Responsibility for PS		
	Hand over	Share	Keep
Hand over	Passive	Theoretically implausible	Theoretically implausible
Share	Shared (leaning passive)	Shared (equally)	Autonomous (leaning shared)
Keep	Shared (divide and share)	Shared (leaning autonomous)	Autonomous (consumerist)

Responsibility for all problem-solving (PS) and decision-making (DM) items were initially measured on following scale: 1 = doctor alone; 2 = mostly the doctor, 3 = doctor and you equally, 4 = mostly you, 5 = you alone.

Mean scores for each dimension were then categorized as: Hand over, mean score on that dimension < 3; Share, mean score on that dimension between 3 and 3.99; Keep: mean score on that dimension ≥ 4 .

'leaning autonomous' and 'divide and share'. *Autonomous* patients want to retain some control of both PS and DM (keep PS, and share or keep DM); this category can also be subdivided into 'leaning shared' and 'autonomous/consumerist'. It was considered theoretically implausible for an individual to wish to assume control for PS but not for DM. The categorization is shown in Table 1.

The PSDM categories have similarities and differences to other measures of patient roles. In particular, although our 'passive' category closely resembles what others term 'paternalistic', the literature reflects some confusion as to how best to define the meaning of 'shared'.^{37,38} Thus, although the PSDM categorization places 'Divide and Share' as a variant of 'shared', other papers which do not distinguish between PS and DM have classified this as 'consumerism', defining it as 'my doctor tells me my options and the pros and cons of each and then I decide what to do';²⁷ this approach cannot capture models in which patients may also want to assume a role in PS.

Another advantage of the PSDM is that it is designed to allow the researcher to vary the clinical situation described in the case vignette. To allow comparison of the results in a particular patient population with results from other studies, several studies reported here have employed the *chest pain* vignette plus at least one other vignette. The chest pain vignette reads: 'suppose you had mild chest pain for three days and decided that you should visit your doctor about this'. It deals with a situation which could be life-threatening, and about which most patients would not feel expert; it also resembles the

vignette used in a pioneering study of decision-making by Ende.¹⁴ The *current health* vignette, by definition, varies across studies; it asks about decision-making for the patient's current health condition (defined as the condition for which they were attending the particular health-care setting in which they were surveyed). We hypothesized that there will be a greater willingness to hand over control to the doctor in the chest pain vignette than in the current health vignette.

The PSDM scale has been shown to have favourable psychometric properties. Cronbach's alpha for the PS component of the PSDM (measured for combinations of one, two and three vignettes in two separate studies) ranged from 0.79 to 0.90, and for the DM ranged from 0.68 to 0.90.^{33,36}

Because other research suggests that there is likely to be considerable variation in the desire for participation as a function of such factors as age, education, and whether the disease is chronic (as patients more experienced with their illness would have more time to become well informed),^{18,39-45} most of the studies analysed here also collected information on such respondent's socio-demographic characteristics as age and education, as well as perceived knowledge of the particular health conditions.

The study populations

This secondary analysis synthesizes findings from several Canadian studies using the PSDM, conducted in 12 different populations. The primary studies tested a variety of hypotheses, and used a variety of designs; to the extent that

similar results are found despite the methodological variation across these studies, one can have greater confidence in the validity of the findings.⁴⁶ Some populations studied were sufficiently heterogeneous that the individuals captured would be at different stages of their illness trajectory; others were more homogeneous. All studies were approved by the Human Subjects Review Committees of the relevant universities and/or hospitals or clinics. Inclusion criteria for all studies specified that respondents must be over age 18, be sufficiently fluent in English to be able to complete the questionnaires and agree to participate. Participants were informed that participation was purely voluntary, that none of their carers would see their responses, that their decision about whether or not to participate would not have any effect on their care, and that all responses would be anonymous. Agreement to participate was agreed to constitute informed consent.

These studies were conducted in a health-care system under which respondents would be fully insured for all medically necessary hospital and doctor care. Although such coverage might be expected to constrain any need to be consumerist for economic reasons (because, for the most part, care recipients would not need to spend their own money to receive such services), this should not affect the array of non-economically based reasons why people might wish to be autonomous and control their own lives. Using a single cross-sectional survey also limited the ability to examine changes over time. The design would not capture individuals whose faith in medicine was sufficiently low that they would not seek care in outpatient clinics, but otherwise captured an extensive group of individuals with a variety of health conditions of varying severity.

Breast cancer, prostate disease, fracture

These three outpatient clinics were included in a study by Sharpe analysing the impact of trust on preferred role.^{35,36} They were all located in a Canadian teaching hospital, selected for its size, proximity and ease of access; it treats a large number of patients from the Toronto and

surrounding area. The clinics were selected to ensure that the sample included both men and women, with a range of ages, and a mixture of severities of illness. The fracture clinic population not only included patients with fractures, but also patients with spina bifida and low back pain. Potential participants were identified through a daily patient caseload sheet provided by the clinic staff at each site, and approached by the research assistant, using a standard script. To ensure that anonymity could not be breached, no names were collected. Data collection began in January 1997 and was completed in April 1997.^{35,36}

Of the 611 patients identified by staff of these three clinics as eligible to participate in the study, 202 respondents from each of the three clinics (breast cancer, fracture and prostate disease) completed and returned a questionnaire while in the clinic, for a response rate of 99%. Three of the five non-participating patients were excluded due to language difficulty; there were two refusals. The very high response rate appears to have resulted from a combination of personal distribution of the survey, relatively long waiting times in the clinics, and few other distractions.

Contenance, orthopaedic, rheumatology

Questionnaires were distributed in these three clinics by Boblin and her nursing students, as part of a larger study. Although full detail about response rates (refusals) is not available, there were 46 respondents from the continence clinic, 111 from the orthopaedic clinic and 56 from the rheumatology clinic.

Multiple sclerosis

The PSDM was administered by Carlin as part of a qualitative study of autonomy, involving in-depth interviews with 22 multiple sclerosis (MS) patients living in the community.⁴⁷

HIV/AIDS

Respondents were drawn from the population of individuals enrolled in the HIV Ontario Observational Database (HOOD). HOOD enrolled

people with HIV/AIDS (PHAs) from specialty care clinics and primary care practices with a large number of PHAs; these clinics see over 50% of all reported cases of HIV in the province. Enrolment in HOOD was voluntary; however, over 80% of eligible persons agreed to enrol when approached.^{48–50}

In accordance with the research ethics requirements of HOOD, questionnaires were distributed only to those enrolled individuals who had previously consented to participate in additional research. To preserve confidentiality, HOOD staff generated a unique set of identifiers for eligible respondents; questionnaires were then pre-labelled with the unique identifiers and distributed to participating clinics. Patients were not contacted by members of the study team; instead, HOOD staff at the clinics agreed to place the questionnaires in the corresponding patient chart for distribution at the next clinic visit. To further ensure anonymity, no follow-up was allowed. Questionnaires were distributed between July 1999 and February 2000.

A total of 1664 self-administered questionnaires were sent to the HOOD co-ordinators at the 13 participating sites; 372 potential respondents were either deceased or lost to follow-up, and others may have been, but did not have a scheduled clinic visit over the study period. The sites accordingly distributed 809 surveys and obtained 431 responses (53.3% response rate), with no follow ups. There were 100 refusals. Respondent demographics were obtained from the HOOD database, and linked by them through anonymous data linkage, using the unique identifier placed on the survey instruments.

Infertility

The PSDM was also included in a study by Stewart *et al.* which examined the preferred role in medical decision-making of women undergoing fertility treatments.⁵¹ Participants were recruited from two clinics based in teaching hospitals and one private fertility clinic in Ontario, Canada. The published study reported results for 404 women (response rate 85%), but

we have obtained and analysed the raw data with PSDM results for 454 women.

Benign prostatic hyperplasia

An evaluation of the value of shared decision-making using interactive videodiscs studied 713 men with benign prostatic hyperplasia (BPH) at nine outpatient hospital sites across Canada.⁵² All completed a pre-test questionnaire before viewing the videodisc, and were asked to complete a post-viewing questionnaire after seeing it. The post-viewing questionnaire contained the PSDM scale. Questionnaires were distributed from 1993 to 1995; 678 patients completed the PSDM scale (95%).

Cardiac

In this study, 464 patients from a Cardiovascular Investigative Unit of a teaching hospital located in Ontario, Canada were asked to complete a questionnaire.^{33,34} Of those, 416 (89%) were eligible for the study, 41 (9%) were excluded and seven (1%) refused to participate. Three hundred (72%) responses were received.

Nursing students

To assess the reliability of the PSDM, 50 nursing students from an Ontario university completed an in-class survey; 41 repeated it 4 weeks later. Test-retest reliability was computed.³³ We here report the results for the initial PSDM administration in this healthy population.

Statistical analysis

Statistical analysis employed SAS-PC. Basic descriptive analysis (frequencies and cross tabs) were used. Where required, variables were recoded to ensure that response categories were consistently defined across studies.

Results

A summary of demographic characteristics is included in Table 2.

Table 2 Demographic information on study participants, by group

	Breast cancer	Prostate disease	Fracture	Continenence	Orthopaedic	Rheumaology	MS	HIV/AIDS	Infertility	BPH	Cardiac	Nursing students	Grand total
<i>N</i>	202	202	202	46	111	56	22	431	454	678	300	50	2754
Age (mean)	55.8	66.1	46	62.4	45	47.1	45.8	43.7	34.8	64.4	59.6	44.3	52.2
Age (range)	16-90	33-90	16-88	28-83	18-78	20-71	27-61	23-73	21-48	39-88	25-83	34-68	16-88
Male (%)	0	100	46.5	24.4	36.4	11.8	36.4	90.9	0.0	100.0	74.7	6.0	60.2
Education (%)													
Some high school or less	26.24	23.74	24.87	34.09	25.25	27.45	13.64	24.21	4.26	27.87	30.93	0.00	22.47
Completed high school	18.81	15.84	16.75	22.73	25.25	23.53	18.18	17.37	16.54	18.73	23.71	0.00	18.43
Some post-high school (university/college/trade school)	17.33	11.39	18.78	15.91	21.21	17.65	13.64	18.16	NA	16.52	14.78	46.00	14.43
Completed university/college	26.73	30.69	30.46	13.64	17.17	17.65	45.45	29.74	62.66	21.98	11.00	42.00	30.44
Some professional or graduate school	2.97	0.99	3.05	9.09	5.05	3.92	NA	3.16	NA	NA	4.81	8.00	2.11
Completed professional or graduate school	7.92	17.33	6.09	4.55	6.06	9.80	9.09	7.37	16.54	14.90	14.78	4.00	12.12

Preferred role

Table 3 indicates the categorization of preferred role for the 10 populations responding to a current health vignette, listed by decreasing proportion of those preferring a passive role. Table 4 presents similar results for the 10 populations responding to the chest pain vignette.

Almost no respondents preferred an autonomous role (1.0% current health; 0.6% chest pain). However, most respondents did not wish to assume a passive role either. Instead, there was a strong preference, across all study populations, for a shared role. This preference was higher for the current health condition (78.1%) than for the less-familiar chest pain (65.2%) vignette, suggesting that greater familiarity with a health condition increases desire to participate. Those who preferred a shared role tended to fall into two of its four subcategories – ‘leaning passive’ (ranged from 20.2% to 45.8% on the current health vignettes; 23.2% to 49.8% for chest pain) and ‘divide and share’ (ranged from 11.4% to 42.9% current health; 16.3% to 48.0% chest pain). Preferences for a passive role also varied across study groups, in part as a function of age and education. For the current health vignette, for example, over 1/3 of the breast cancer population wished to assume a passive role, in comparison with <5% for the MS sample.

Cross-tabulation of preferred role by sex revealed no statistically significant relationship (data not shown). *t*-tests comparing mean age among those preferring a passive role vs. those preferring a shared role showed consistently significant relationships, both in the full sample and in each group, with the passive group being between 5 and 8 years older (data not shown). The individual studies reported significant relationships between preferred role and educational level, and between age and education; we accordingly suspect that the relationship between age and role may largely reflect educational differences. However, because the studies defined educational level differently, we did not analyse this directly.

Table 3 Categorization of preferred roles, by group: current health condition vignette

Preferred role	Breast cancer (%)	Prostate (%)	Fracture (%)	Continence (%)	HIV (%)	BPH (%)	Orthopaedic (%)	Rheumatology (%)	Infertility (%)	MS (%)	Grand total (%)
P: Total passive	35.5	27.8	25.8	22.7	20.9	19.4	17.3	15.4	10.3	4.8	20.4
Shared: of which											
leaning passive	26.5	20.2	24.7	43.2	45.8	34.4	39.1	40.4	37.4	33.3	34.8
shared equally	0.5	0.5	3.5	11.4	5.9	11.5	8.2	11.5	8.6	4.8	7.1
leaning autonomous	5.0	9.1	3.5	9.1	5.0	11.1	9.1	7.7	8.2	9.5	7.9
divide and share	32.0	37.4	38.9	11.4	22.1	22.4	22.7	23.1	35.0	42.9	28.3
S: Total shared	64.0	67.2	70.7	75.0	78.9	79.4	79.1	82.7	89.2	90.5	78.1
Autonomous: of which											
leaning shared	0.0	0.0	0.0	0.0	0.0	0.2	0.0	0.0	0.0	0.0	0.0
autonomous/consumerist	0.5	5.0	3.0	2.3	0.2	0.5	0.9	0.0	0.0	0.0	1.0
A: Total autonomous	0.5	5.0	3.0	2.3	0.2	0.6	0.9	0.0	0.0	0.0	1.0
I: Theoretically implausible*	0.0	0.0	0.5	0.0	0.0	0.6	2.7	1.9	0.5	4.8	0.6
Overall total (P + S + A + I)	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Valid (n)	200	198	198	44	421	620	110	52	428	21	2292
Missing (n)	2	4	4	1	10	58	1	4	26	1	111
Total (n)	202	202	202	45	431	678	111	56	454	22	2403

Totals and subtotals may vary slightly due to a rounding error.

*For all other analysis, the 'theoretically implausible' response was also set to missing and excluded from further analysis.

Table 4 Categorization of preferred roles, by group: chest pain vignette

Preferred role	Breast cancer (%)	Prostate disease (%)	Fracture (%)	Continenence (%)	Cardiac (%)	Orthopaedic (%)	HIV (%)	Rheumatology (%)	Nursing students (%)	Grand total (%)
P: Passive	55.8	49.0	45.4	39.5	33.5	30.6	17.6	16.4	4.0	33.9
Shared: of which										
leaning passive	23.4	23.2	32.7	34.9	47.2	42.6	49.8	49.1	30.0	38.8
shared equally	0.0	1.0	1.0	4.7	1.4	2.8	6.0	10.9	8.0	3.1
leaning autonomous	1.5	5.1	2.0	4.7	1.4	2.8	3.8	5.5	10.0	3.2
divide and share	18.8	19.7	17.9	16.3	16.5	20.4	21.4	18.2	48.0	20.1
S: Total shared	43.7	49.0	53.6	60.5	66.5	68.5	81.0	83.6	96.0	65.2
Autonomous: of which										
leaning shared	0.0	0.0	0.0	0.0	0.0	0.0	0.7	0.0	0.0	0.2
autonomous/consumerist	0.5	2.0	1.0	0.0	0.0	0.0	0.0	0.0	0.0	0.5
A: Total autonomous	0.5	2.0	1.0	0.0	0.0	0.0	0.7	0.0	0.0	0.6
I: Theoretically implausible*	0.0	0.0	0.0	0.0	0.0	0.9	0.7	0.0	0.0	0.3
Overall total (P + S + A + I)	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Valid (n)	197	198	196	43	284	108	420	55	50	1551
Missing (n)	5	4	6	2	16	3	11	1	0	48
Total (n)	202	202	202	45	300	111	431	56	50	1599

Totals and subtotals may vary slightly due to rounding error.

*For all other analysis, the 'theoretically implausible' response was also set to missing and excluded from further analysis.

	Consistent (%)	Current health > chest (%)	Current health < chest (%)	Total (%)
Rheumatology	92.0	4.0	4.0	100
HIV/AIDS	89.0	4.4	6.6	100
Orthopaedic	79.8	17.0	3.2	100
Breast	80.6	19.4	0.0	100
Prostate disease	77.0	23.0	0.0	100
Fracture	74.2	23.2	2.6	100
Continence	61.9	28.6	9.5	100
Total	76.3	22.3	1.4	100

Table 5 Change in role preference between current health and chest pain vignettes

For those studies employing both the chest pain and current health vignettes, we cross-tabulated preferred role (Table 5). In general, most respondents (76.3%) were consistent. As hypothesized, most of those who did shift tended to want a more active role for their current health condition (22.3%). The small proportion who wished to be more passive for their current health condition were relatively more common in certain subpopulations (especially HIV/AIDS), but represented a small proportion in all groups studied.

Discussion

The doctor–patient relationship has evolved since the times of paternalistic medicine and with it so has the definition of what it means to be an autonomous decision maker. Patients have seen their role broaden from one of passive recipient of care, to involved partner. This series of studies provides a helpful way of categorizing individuals receiving care, and highlighting how few wish to play an autonomous/consumerist role. It suggests that the preferred relationship recognizes patient autonomy, not as control, but as an active role in treatment decision-making within in the context of a shared relationship with a trusted provider.³⁶

The results of this study indicate that the majority of the respondents prefer a shared relationship with their provider in which PS is either shared or left to the expert provider, and the patient is welcomed and encouraged to participate in DM tasks. These results are not what one would expect in a health-care envi-

ronment that is strongly influenced by advocates of health-care consumerism; however, they are consistent with a growing body of literature that suggests that a shared model of the doctor–patient relationship is desirable.^{17,53–58} These results help to shed light on what is meant by the ‘autonomous’ patient. The strong preference for a shared role suggests that involved patients wish to understand their disease and the choices available to them, and to be involved in aspects of decision-making that will affect their quality of life. However, they do not wish to take on the provider’s role; they are willing to leave much of the responsibility for tasks that require expertise to the provider. The ‘new patient’ wants their providers to work with them to ensure that they have the information they need to make often-difficult decisions.

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Conflict of interest

The authors do not have any conflict of interest related to this research.

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