RESEARCH PAPER

How Consumerist Do People Want to Be? Preferred Role in Decision-Making of Individuals with HIV/AIDS

Dans quelle mesure les gens veulent-ils être consommateuristes? Rôle préféré des personnes atteintes de VIH/sida dans le processus décisionnel

by SARA UROWITZ, MA, MSW, PHD
Oncology Education Informatics Program, Princess Margaret Hospital
University Health Network
Toronto, ON

RAISA DEBER, PHD
Department of Health Policy, Management and Evaluation
University of Toronto
Toronto, ON

Abstract

Background: North American bioethics emphasizes autonomy, but do care recipients want an autonomous role in treatment decision-making?
Participants: We surveyed people living with HIV/AIDS (PHAs) treated at 12 clinics affiliated with the HIV Ontario Observational Database (HOOD).

Design: The clinics distributed 809 surveys. Demographic information was merged from the HOOD database.
Measurements: The survey included questions about preferred role, satisfaction with role, trust in physicians, and use and helpfulness of information sources.
Results: The 431 responses (response rate 53.3%) reflected the group believed most consumerist (well-educated gay men). Most (87%) had high/moderate trust in physicians and were satisfied with their level of involvement in treatment decision-making. They sought information from many sources (mean 8.2), particularly health providers, but also the Internet (used by 42%, seen as somewhat helpful). Nonetheless, only one respondent (0.2%) was categorized as autonomous/consumerist; 20.9% were passive, while 78.9% wanted a shared role.
Conclusions: Consumerist rhetoric, with its emphasis on patient autonomy, is oversimplified. Even in this knowledgeable population, respondents wanted to understand their disease and options, but not to take on the provider's role. To our respondents, the optimal doctor–patient relationship is best characterized by a shared, trusting relationship between informed patients and expert providers.

Résumé

Contexte : La bioéthique nord-américaine met l'accent sur l'autonomie, mais les bénéficiaires de soins veulent-ils jouer un rôle dans le processus décisionnel lié au traitement?
Participants : Nous avons interrogé des personnes vivant avec le VIH/sida (PVAS) traitées dans 12 cliniques affiliées à la base de données d'observation de l'Ontario sur le VIH (HOOD).
Conception : Les cliniques ont distribué 809 questionnaires, auxquels ont été ajoutés des renseignements démographiques extraits de la HOOD.
Mesures : Le sondage comprenait des questions sur le rôle préféré, la satisfaction à l'égard du rôle, la confiance envers les médecins ainsi que l'utilisation et l'utilité des sources d'information.
Résultats : Les 431 réponses (TR=53,3 %) reflétaient le groupe considéré comme étant le plus consommateuristes (hommes homosexuels instruits). La majorité (87 %) des répondants avaient une confiance élevée ou moyenne à l'égard des médecins et étaient satisfaits de leur niveau de participation au processus décisionnel lié au traitement. Ils ont cherché à obtenir des renseignements auprès de plusieurs sources (moyenne : 8,2), surtout auprès des intervenants en soins de santé, mais également sur Internet (utilisé par 42 % des répondants, jugé relativement utile). Néanmoins, seulement un répondant (0,2 %) a été classé comme étant autonome ou consommateuristes; 20,9 % avaient une attitude passive, tandis que 78,9 % voulaient un rôle partagé.
Conclusions : Avec l'accent qu'il place sur l'autonomie des patients, le discours consumériste est simplifié à l'extrême. Même au sein de cette population renseignée, les

répondants voulaient comprendre leur maladie et les choix qui s'offraient à eux, mais ils ne souhaitaient pas assumer le rôle du fournisseur de soins de santé. Pour nos répondants, la relation optimale médecin-patient se caractérise le mieux par un rapport de confiance mutuelle entre des patients informés et des fournisseurs experts.

* * *

WHAT ROLE DO PATIENTS WANT TO PLAY IN TREATMENT DECISION-making? The new physician–patient relationship is popularly characterized in the language of consumerism; some speak of the "new patients," armed with reams of Internet printouts, telling their doctors how they wish to be treated (Eysenbach and Jadad 2001; Haugh 1999). This emphasis is supported by medical ethics, which has long stressed respecting patient autonomy (Beauchamp and Childress 2001; Katz 1984; President's Commission 1982); by legal standards requiring informed consent (Caulfield 2004; Etchells et al. 1996; Rozovsky 1997); and by the consumer movement, which encourages patient empowerment, medical consumerism and informed choice (Epstein 1996; Haug and Lavin 1983; Lupton 1997; Williamson 1992; Wood 2000). However, many providers continue to argue that this portrait does not depict the patients they see, that consumerist expectations are unrealistic and that their patients do not wish to be autonomous decision-makers.

A growing body of literature on shared decision-making (Charles et al. 1997; Coulter 2002; Coulter and Rozansky 2004; Deyo 2001; Frosch and Kaplan 1999; Kaplan 1999; McNutt 2004; Sevdalis and Harvey 2006) emphasizes the importance of partnership between providers and patients. Deber and colleagues (Deber 1994; Deber and Baumann 1992; Deber et al. 1996) further defined "preferred" role by distinguishing between two dimensions of "participation," which they termed "problem-solving" (PS) and "decision-making" (DM). PS tasks have "right" and "wrong" answers, determination of which often requires expertise, whereas DM tasks incorporate both factual knowledge and individual preferences. These authors' research confirmed that few care recipients in the populations they studied wished to assume responsibility for PS, although many did wish involvement in DM (Deber and Sharpe 1999; Deber et al. 1996; Kraetschmer et al. 2004; Stewart et al. 2001; Deber et al. 2007).

We accordingly surveyed people living with HIV/AIDS (PHAs), a population widely believed to be both highly knowledgeable about their disease and more actively involved in making treatment decisions (Epstein 1996; Furin 1997) and hence relatively likely to wish to assume an autonomous role. Indeed, in the early days of the epidemic, researchers found that many PHAs distrusted organized medicine. These attitudes were said to be fuelled by a combination of radical AIDS activism, reactions to perceptions of homophobia among healthcare providers (Douglas et al. 1985; Epstein 1996; O'Hare et al. 1996) and recognition of the limited ability of the medical establishment to deal effectively with this new disease (Epstein 1996). Consequently, many PHAs became experts in the disease and its treatment, attending conferences, presenting to peers, participating on pharmaceutical, government, policy and research advisory boards, and institutionalizing these efforts through AIDS service organizations (ASOs) (Kayal 1993).

This history suggests that PHAs are more likely than most care recipients to have relatively strong consumerist tendencies related to making their own healthcare choices. We asked PHAs about their preferences for involvement in treatment decision-making, their level of satisfaction with their current role in treatment decision-making, their trust in organized medicine and their use and views of a series of potential information sources.

Methods

Population

Respondents were drawn from the population of individuals enrolled in the HIV Ontario Observational Database (HOOD). HOOD enrolled PHAs from specialty care clinics and primary care practices with a large number of PHAs; these clinics saw 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.

This study surveyed enrollees from nine specialty care clinics in urban and rural settings and three primary care practices from across Ontario, Canada. Although HOOD attempts to represent the Ontario HIV population, enrollees from endemic countries and individuals with new infections are underrepresented, while Caucasian people and men who have sex with men are overrepresented (Forte et al. 2003). HOOD thus overrepresented the segment of the HIV/AIDS population believed most likely to desire an autonomous/consumerist role.

Survey distribution

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, pre-labelled questionnaires with these identifiers, and distributed them to participating clinics by placing them in the corresponding patient chart for distribution at the next clinic visit, for visits between August 1999 and February 2000. To further ensure anonymity, no follow-up was allowed.

Ethics approval was obtained from the University of Toronto Office of Research Services (May 28, 1999), the HOOD research review committee (May 1999) and any participating study sites requiring internal ethics reviews. Input from an advisory committee composed of members from HIV/AIDS service organizations and community representatives helped ensure that the questionnaire was clear, relevant and of minimal burden to respondents.

Scales

Each respondent was asked for 21 potential *sources of information*, whether they used that source to "get information about their illness" and, if they did, how helpful they found that source, scored on a three-point Likert scale, where 3 = very helpful, 2 = somewhat helpful and 1 = not at all helpful.

Preferred role was measured by the PSDM (Deber 1994; Deber and Baumann 1992; Deber et al. 1996; Deber et al. 2007). The PSDM presents respondents with one or more brief vignettes, each of which has six "who should decide" questions. Factor analysis has confirmed that four correspond to PS tasks and two to DM tasks. The four PS tasks are: *Who should determine what the likely causes of your symptoms are? Who should determine what the treatment options are? Who should determine what the risks and benefits of 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 which treatment option should be selected?*

The response categories for each question follow those used by Ende et al. (1989) in a study of patient preferences: 1 = the doctor alone; 2 = mostly the doctor; 3 = doctor and you equally; 4 = mostly you; and 5 = you alone. Mean scores are then computed separately for the PS and DM dimensions for each respondent, classified as hand over (<3), share (3–3.99) or keep (≥4), and used to place respondents into one of three categories (Table 1). Passive patients wish to hand off both PS and DM, autonomous/consumerist patients want to retain some control of both PS and DM, while shared patients want to hand off or share PS but share or keep DM. It was considered theoretically implausible for an individual to wish to assume control for PS but not for DM (Deber and Sharpe 1999; Kraetschmer et al. 2004; Stewart et al. 2001).

This study used two PSDM vignettes: the "chest pain" vignette used in previous studies ("Suppose you had mild chest pains for three days and decided that you should visit your doctor about this"), plus a disease-specific vignette developed with the assistance of our advisory committee ("Suppose you have been HIV positive for five years, your CD4 count has never gone below 600 and you are currently not taking any drug treatments. You have been doing well, but for the last two weeks you have noticed a new symptom—a rash").

TABLE 1. Categorization of preferred roles

Responsibility for DM (Decision-Making)	**Responsibility for PS (Problem-Solving)**		
	Hand Over	**Share**	**Keep**
Hand Over	Passive	Theoretically Implausible	
Share	Shared (Leaning Passive)	Shared (Equally)	Autonomous (Leaning Shared)
Keep	Shared (Divide and Share)	Shared (Leaning Autonomous)	Autonomous (Consumerist)

Responsibility for PS and DM items initially measured on the following scale: 1 = doctor alone, 2 = mostly the doctor, 3 = doctor and you equally, 4 = mostly you, 5 = you alone
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

The *trust in physician* scale measures the patient's interpersonal trust in his or her physician (Anderson and Dedrick 1990). Items tap patients' perceptions of their confidence in the dependability, knowledge and reliability of information from the physician, scored on a five-point Likert scale from 1 = strongly disagree to 5 = strongly agree; scoring on some items is reversed to avoid response set bias. The scale authors categorize average scores <3 as low trust, those 3–3.99 as moderate trust and those ≥4 as high trust (Anderson and Dedrick 1990). In previous work, we have found it helpful to subdivide the high-trust category into high (4–4.99) and blind trust (5) (Kraetschmer et al. 2004).

Satisfaction with their level of participation in treatment decision-making about managing their HIV was measured on a five-point Likert scale ranging from 1 (very dissatisfied) to 5 (very satisfied).

Results

Response rate

Twelve sites distributed 809 surveys and obtained 431 responses; there were 100 refusals. Our response rate (53.3%) exceeds the literature recommendation (at least 50%) (Dillman 2000; Rubin and Babbie 2004).

Respondent demographics

Respondent demographics were available in the HOOD database and anonymously linked using the unique identifier placed on the survey instruments. We then computed risk factors for contracting HIV, using the algorithm prepared by Millson and used for other HOOD studies (Remis et al. 2003). The overwhelming majority of respondents (90.9%) were male. Of the male respondents, 81.5% reported only sex with other men as the risk factor for contracting HIV. They ranged in age from 23 to 73 years of age (mean 43.7 years, SD 8.6). Most were Caucasian (86.7%) and well educated. None was newly diagnosed (first positive test within last 12 months). On average, respondents had been living with a positive test for 8.3 years (SD 3.5 years), with 73.1% having been diagnosed less than 10 years before, and 26.9% living with HIV for more than 10 years. Compared with the HOOD population agreeing to participate in research (Table 2), the respondents did not differ with respect to sex or ethno-cultural background, but were somewhat older (underrepresenting those under age 39) and better educated (underrepresenting those with high school or less). They were slightly more likely to be partnered and less likely to be intravenous drug users. In short, the sample is indeed somewhat biased, but in a direction that would be expected to make these respondents more rather than less consumerist/autonomous.

Source of information

The mean number of sources of information used was 8.2. Only eight people (1.9%) used only one source of information, while one respondent indicated using 20 different sources; 74.3% of respondents used 5–12 different sources. Table 3 presents the results for the proportion using each potential source for information and its helpfulness score (maximum score 3). Respondents considered all sources at least somewhat helpful (Table 3).

The most commonly used information sources were all traditional healthcare providers, with 93.0% of respondents obtaining information from an HIV specialist, 87.4% from a primary care physician and 72.4% from another healthcare professional (nurse, social worker or other clinic staff). These sources were also rated near the top in helpfulness, with a mean helpfulness score of 2.7 (ranging from 2.6 to 2.9). Certain support groups and local ASOs, although used by a smaller proportion, also scored highly.

In contrast, the Internet ranked 11th, being used by less than half of the respondents (41.8%). It was also seen as less helpful than health professionals, with a mean helpfulness score of 2.3; 41.3% of those using it found it very helpful. The lowest helpfulness score was assigned to "the press," possibly because it was judged less likely to have specific information tailored to the needs of individuals. When asked where they would go first for information if they found themselves in a situation similar to the one described in the HIV vignette, most of the respondents to this question (n=389) identified either their primary care physician (63.8%) or their HIV specialist (26.7%).

TABLE 2. Demographic characteristics: Study population vs. HOOD population

Characteristics	n	%	n	%
	Study Population (n=431)		HOOD Population (n=2160)	
Sex				
Male	380	90.9	1925	90.9
Female	38	9.1	193	9.1
n (valid responses)	418	100.0	2118	100.0
Age				
(Mean/range)	43.7 yrs / 23–73 yrs		41.0 yrs / 19–74 yrs	
Under 39	156	36.2	157	48.9
40–49	179	41.5	745	34.5
50–59	73	16.9	284	13.2
60+	23	5.3	74	3.4
n (valid responses)	431	99.9	2160	100.0
Ethno-Cultural Background				
Asian	11	2.6	50	2.4
Black	12	2.8	92	4.4
Indo-Asian	1	0.2	9	0.4
First Nations	7	1.7	49	2.3
White	366	86.7	1784	84.5
Other	25	5.9	126	6.0
n (valid responses)	422	99.9	2110	100.0
Education				
High school or less	106	25.2	781	36.9
Community college	124	29.5	576	27.2
Partial university	76	18.0	308	14.6
Graduated university	86	20.4	320	15.1
Post-graduate	29	6.9	131	6.2
n (valid responses)	421	100.0	2116	100.0
Partnered				
Yes	244	58	1060	50.3
No	177	42	1048	49.7

TABLE 2. Continued

n (valid responses)	421	100.0	2108	100.0
First Positive Test				
< 1 year	0	0	16	0.8
2–10 years	307	73.1	1567	74.9
> 10 years	13	26.9	507	24.3
n (valid responses)	320	100.0	2090	100.0
Risk Factors				
Males				
Men having sex with men (MSM)	300	81.5	1385	75.4
Intravenous drug use (IDU)	14	3.8	144	7.8
MSM and IDU	13	3.5	94	5.1
Blood/blood products	14	3.8	85	4.6
Heterosexual contact	25	6.8	127	6.9
Work-related	2	0.5	3	0.2
n (valid responses)	368	99.9	1838	100.0
Females				
Intravenous drug use (IDU)	3	8.6	45	24.7
Heterosexual contact	28	80	121	66.5
Blood/blood products	3	8.6	15	8.2
Lesbian contact	1	2.8	1	0.6
n (valid responses)	35	100.0	182	100.0

Note: As a result of rounding, percentages may not add up to 100%.

Trust in physician

The majority (87.1%) of respondents had high to moderate levels of trust in physicians; 4.7% of respondents exhibited blind trust and 8.1% low trust.

Preferred role

As Table 4 demonstrates, the chest pain and HIV vignettes yielded similar results. An overwhelming majority wished to share decision-making with their providers (81.3% chest pain; 78.9% HIV). Only one respondent (0.2%) desired a consumerist/autonomous role, with the rest preferring a passive role (17.7% chest pain vignette, 20.9% HIV).

TABLE 3. Use and perceived helpfulness of sources of information (n=428)

Source	% Using This Source	Mean Helpfulness Score	Very Helpful (%) (3)	Somewhat Helpful (%) (2)	Not Helpful at All (%) (1)
Highly helpful sources (very helpful > 50%)					
HIV specialist	93.0	2.9	86.8	12.9	0.3
Family doctor	87.4	2.7	70.3	27.2	2.5
Nurse or social worker	72.4	2.6	65.3	33.8	0.9
Support group	22.2	2.6	67.0	29.6	3.4
Other specialist	29.1	2.6	65.8	30.1	4.1
Moderately helpful sources (very helpful between 25 and 50%)					
Spouse/partner	39.0	2.4	46.3	50.6	3.1
National ASO	36.9	2.4	48.7	46.1	4.6
Medical libraries	11.0	2.4	44.4	53.3	2.2
Internet	41.8	2.3	41.5	55.6	2.9
CAM provider	14.3	2.3	40	50	10
Provincial ASO	12.9	2.3	43.1	51.0	5.9
Friends	62.9	2.2	31.1	65.5	3.4
Public library	6.3	2.2	25	75.0	0.0
Women's ASO	5.4	2.2	33.3	57.1	9.5
Less helpful sources (very helpful < 25%)					
Newsletters	60.5	2.2	24	72.4	3.6
Gay press	52.1	2.2	22.9	69.4	7.7
Family	27.6	2.2	27.8	64.4	7.8
Hotlines	6.5	2.2	30.8	53.8	15.4
Press	70.1	2.1	15.4	76.4	8.2

ASO = AIDS Service Organization (each ASO category can include a variety of organizations)
CAM = Complementary and alternative medicine

Preferred role interacted with information use, with a statistically significant difference ($p<.0001$) in the mean number of sources of information used by those who prefer a passive role (6.0 sources), compared with those who preferred a shared or autonomous role (8.1 sources).

TABLE 4. Preferred roles: Chest pain and HIV vignettes

Responsibility for DM (Decision-Making)	Responsibility for PS (Problem-Solving)		
	Hand Over	**Share**	**Keep**
Hand Over	Passive Chest Pain: 17.7% HIV: 20.9%	Theoretically Implausible Chest Pain: 0.7% HIV: 0%	
Share	Shared (Leaning Passive) Chest Pain: 50% HIV: 45.8%	Shared (Equally) Chest Pain: 6% HIV: 5.9%	Autonomous (Leaning Shared) Chest Pain: 0.2% HIV: 0%
Keep	Shared (Divide and Share) Chest Pain: 21.5% HIV: 22.1%	Shared (Leaning Autonomous) Chest Pain: 3.8% HIV: 5.0%	Autonomous (Consumerist) Chest Pain: 0% HIV: 0.2%

Note: Total Chest Pain: n = 418 (99.9%); Total HIV: n =421 (99.9%)

Satisfaction with role

The vast majority of respondents were satisfied with their current level of involvement in making treatment decisions about managing their HIV/AIDS, with 42.6% being "very satisfied" and another 45.4% being "satisfied." A t-test confirmed that there was no statistically significant difference in mean satisfaction score between those preferring a passive role and those preferring a shared role.

Discussion and Conclusions

Our results are consistent with the shared decision-making literature and suggest that much of the "consumerist" rhetoric is oversimplified. Even within a well-educated group of PHAs – widely reputed to be knowledgeable, activist and autonomous – only one respondent wished to adopt a consumerist role. Nonetheless, these respondents were not calling for a return to passivity or physician dominance, and did not want to be left out of the decision-making process. Instead, they sought (and, it appears, largely had) a shared trusting relationship with their providers, in which PS is left to the expert provider and the patient is welcomed and encouraged to participate in DM tasks. Contrary to the findings of earlier sociological studies of PHAs (Epstein 1996; Kayal 1993), our respondents showed a high level of satisfaction with their involvement in making treatment decisions. Similarly, despite suggestions that the Internet is replacing physicians (Eysenbach and Jadad 2001), our respondents relied on both, with clinicians placed above both the less-personalized forms of information available through most published sources and the information provided by national and provincial ASOs.

Discussion of our findings with our expert advisory committee confirmed the implication that the changing nature of the HIV epidemic in North America may have moved PHAs closer to the medical mainstream than they were in the earlier days of the epidemic. Our results cannot be explained by changes in the population groups affected by the epidemic, since our respondents still heavily represent the population of educated men having sex with men who were considered most likely to desire a consumerist role. Our results are instead likely to reflect the fact that, as knowledge about HIV/AIDS and its treatment options has increased and improved therapies and specialized clinics have emerged, HIV/AIDS is looking more like other chronic diseases.

Our respondents showed a very high level of trust in healthcare providers, ranking them higher than any of the alternative sources of information. However, although providers were the most common (and valued) sources of information, our respondents also displayed a very high desire for information, using a large number of different sources. The Internet appears to be a potentially valuable source of information but has not replaced the knowledgeable professional needed to help make sense of the information. Instead, these results suggest that educational materials and decision-making aids would be more valuable if they were designed to focus on the actual decisions that must be made and to clarify any trade-offs involved.

Our findings suggest that it is time to broaden the understanding of what it means to be an autonomous participant in the healthcare encounter. Our results suggest that the "new patient" indeed requires a redefinition, but not a de-professionalization, of provider roles. Our respondents strongly wished to understand their disease and the choices available to them, and to be involved in certain aspects of decision-making, particularly those that could affect their quality of life. However, they did not wish to take on the provider's role; they were willing to leave much of the responsibility for tasks that require expertise to the providers, but to work with them in determining the best course of action in making often-difficult decisions.

Final caveat: This research was conducted in Canada, a country with universal healthcare that provides full insurance coverage for physician and hospital services. It is therefore unclear whether the results would be generalizable to PHAs living in countries with different healthcare systems.

Correspondence may be directed to: Raisa B. Deber, PhD, Department of Health Policy, Management and Evaluation, University of Toronto, 155 College St., Suite 425, Toronto, ON M5T 3M6; tel.: 416-978-8366; fax: 416-978-7350; e-mail: raisa.deber@utoronto.ca.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the critical contributions of the co-investigators on this project: Dr. Mark Halman, Dr. Peggy Millson, Dr. Ted Myers, Dr. Donna Stewart, Dr. Sharon Walmsley, Dr. Andrea Baumann and Dr. Sheryl Boblin. Invaluable suggestions were also made by the community advisory committee, particularly Dr. Gregory Robinson (Chair), RonniLyn Pustil and Glen Brown. We also thank the clinics, clinic staff and PHAs who were instrumental in ensuring the success of this research, and the HIV Ontario Observational Database (HOOD), a project of the Ontario HIV Treatment Network (OHTN).

This research was supported by grants from the Ontario HIV Treatment Network (OHTN) and the Health Evidence Applications and Linkage Networks (HEALNet), and by a Canadian Institutes of Health Research (CIHR) Training Award to Sara Urowitz.

REFERENCES

Anderson, L.A. and R.F. Dedrick. 1990. "Development of the Trust in Physician Scale: A Measure to Assess Interpersonal Trust in Patient–Physician Relationships." *Psychological Reports* 67(3): 1091–100.

Beauchamp, T.L. and J.F. Childress. 2001. *Principles of Biomedical Ethics.* New York: Oxford University Press.

Caulfield, T. 2004. "Medical Malpractice, the Common Law, and Health-Care Reform." In T. Caulfield, *The Fiscal Sustainability of Health Care in Canada: Romanow Papers, Volume 1.* Toronto: University of Toronto Press.

Charles, C.A., A. Gafni and T. Whelan. 1997. "Shared Decision Making in the Medical Encounter: What Does It Mean? (Or, It Takes at Least Two to Tango)." *Social Science and Medicine* 44(5): 681–92.

Coulter, A. 2002. "Whatever Happened to Shared Decision-Making?" *Health Expectations* 5(3): 185–86.

Coulter, A. and D. Rozansky. 2004. "Full Engagement in Health." *British Medical Journal* 329(7476): 1197–98.

Deber, R. 1994. "Physicians in Health Care Management: 8. The Patient–Physician Partnership: Decision Making, Problem Solving, and the Desire to Participate." *Canadian Medical Association Journal* 151(4): 423–27.

Deber, R. and A.O. Baumann. 1992. "Clinical Reasoning in Medicine and Nursing: Decision Making Versus Problem Solving." *Teaching and Learning in Medicine* 4(3): 140–46.

Deber, R., N. Kraetschmer and J. Irvine. 1996. "What Role Do Patients Wish to Play in Treatment Decision Making?" *Archives of Internal Medicine* 156(13): 1414–20.

Deber, R.B., N. Kraetschmer, S. Urowitz and N. Sharpe. In press. "Do People Want to Be Autonomous Patients? Preferred Roles in Treatment Decision-Making in Several Patient Populations." *Health Expectations* 10(3): 248–58.

Deber, R. and N. Sharpe. 1999. "One Million Decisions at the Micro-Level: Patient Choice." In D. Drache and T. Saltman, eds., *Health Reform: Public Success, Private Failure* (pp. 275–91). New York: Routledge.

Deyo, R.A. 2001. "A Key Medical Decision Maker: The Patient." *British Medical Journal* 323(7311): 466–67.

Dillman, D.A. 2000. *Mail and Internet Surveys: The Tailored Design Method.* Toronto: John Wiley & Sons.

Douglas, C.J., C.M. Kalman and T.P. Kalman. 1985. "Homophobia among Physicians and Nurses: An Empirical Study." *Hospital & Community Psychiatry* 36(12): 1309–11.

Ende, J., L. Kazis, A.B. Ash and M.A. Moskowitz. 1989. "Measuring Patients' Desire for Autonomy: Decision Making and Information-Seeking Preferences among Medical Patients." *Journal of General Internal Medicine* 4(1): 23–30.

Epstein, S. 1996. *Impure Science: AIDs, Activism, and the Politics of Knowledge.* Berkeley: University of California Press.

Etchells, E., G. Sharpe, P. Walsh, J.R. Williams and P.A. Singer. 1996. "Bioethics for Clinicians: 1. Consent." *Canadian Medical Association Journal* 155(2): 177–80.

Eysenbach, G. and A.R. Jadad. 2001. "Evidence-Based Patient Choice and Consumer Health Informatics in the Internet Age." *Journal of Medical Internet Research* 3(2): e19.

Forte, T., A.M. Bayoumi, R.S. Remis, C. Swantee, A. Andrews, C.M. Goia, P. Millson, A. Rachlis and G. Robinson. 2003. "Representativeness of the HIV Ontario Observational Database (HOOD)." In *12th Annual Canadian Conference on HIV/AIDS Research 2003.* Halifax, Nova Scotia, April 10–13.

Frosch, D.L. and R.M. Kaplan. 1999. "Shared Decision Making in Clinical Medicine: Past Research and Future Directions." *American Journal of Preventive Medicine* 17(4): 285–94.

Furin, J.J. 1997. "You Have to Be Your Own Doctor: Sociocultural Influences on Alternative Therapy Use Among Gay Men with AIDS in West Hollywood." *Medical Anthropology Quarterly* 11(4): 498–504.

Haug, M.R. and B. Lavin. 1983. *Consumerism in Medicine: Challenging Physician Authority.* Beverly Hills, CA: Sage.

Haugh, R. 1999. "The New Consumer." *Hospital & Health Networks/AHA* 73(12): 30–34, 36.

Kaplan, R.M. 1999. "Shared Medical Decision-Making: A New Paradigm for Behavioural Medicine." *Annals of Behavioral Medicine* 21(1): 3–11.

Katz, J. 1984. *The Silent World of Doctor and Patient.* New York: Free Press.

Kayal, P.M. 1993. *Bearing Witness: Gay Men's Health Crisis and the Politics of AIDS.* Boulder, CO: Westview Press.

Kraetschmer, N., N. Sharpe, S. Urowitz and R. Deber. 2004. "How Does Trust Affect Patient Preferences for Participation in Decision Making?" *Health Expectations* 7(4): 317–26.

Lupton, D. 1997. "Consumerism, Reflexivity and the Medical Encounter." *Social Science and Medicine* 45(3): 373–81.

Mansell, D., R.M. Poses, L. Kazis and C.A. Duefield. 2000. "Clinical Factors That Influence Patients' Desire for Participation in Decisions about Illness." *Archives of Internal Medicine* 160(19): 2991–96.

McNutt, R.A. 2004. "Shared Medical Decision Making: Problems, Process, Progress." *Journal of the American Medical Association* 292(20): 2516–18.

Millson, M.E., A. Peter, A. Rachlis and G. Robinson. 1995. "The HIV Ontario Observational Database." *Ontario Medical Review* 62: 22–24.

Millson, M., G. Robinson, A. Rachlis, R. Palmer, R. Galli and C. Major. 1998. "Representing Diversity in an Observational Database: The Current Demographics of HOOD Enrollees." Abstract. *Canadian Journal of Infectious Diseases* 9(Suppl. A): 39A.

O'Hare, T., C.L. Williams and A. Ezoviski. 1996. "Fear of AIDS and Homophobia: Implications for Direct Practice and Advocacy." *Social Work* 41(1): 51–58.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1982. *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient–Practitioner Relationship.* Washington, DC: Government Printing Office.

Remis, R.S., C. Swantee, K. Rottensten, L. Schiedel and M. Fikre Merid. 2003 (November). *Report on HIV/AIDS in Ontario 2002.* Toronto: Ontario Ministry of Health and Long-Term Care. Retrieved January 19, 2008. <http://www.phs.utoronto.ca/ohemu/doc/technical%20reports/Phero2002v4_lorraine.pdf>.

Rozovsky, L.E. 1997. *Canadian Law of Consent to Treatment.* Toronto: Butterworths.

Rubin, A. and E. Babbie. 2004. *Research Methods for Social Work.* Pacific Grove, CA: Wadsworth Publishing.

Sevdalis, N. and N. Harvey. 2006. "Predicting Preferences: A Neglected Aspect of Shared Decision-Making." *Health Expectations* 9(3): 245–51.

Stewart, D.E., B. Rosen, J. Irvine, P. Ritvo, H. Shapiro, J. Murphy, J. Thomas, G.E. Robinson, J. Neuman and R. Deber. 2001. "The Disconnect: Infertility Patients' Information and the Role They Wish to Play in Decision Making." *Medscape Womens Health* 6(4): 1.

Williamson, C. 1992. *Whose Standards? Consumer and Professional Standards in Health Care.* Philadelphia: Open University Press.

Wood, B. 2000. *Patient Power? The Politics of Patients' Associations in Britain and America.* Buckingham, UK: Open University Press.