Joint replacement recipients' views about health information privacy

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Accepted for publication

30 August 2013

Keywords: health information privacy, joint replacement patients, patients' attitudes

Abstract

Background Researchers are concerned about the possibility of restricted access to data as a result of specific consent requirements in privacy legislation, potentially resulting in smaller samples and a lack of representativeness which could bias results. In addition, there is uncertainty about what influences individuals to give consent for the use of their personal health information.

Objective To measure joint replacement recipients' health information privacy views and to assess potential predictors of these views.

Design Cross-sectional survey.

Setting and participants Potential joint replacement recipients from two teaching hospitals in London, Ontario, Canada.

Main variables Age, gender, education, employment status, anticipated joint replacement, and expectations for surgery.

Main outcome measures Privacy concerns as measured by the Concern Scale.

Results The response rate was 182/253 or 72%. The mean Concern score was 143.9/235.0 for the total sample (range = 82–216). Women had higher levels of privacy concerns than men on slightly over half of the individual questionnaire items. In women, surgical joint, age and employment explained 15% of the variance in concerns about personal health information privacy ($P = 0.001$). The model explained 6% of the variance in concerns in men ($P = 0.138$) and was not statistically significant.

Discussion and conclusion This study indicates that demographic characteristics and health-care experiences play a role in the

variability of health information privacy concerns. A greater understanding of patients' privacy views about health information could lead to a greater harmonization among privacy rules, research and data access, and the preferences of health-care consumers.

Introduction

Increasingly, patient registries have become important for research and health care.^{1,2} In Canada, the Canadian Joint Replacement Registry is tangible evidence of the growing importance of joint replacement registries in this country.³ Registries are able to collect, store and link personal health information, possibly presenting increased risks to personal health information privacy.^{4,5} Researchers are concerned about the possibility of restricted access to data as a result of specific consent requirements in privacy legislation, potentially resulting in smaller samples with less statistical power and a lack of representativeness, which could bias results.^{6–9} In addition, there is ambiguity about what influences individuals to give consent for the use of their personal health information.^{10–14} A Canadian study found that significant selection biases resulted from the implementation of consent in a registry of stroke patients.¹⁵ Therefore, it is important to understand any barriers that may exist to the implementation of patient registries, particularly those that may arise from privacy concerns of patients.

In terms of broad public opinion regarding privacy, a poll released in 2013 suggests that Canadians are concerned about their privacy in general, and the majority think the protection of personal information is a key issue for the coming decade.¹⁶ While the aforementioned survey suggests that perceptions of privacy risk with regard to health/medical information were very low, other polls report strong concerns on the part of Canadians about the security and safety of their personal health information.¹⁷ Most recently, a poll indicated that the majority of Canadians support the use of their personal information for health research purposes.¹⁸ A common finding from two surveys was that familiarity with privacy laws and

rights is relatively low among Canadians.^{16,17} These polls provide general information regarding public opinion about health information privacy; however, they do not reflect the views held by specific patient groups.

In a review of the literature, we identified ten quantitative studies specific to patients' views about personal health information privacy.^{14,19–27} These studies examined privacy views among different groups of patients, including those with 'potentially stigmatizing conditions',¹⁴ genetic conditions,²⁰ cancer,²³ other conditions,²⁶ those in primary health-care settings^{19,21,22,25} and the general public.^{24,27} None reported using a validated questionnaire to measure privacy views. Five further studies focused on sharing information or participation in patient registries.^{15,28–31} The findings of these studies suggest that there is some uncertainty about how individuals will respond to requests to use their personal health information and some variation in whether patients make a distinction between identifiable and non-identifiable health records.

Uncertainty also exists with regard to the potential influence of demographic characteristics on privacy views. Public opinion results suggest age and education play a role in the level of privacy concerns.¹⁶ In the research literature, characteristics such as gender, race, age, education, and employment status have been associated with differing privacy views,^{20,23,25–27} other studies have found no effect.¹⁹ Specifically, there is mixed evidence with regard to the role of gender in privacy views. In our previous study among joint replacement recipients who had already undergone surgery, gender played a significant role in explaining variance in privacy concerns.³² While five previous studies of health information privacy views found gender differences^{14,20,23,25,26} two did not.^{19,27} Among the studies exploring registry participation, only one, a family registry for breast cancer studies,²⁸

found a gender difference, while four others did not.^{15,29–31}

Despite the rising interest in the use of personal health information for purposes such as patient registries and research and the importance of reducing non-response bias, there is not yet a substantial body of evidence using validated survey instruments, which would establish the privacy views of patients with regard to sharing information. In particular, the views of joint replacement recipients are unknown, which is interesting given the rise of the national joint replacement registry in Canada.³ Therefore, we set out to better understand the health information privacy views of joint replacement recipients. Using a validated questionnaire,³³ this study measured the health information privacy views of joint replacement recipients who were waiting for total joint replacement surgery; we also assessed potential predictors of these views.

Patients and methods

Study sample

Joint replacement recipients treated at two teaching hospitals in London, Ontario, Canada were eligible if they were more than or equal to 50 years of age, scheduled to receive a hip or knee arthroplasty from January to May, 2005, not having an emergency or non-elective procedure and a Canadian resident. Master scheduling records for six orthopaedic surgical practices were examined to include all potentially eligible participants in the target sample.

The required sample size was calculated using Cohen's method;³⁴ to detect an R^2 value of 0.10 or larger with a 5% significance level for a two-tailed test with 80% power, 135 participants were needed.³⁴ This was increased to 235 because previous pilot work yielded a 57% response rate.³³ A mid-study review of responses and ineligible participants led us to add 50 potential participants from the master list described above; this brought the targeted total to 285. This study received clearance from The University of Western Ontario's Research Ethics Board.

Data collection

Initial contact with potential participants was made through a cover letter which requested participation in the study, signed by three of the study authors (R.B., M.S., and A.T.), and the patient's surgeon. Participants were invited to complete the self-administered mail-in questionnaire, which was validated in a previous pilot study.³³ We used a modified version of the Dillman method for questionnaire administration.³⁵

Measurement

The questionnaire contained items regarding demographic information, joint replacement surgery information, views towards personal health information privacy, and willingness to participate in patient registries. We focus herein on health information privacy views.

Independent variables

Demographic variables included age, gender, education, and employment status. We included these variables based on demographic differences in overall privacy views¹⁶ and health information privacy views.^{20,23,25–27} Information regarding anticipated joint replacement, including specific surgical joint, surgery type (primary or revision), sidedness and bi- or unilateral joint replacement was also collected. Expectations for surgery were derived from respondents' estimation of the likelihood that they would experience complications as a result of their joint replacement surgery.³⁶ We used this measure of expectations as it is an independent predictor of greater satisfaction in individuals undergoing total joint replacement surgery and has been validated with the patient group of interest.³⁶

Dependent variables

The dependent variable in this study was derived from the 'Concerns About Personal Health Information Privacy Scale' (Concern Scale), developed by the study authors. The Concern Scale contains 47 items, each with a 5-point Likert-type response format to measure views about personal health information pri-

vacy. As responses are summed for all items in the scale, the potential range in scores is 47 (low concern) to 235 (high concern). The personal health information privacy concern domain was originally hypothesized to comprise four subdomains (Table 2): privacy (nos 1–8), consent (nos 9–13), governance (nos 14–16) and registry (nos 17–20). The consent subdomain was further broken down by different combinations of users and uses of personal health information, and identifiability vs. anonymity. Consent for different uses of personal health information when individuals could be identified were items 9 a–k; and under conditions of anonymity, items 10 a–k. Various uses of personal health information were captured in items 11 a–d when people could be identified and items 12 a–d when they could not. Items 13 a and b tapped the specific use of evaluating the health-care system and patient care. As this hypothesized subscale structure was not fully supported by the results of the pilot study,³³ the Concern Scale was analysed as a simple summary score, with the individual items and subscale scores used as a descriptive aid to interpretation. Additional questionnaire detail is provided elsewhere.³³ The Concern Scale was shown to have satisfactory internal consistency, test–retest reliability, construct and content validity in pilot testing.³³ Similar results on these measures were obtained in this study.

Analysis

Following descriptive analyses, *t*-tests and one-way analysis of variance (ANOVA) were used to examine relationships among independent and dependent variables.

Modelling

Multivariable analyses were conducted using multiple linear regression. The ultimate goal was to explain as much variance as possible in participants' privacy concerns. Initially, all variables were entered to estimate the relationship between the independent variables and the Concern score. Effect modification was tested by creating interaction terms between gender

Table 1 Concern scores by categorical independent variables (*N* = 182)

Participant characteristics	%* (<i>n</i>)	Mean concern score (SD) 47 = low concern, 235 = high concern
<i>N</i> = 182		143.9 (21.7)
Sex		
Men	45 (81)	143.0 (18.7)
Women	56 (101)	144.5 (23.9)
Missing	0	
Age (years)		
50–60	20 (36)	143.8 (23.1)
61–70	21 (38)	146.3 (22.3)
71–80	42 (76)	144.4 (21.7)
>80	15 (27)	141.1 (20.5)
Missing	3 (5)	
Education		
Less than grade 9	19 (34)	145.8 (21.8)
Some secondary school	20 (37)	140.2 (22.2)
Completed secondary school	13 (24)	147.9 (22.5)
Some post-secondary	15 (28)	138.2 (21.6)
Completed post-secondary	31 (56)	145.3 (21.2)
Missing	2 (3)	
Employment status		
Employed FT/PT	17 (31)	147.8 (24.4)
Sick Leave /disability	8 (15)	145.6 (16.1)
Other (retired, not working for another reason, looking for work, homemaker, multiple responses)	74 (135)	142.6 (21.7)
Missing	1 (1)	

*Percentages may not add to 100% due to rounding.

and the other independent variables.^{37,38} On the basis of findings from this analysis, we created separate regression models for men and women. Confounders were assessed by determining which variables changed the coefficient of the variable of primary interest, surgical joint (hip/knee), by more than 10% when each was removed from the model.³⁹ Finally, we forced the primary exposure variable (surgical joint) and confounders to remain in the model

while using backward elimination (alpha of <0.10) to identify any remaining covariates that were significant. IBM SPSS Statistics version 11.0 (IBM Corporation, Armonk, NY, USA) for Windows was used for all analyses.

Results

The response rate was 182/253 or 72% (71 individuals either did not respond or decided not to participate); of the original 285 targeted individuals, 32 or 11% were ineligible to participate (reasons included completion of questionnaire after surgery date, did not meet inclusion criteria, administrative error, e.g. incorrect address).

The characteristics of the respondents are outlined in Table 1. It shows there were more women (55%) in the sample than men, more respondents were older (≥ 71 years of age), most (74%) were either retired, not working for another reason, looking for work, a homemaker, or chose more than one category of employment. Furthermore, nearly 40% of respondents had not completed high school, while nearly one-third had completed post-secondary education. The majority of participants had primary joint replacement surgery (79%), with more than half requiring knee replacements (58%). 70% of participants had high expectations for the outcome of their surgery. There was no statistically significant relationship among education and the Concern score; therefore, the education variable was dropped from subsequent analyses. The mean Concern score was 143.9/235.0 for the total sample (range = 82–216). The overall mean scores for concern between men and women were very similar (143 vs. 144.5).

The mean responses to individual questionnaire items are shown in Table 2. Despite the overall mean scores for concern between men and women being very similar (143 vs. 144.5), these means obscure several gender differences among some individual items and hypothesized subscales. Women expressed greater concern in 26/47 (55%) individual items, as well as in most subscales. The exception was with con-

Table 2 Mean responses to individual questionnaire items

Concern scale	Mean score – responses	
	Men	Women
Questionnaire items*		
1. Importance of privacy	4.00	4.21
2. Concerned about privacy	3.79	3.85
3. View/copy medical charts	4.37	4.37
4. Permission for access to personal health information (PHI)	3.96	4.28
5. Correct errors in medical chart	4.41	4.48
6. How PHI privacy is protected	4.13	4.12
7. Erase/delete database information	3.86	4.15
8. Permission for PHI access	4.26	4.40
9. Allow users of PHI if individual identified		
(a) Health-care administrators	2.34	2.68
(b) Drug companies	3.78	3.63
(c) Employers	3.89	4.03
(d) Government insurers	3.69	3.54
(e) Insurance companies	3.80	3.70
(f) Lawyers	4.05	3.96
(g) Medical device manufacturers	3.02	3.25
(h) Medical doctors	2.05	2.12
(i) Medical students	2.51	2.70
(j) Provincial/federal health agencies	3.14	3.26
(k) University health researchers	2.36	2.63
10. Allow users of PHI if individual not identified		
(a) Health-care administrators	2.10	2.09
(b) Drug companies	2.83	2.49
(c) Employers	3.10	3.13
(d) Government insurers	2.95	2.77
(e) Insurance companies	3.08	2.84
(f) Lawyers	3.51	3.26
(g) Medical device manufacturers	2.47	2.39
(h) Medical doctors	1.87	1.82
(i) Medical students	2.14	2.09
(j) Provincial/federal health agencies	2.54	2.51

Table 2. Continued

Concern scale	Mean score – responses	
	Men	Women
(k) University health researchers	1.96	1.99
11. Allow uses of PHI if individual identified		
(a) Education	2.78	3.03
(b) Health-care administration	2.69	2.87
(c) Insurance purposes	3.50	3.29
(d) Research	2.37	2.68
12. Allow uses of PHI if individual not identified		
(a) Education	2.14	2.10
(b) Health-care administration	2.05	2.16
(c) Insurance purposes	2.89	2.66
(d) Research	1.89	2.05
13. Importance of using grouped PHI to		
(a) Assess the health-care system	1.68	1.69
(b) Assess patient care	1.63	1.63
14. Public say in how PHI is accessed and handled	3.99	4.14
15. Government should create laws about PHI privacy	3.36	2.99
16. Need for strict guidelines and rules about PHI privacy	3.94	3.97
17. Join registry if it follows rules and guidelines for PHI	2.05	2.07
18. Acceptable for PHI to remain in registry forever	2.50	2.37
19. Given choice to have information in a registry	3.89	4.11
20. Permission to share PHI in registry with researchers	3.74	4.00

*Questions 9–13, 17 and 18 were reverse-coded.

sent items concerning various users of personal health information where the person could not be identified. In this case, women expressed more concern in only 2/11 (18%) of items.

Three variables, hip/knee joint (surgical joint), primary or revision hip/knee and specific surgical joint, had significantly different

($P < 0.05$) subgroup mean Concern scores; these relationships essentially reduce to hip/knee joint, shown in Table 3. Women who were hip replacement recipients had higher Concern scores than men (152.4 vs. 146.3). In contrast, the difference in mean Concern scores between men and women who were knee replacement recipients was small (0.4). The interaction terms of gender*age and gender*employment were significant, therefore, sex-specific models were created. In women, surgical joint, age and employment were retained in the model and explained 15% of the variance in concerns about personal health information privacy ($R^2 = 0.15$, $P = 0.001$). In men, age was the only significant term in the model, shown in Table 4. This model explained only 6% of the variance in concerns about personal health information privacy in men ($R^2 = 0.06$) and did not achieve statistical significance ($P = 0.138$).

Discussion

This study examined the influence of gender and health-care experiences on pre-operative views towards personal health information privacy. Women expressed higher privacy concerns in slightly more than half of the questionnaire

Table 3 Concern scores by joint replacement and health-care variables ($N = 182$)

Characteristics of scheduled surgery, past experiences and expectations	%* (n)	Mean concern score (SD) 47 = low concern, 235 = high concern
Primary or revision hip/knee [†]		
Primary		
Hip	29 (53)	147.4 (22.1)
Knee	50 (90)	140.2 (21.6)
Revision		
Hip	11 (20)	153.2 (17.2)
Knee	8 (15)	138.5 (24.2)
Missing	2 (4)	
Expectations		
Low	26 (48)	140.3 (18.6)
High	70 (127)	144.6 (22.8)
Missing	4 (7)	

*Percentages may not add to 100% due to rounding.

[†]Subgroup means are significantly different, $P < 0.05$.

Table 4 Multiple regression analysis of privacy concerns on demographic characteristics and characteristics of scheduled surgery, past experiences, and expectations ($N = 166$)

Independent variables	<i>B</i>	SE	<i>t</i>	<i>P</i> -value	95% CI
Women ($n = 96$)					
Surgical joint (hip/knee; reference is hip)	-14.140	4.704	-3.0	0.003	-23.5, -4.8
Age	0.224	0.281	0.8	0.427	-0.3, 0.8
Age squared	-0.056	0.017	-3.2	0.002	-0.1, -0.02
Employment – sick leave/disability [†]	-16.261	9.316	-1.7	0.084	-34.8, 2.2
Employment – other [‡]	-26.259	9.118	-2.9	0.005	-44.4, -8.1
Employment reference FT/PT	–	–	–	–	–
Adjusted $R^2 = 0.15$, $F = 4.422$, $P = 0.001$					
Men ($n = 70$)					
Surgical joint (hip/knee; reference is hip)*	-2.673	4.986	-0.5	0.594	-12.6, 7.3
Age	-0.918	0.314	-2.9	0.005	-1.5, -0.3
Age squared	-0.029	0.031	-0.9	0.351	-0.1, 0.03
Surgery type (primary/revision; reference is primary)*	8.577	5.606	1.5	0.131	-2.6, 19.8
Expectations (low/high; reference is low)*	-3.269	5.814	-0.6	0.576	-14.9, 8.4
Employment – sick leave/disability** [†]	9.729	19.659	0.5	0.622	-29.6, 49.0
Employment – other** [‡]	6.349	6.577	1.0	0.338	-6.8, 19.5
Employment reference FT/PT	–	–	–	–	–
Adjusted $R^2 = 0.06$, $F = 1.651$, $P = 0.138$					

*Primary exposure variable (surgical joint) and confounders were forced to remain in the models.

[†]On sick leave/disability vs. employed FT/PT.

[‡]Retired, not working for another reason, looking for work, homemaker, multiple response vs. employed FT/PT.

items, as well as in most subscales. The findings showed that gender was a significant effect modifier in the relationship between age, employment and personal health information privacy concerns. This interaction may have reflected higher Concern scores among women vs. men who received hip replacements. Gender differences in mean Concern scores among knee replacement recipients were smaller.

There were mixed results in terms of our hypothesized predictors (health-care experiences e.g. surgical joint and expectations of surgery and patient characteristics) in this patient group. Gender and age were important patient characteristics which explained part of the variance in Concern scores among the respondents. The

type of joint replaced and employment status were also important variables in explaining the variance in Concern scores among women. Individuals having a hip vs. knee joint replacement, or those having a primary vs. revision surgery, had significantly different levels of concern at the bivariate level. These findings suggest that men and women differ in the factors that are associated with privacy concerns.

In this study, older men and women were less concerned about health information privacy. Similar to our findings, one study found those who were older (60+ years) were less concerned, with the exception of 18- to 19-year-olds.²⁷ In contrast, another opinion poll¹⁶ and research results²³ suggest that privacy concerns

are higher in older individuals. It should be kept in mind that elective joint replacement recipients are generally older individuals, as is the case with the population in this study.

Women in our study who were knee replacement recipients were less concerned than those who were hip replacement recipients. While there are differences in the clinical outcomes of these groups,⁴⁰ it is difficult to interpret these results because we do not know how pre-surgical concerns, gender and post-surgical outcomes are related. This represents an opportunity for further inquiry. Finally, women who were not currently employed were less concerned than those who were employed. The research evidence is mixed in this regard – one study of the public's views had similar findings to ours,²⁷ while in the other, employed individuals who were in one of three patient groups had a greater likelihood of requiring consent for access to personal health information.²⁶ Overall, these findings reflect the variable contextual factors influencing privacy views and the importance of creating studies that can address this complexity.

Gender can be an important factor in the study of individuals' views, for example, in examining political attitudes⁴¹ and fear of crime.⁴² There also appears to be some evidence regarding the importance of gender in exploring health information privacy views;^{14,20,23,25,26} however, the picture with regard to participation in patient registries is less clear.^{28–31} In concert with this study, much of the evidence from the literature suggests higher health information privacy concerns exist among women.^{14,23,25,26} In addition, there are differences in health status between men and women, and differences in the use of health-care services within this patient population.^{37,43} Given this, our gender findings are perhaps not surprising. It may be that gender is a factor that needs to be considered in achieving a better understanding of health information privacy views and consent to sharing health information. Although we were able to explain a portion of the variance in privacy concerns among women, additional participant characteristics will need to be explored in future

studies to more fully illuminate variance in privacy concerns.

In this study, wait time for surgery was not assessed. Although we were not able to measure pre-operative functional status as a variable to control for, this factor is not associated with levels of patient expectations.³⁶ In our original study plan, we set out to explain the variance in privacy concerns among joint replacement recipients. Having found significant effect modification among gender, age, employment and personal health information privacy concerns in the course of our analyses, we chose to focus on this aspect of the pre-operative data analysed in this study. The sample size calculations for this study did not anticipate the need for a gender-specific analysis, which was necessitated by significant effect modification by gender. This led to an analysis among men that was underpowered. Therefore, while we found age, surgical joint and employment to be important variables related to privacy concerns in women, it is difficult to make comparisons between men and women. We found relatively small differences in Concern scores; this may be one of the reasons for not observing large differences between groups. The precise meaning of the Concern score differences could be understood through future qualitative research (for example, using cognitive interviewing); until then, it is difficult to address what these differences mean.

One of the strengths of our study was the response rate (72%), and an additional limitation is that we were unable to determine any differences between responders and non-responders to our request for participation in this study. However, even with a homogeneous patient group undergoing a procedure with high efficacy, we were able to explain 15% of the variance in privacy concerns among women. The distribution of participants' characteristics indicated that the sample was representative of the population of interest.⁴⁴ While our study sample did contain more patients receiving revision joint replacements (19%), compared to the patient population (13%),⁴⁵ it established a baseline of privacy views within a group of total hip and knee joint recipients.

This study indicates that demographic characteristics and health-care experiences play a role in the variability of health information privacy concerns expressed by joint replacement recipients. A greater understanding of patients' privacy views about health information may benefit the public, researchers, policymakers and legislators. This could lead to a greater harmonization among privacy rules, research and data access, and the preferences of health-care consumers.

Acknowledgements

We thank the participants in this study. This research was supported by a grant from the Canadian Arthritis Network. The study was conducted while Dr. Terry was a Ph.D. candidate in the Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, The University of Western Ontario. Dr. Terry held a post-doctoral fellowship from 2008 to 2010, which was funded by the Canadian Health Services Research Foundation and the Canadian Institutes of Health Research.

Conflict of interest

The authors have no conflicts of interest to report.

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