

Primary Care Providers' Attitudes towards Recommending Cancer Screening to Patients
with Intellectual Disability: A cross-sectional survey

Genevieve Breau, Sally Thorne, Jennifer Baumbusch, T. Greg Hislop, Arminee Kazanjian

Genevieve Breau, PhD,
Postdoctoral Research Fellow,
Collaboration for Outcomes Research and Evaluation,
Faculty of Pharmaceutical Sciences,
University of British Columbia,
2405 Wesbrook Mall,
Vancouver, BC V6T 1Z3 CANADA
genevieve.breau@alumni.ubc.ca

Sally Thorne, PhD, RN DSc (Hon), FAAN, FCAHS
Professor,
School of Nursing,
University of British Columbia,
T201-2211 Wesbrook Mall,
Vancouver, BC V6T 1Z3 CANADA
sally.thorne@nursing.ubc.ca

Jennifer Baumbusch, PhD, RN
Associate Professor,
School of Nursing,
University of British Columbia,
T201-2211 Wesbrook Mall,
Vancouver, BC V6T 1Z3 CANADA
Jennifer.baumbusch@nursing.ubc.ca

T. Greg Hislop, MD, MSc.,
Clinical Professor,
School of Population and Public Health,
University of British Columbia,
2206 East Mall,
Vancouver, BC, V6T 1Z3 CANADA
tgreghislop@gmail.com

Arminee Kazanjian, Dr Soc.,
Professor,
School of Population and Public Health,
University of British Columbia,
2206 East Mall,
Vancouver, BC, V6T 1Z3 CANADA
Arminee.kazanjian@ubc.ca

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Abstract

Individuals with intellectual disability obtain breast, cervical, and colorectal cancer screening at lower rates, relative to the general population. This cross-sectional survey study explored how primary care providers and trainees recommend cancer screening to patients with intellectual disability, using a standardized attitudes questionnaire and vignettes of fictional patients. In total, 106 primary care providers and trainees participated. Analyses revealed that participants' attitudes towards community inclusion predicted whether participants anticipated recommending breast and colorectal cancer screening to fictional patients. Further research is needed to explore these factors in decisions to recommend screening, and how these factors contribute to cancer screening disparities.

Keywords: family physician, early detection of cancer, primary health care, intellectual disability, primary care

Background

Cancer screening improves patient outcomes through early detection of cancer. Women with intellectual disability do not receive screening for breast or cervical cancer at rates comparable to the general population, and individuals with intellectual disability face disparities in obtaining colorectal cancer screening. A recent study in Ontario, Canada reports that women with intellectual disability were less likely to have had a Pap test in the previous three years (adjusted odds ratio (OR) =0.21, 95% confidence interval (CI) 0.20-0.21) and women with intellectual disability aged 50-69 were less likely to have received a mammogram in the previous

two years (adjusted OR = 0.46, 95% CI 0.43-0.49) (Cobigo, Ouellette-Kuntz, Balogh, Leung, Lin, & Lunsky, 2013). Similarly, individuals with intellectual disability were less likely to have received a fecal occult blood test for colorectal cancer in the previous two years (adjusted OR=0.68, 95% CI 0.65-0.71) relative to members of the general population (Ouellette-Kuntz, Coo, Cobigo, & Wilton, 2015). These studies raise the possibility that those with intellectual disability may face poorer outcomes due to their cancer being detected at later stages.

The reasons for these disparities have not been extensively studied. One potential reason is that health professionals may have negative attitudes towards individuals with intellectual disability, and thus do not recommend cancer screening to these patients. Research has shown that a health professional's recommendation is a key factor in obtaining screening (Coughlin, Breslau, Thormson, & Benard, 2005), and some health professionals may have negative attitudes towards this group (Matziou, Galanis, Tsoumakas, Gymnopoulou, Perdikaris & Brokalaki, 2009). Additionally, there are reports by both women with physical and intellectual disability (Llewellyn, Balandin, Poulos, & McCarthy, 2011), and their family members (Swaine, Dababnah, Parish, & Luken, 2013), that they have been told by health professionals that cancer screening is not necessary for them, although most people with intellectual disability should undergo routine cancer screening in accordance with their jurisdictions' guidelines.

Currently, no studies to date have shown that health providers' attitudes towards people with intellectual disability impact the provision of care, specifically recommendations for cancer screening. However, other researchers have demonstrated that health professional's attitudes are related to intention to perform other clinical actions, for example screening cardiac patients for depression (Hart & Morris, 2008). Given that attitudes are related to health provider behavior in

other clinical situations (Hart & Morris), that health professionals may have negative attitudes towards patients with intellectual disability (Matziou et al., 2009), and that a recommendation for cancer screening from a primary care provider is a key determinant in whether individuals receive cancer screening (Coughlin et al., 2005), it is possible that primary care providers' general attitudes towards people with intellectual disability is a predictor of whether they recommend cancer screening to this patient group. A potential lack of cancer screening recommendation may then contribute to the cancer screening disparities experienced by individuals with intellectual disability. If negative attitudes do impact provision of care, then educational programs or specific clinical training to ameliorate primary care providers' attitudes towards this population may contribute towards higher uptake of cancer screening in this group.

The overarching aim of this mixed-methods study was to explore how primary care providers recommend cancer screening to their patients with intellectual disability, and which factors contribute to their decision-making in this area. The primary objective of the quantitative phase, presented here, was to determine whether clinicians' attitudes towards the community inclusion of individuals with intellectual disability are related to whether they anticipate recommending screening to fictional patients. A secondary objective, explored in the qualitative phase and reported elsewhere, was to describe primary care providers' experiences recommending cancer screening to patients with intellectual disability.

Methods

This study employed a mixed methods design, with a cross-sectional survey of physicians and primary care trainees (quantitative phase) aimed at addressing the primary objective of the study. Data collection and analysis occurred separately for both phases, and the results of the

quantitative phase are presented here, while the results of the qualitative phase are presented elsewhere.

Setting and Participants

All family medicine trainees at a Western Canadian university were invited to participate and all primary care nurse practitioner students at three universities in Western Canada were also invited to participate via an online survey. In total, electronic invitations were sent to approximately 150 family medicine trainees and 90 nurse practitioner students. In addition, family physicians practicing within this province were recruited through the provincial College of Physicians and Surgeons' 2015 medical directory. A random sample of 670 registered family physicians was generated and all physicians in this sample were mailed surveys. Data collection occurred from January to June 2015.

The overall response rate for the quantitative phase was 11%, with 58 family physicians, 28 family medicine trainees, and 9 primary care nurse practitioner students responding. Fifty-eight (58) participants were female (56.8% of the total sample), and 44 were male (43.1%). The majority of participants were between the age of 26 and 35 years. A minority had previous personal and work experience with people with intellectual disability, although the majority of participants in the quantitative phase were practicing independently as family physicians and had extensive clinical experience, with approximately 60% of quantitative participants having more than 20 years' experience practicing as primary care providers. Unfortunately, due to confidentiality requirements it is not known what the demographic composition of non-respondents was.

Instruments

A demographic form was administered to participants prior to their completing other measures. The two instruments that were used for the survey portion of the study were: 1) the Community Living Attitudes Scale-Intellectual Disability version (CLAS-ID) (Henry, Keys, Jopp, & Balcazar, 1996), which measures attitudes regarding the community inclusion of individuals with intellectual disability; and 2) a series of vignettes developed for this study. The vignettes presented hypothetical patients meeting provincial screening criteria at the time of data collection, and participants rated how likely they were to recommend screening to each patient.

The Community Living Attitudes Scale-Intellectual Disabilities version (CLAS-ID) was developed by Henry et al. (1996) to measure university students' and professionals' attitudes towards community inclusion for individuals with intellectual disability. We received permission to use the scale.

There are 40 items in total on the CLAS-ID: 12 items on the Similarity subscale, 13 items on the Empowerment subscale, 7 items on the Sheltering subscale, and 8 items on the Exclusion subscale. All items are scored on a six-point Likert scale, ranging from (1) Strongly disagree to (6) Strongly agree. Negative items are reverse coded, and subscale items are then summed to create a total subscale score. Typically, a total score is not produced. Instead, the subscale scores are treated as individual variables. All four subscale scores are then divided by the number of items in each subscale in order to create a standardized subscale score that ranges from 1-6.

The 40-item CLAS-ID was then administered to 355 staff members from 81 agencies whose clientele consisted primarily of people with intellectual disability. Henry et al. (1996) conducted a confirmatory factor analysis to assess the construct validity and found that the four-

factor model of the CLAS-ID was a good fit: the adjusted goodness-of-fit index was .92 and the root mean square residual was .09. In addition, all 40 items had significant factor loadings of .31 or greater, in the appropriate direction, to their corresponding subscale, with most factor loadings falling in the .4-.7 range. This secondary analysis supports the subscale structure of the CLAS-MR and is evidence of good construct validity.

Henry et al. (1996) also determined the internal reliability and concurrent validity of the 40-item CLAS-ID using Cronbach's alpha, which refers to the variability of individual items and how this variability relates to the total scores (Polit, 2010). A Cronbach's alpha of .70 to 0.75 is acceptable and Cronbach's alphas of 0.80 and above are considered desirable (Polit, 2010). All four subscales had Cronbach's alphas of .7 or greater, indicating that the items were internally reliable; that they are related to the subscale to which they were assigned. In addition, subscales of the CLAS-ID correlated moderately (Pearson r 's between .31-.87) and in the appropriate direction with subscales of the Scale of Attitudes Toward Disabled Persons (Antonak et al., 1982), a questionnaire that measures respondents' non-specific attitudes towards individuals with many types of disabilities. This provides evidence that the two scales measure a similar construct and supports the concurrent validity of the CLAS-ID. Thus, based on these analyses the authors conclude that the CLAS-ID is reasonably reliable and valid.

Cancer Screening Vignettes

A series of eight vignettes was developed by the first author to measure primary care providers' likelihood of recommending cancer screening to hypothetical patients with intellectual disability and hypothetical patients with other health conditions. These vignettes were developed based on BC Cancer Agency guidelines for cancer screening and were pilot tested along with the

other study instruments. Clinical vignettes have been demonstrated to be as reliable and valid as actors portraying patients in studies examining physicians' clinical practices (Dresselhaus et al., 2004; Peabody et al., 2000; Peabody et al., 2004). Clinical vignettes are also more reliable and valid, and less time consuming, than abstracting information from patients' medical charts. Vignettes have been used to assess general practitioners' recommendations for preventive screenings (Dresselhaus et al., 2004) and for providing general medical care to patients (Peabody et al., 2000; Peabody et al., 2004).

In this study, four vignettes portrayed individuals with intellectual disability, and four vignettes portrayed individuals with a chronic health condition, for a total of eight vignettes. The four patients with a chronic health condition served as controls in the event that participants had negative attitudes concerning a specific type of screening. For the vignettes portraying individuals with intellectual disability, one presented a female patient in need of a screening mammogram, one presented a female patient in need of a cervical cancer screening test, one presented a female patient in need of a colorectal cancer screening test, and one presented a male patient in need of a colorectal cancer screening test. Vignettes 1, 3, 5, and 7 portrayed patients with intellectual disability, and vignettes 2, 4, 6, and 8 portrayed patients with chronic health conditions. The latter vignettes were utilized as control conditions, and these vignettes are not described further in this paper.

Data Analysis

A series of three forced-entry multiple logistic regressions was conducted to determine if five demographic variables (age, gender of participant, professional status (physician or trainee), and personal and work experience with individuals with intellectual disability) and the four

CLAS-ID subscales predicted participants' anticipated recommendation of cancer screening to fictional patients.

Ethics, Consent, and Permissions

Ethical approval for the study was reviewed by and obtained from the research ethics boards (Canadian equivalent to institutional review boards) at two participating universities, and approval was obtained from the Provost's Office at an additional university (following institutional guidelines for conducting research with students). The heads of nurse practitioner programs at the three universities and the Faculty of Medicine Research Committee's permission was obtained in order to conduct research involving trainees in the Faculty of Medicine. Participants provided informed consent at the time of completing the survey, and all interviewees provided written consent prior to participating in interviews.

Results

Descriptive Statistics

Seven participants were outliers on one or more CLAS-ID subscales and were removed from further analysis, thus the final analyses had 95 participants. Mean CLAS-ID subscale scores indicated that participants generally had positive attitudes, with high standardized mean scores on the Similarity and Empowerment subscales and low standardized mean scores on the Exclusion and Sheltering subscales. Anticipated recommendation scores for fictional patients were generally high with the mean rating for the breast cancer vignette was 5.74 out of 6 (95% CI 5.57-5.94), the mean rating for the cervical cancer screening vignette was 4.69 (95% CI 4.33-5.08), and the mean rating for the colorectal cancer screening vignette was 5.78 (95% CI 5.58-5.93).

Multiple Logistic Regression Analyses

Three multiple logistic regressions were conducted, one for each vignette depicting a patient with an intellectual disability. The predictor variables for the forced-entry regressions were added in blocks: block one was demographic factors, and block two was the four CLAS-ID subscales. In addition, the ratings for each anticipated recommendation of cancer screening were dichotomized around the median.

For the breast cancer screening vignette, the Hosmer and Lemeshow Test was significant ($\chi^2(8) = 18.339, p = 0.019$) indicating that including all of the variables in the analysis did not produce a good fit for the model. Nonetheless, the full model had a Nagelkerke R^2 of 0.396, indicating that the predictors in the full model explained approximately 40% of the variance in scores reflecting likelihood of recommending breast cancer screening for a patient with an intellectual disability. Only the CLAS-ID Exclusion subscale beta-coefficient was significant ($\beta = -2.617, 95\% \text{ CI } 0.007-0.735, \text{ Wald} = 4.934, p = 0.026$), indicating those with negative attitudes were less likely to anticipate recommending screening (see Table 1).

For the cervical cancer screening vignette, the Hosmer and Lemeshow Test was non-significant ($\chi^2(8) = 4.490, p = 0.810$), indicating the full model is accurate at predicting the observed dependent variable values. The full model had a Nagelkerke R^2 of 0.123, indicating the full model explained 12% of the variance. However, the beta-coefficients for none of the predictor variables were significant (see Table 2).

For the colorectal cancer screening vignette, the Hosmer and Lemeshow Test was also non-significant ($\chi^2(8) = 5.028, p = 0.755$) indicating that the full model was a good fit for the data, and the full model had a Nagelkerke R^2 was 0.356, indicating that the predictor variables in the

model explained 36% of the variance in the dependent variable. The beta coefficient for the CLAS-ID Exclusion subscale was significant ($\beta = -3.314$, 95% CI .003-.484, Wald=6.298, $p=.012$), indicating that those with more negative attitudes were less likely to anticipate recommending screening (see Table 3).

Discussion

Summary of Key Findings

The aim of this study was to understand how primary care providers recommend cancer screening to patients with intellectual disability, including how providers' attitudes towards the community inclusion of people with intellectual disability contribute to cancer screening. Our findings revealed that primary care providers' negative attitudes toward community inclusion of people with intellectual disability predicted their anticipated likelihood of recommending cancer screening to fictional patients.

Relevance to Previously Published Literature

It is likely that multiple factors influence a primary care provider's decision whether or not to recommend cancer screening to any patient. However, the findings from the quantitative phase of this study indicate that primary care providers' attitudes may influence this decision-making process, and may determine whether a clinician recommends cancer screening. Previous research described reports of individuals with intellectual disability being told by experienced health professionals that cancer screening is not necessary for women with intellectual disability (Llewellyn et al., 2011; Swaine et al., 2013), presumably indicating more negative attitudes, while health professionals in the current study reported more positive attitudes, which is more

similar to other studies that examined attitudes in isolation (Ouellette-Kuntz, Burge, Henry, Bradley, & Leichner, 2003; Ouellette-Kuntz, Burge, Cleaver, Isaacs, Lunsky, & Jones, 2012).

While this study suggests that attitudes of a healthcare provider may be one contributor to a cancer screening recommendation, Ajzen's Theory of Planned Behavior (Ajzen, 1991) posits that while attitudes influence an individual's anticipated behavior, prior experience with the behavior has a greater impact on future behavior (Ajzen & Fishbein, 1977; Kraus, 1995). Given that the majority of participants in the quantitative phase were highly experienced professionals (approximately 60% of physicians had been practicing for more than 20 years) it is possible that participants' previous experience informed their responses to the survey, and factors extraneous to attitudes contributed to participants' responses, including anticipated likelihood of recommending cancer screening.

Limitations

The quantitative phase of the study had a low response rate, and employed convenience sampling. Thus, some bias in sampling is probable, because it is likely that responders had both positive attitudes towards people with intellectual disability and a special interest in the topic. In addition, the overall 11% response rate, while similar to the expected 15% response rate, was lower than other studies in which trainees were surveyed with the same or similar instruments (e.g. Ouellette-Kuntz et al., 2012). However, in this study, due to institutional requirements, the surveys were distributed electronically rather than with paper copies to trainees, and were distributed by administrative staff rather than faculty, both of which likely contributed to the lower response rate. In addition, due to limited resources multiple mailings and monetary incentives, methods which have been shown to increase response rates in other survey studies, were not feasible for the current study (Dilman, Smyth, & Christian, 2009).

Implications

This research has implications for how primary care providers recommend cancer screening to patients with intellectual disability, and how individuals with intellectual disability receive primary care in a manner similar to the general population. These results, demonstrating how primary care providers recommend cancer screening, also have implications for how primary care providers recommend other forms of preventive care, such as nutrition or physical activity, and have implications on how primary care providers can better include patients with intellectual disability as part of their general practice. Given that individuals with intellectual disability experience multiple health disparities (Haider, Ansari, Vaughan, Matters, & Emerson, 2013), if there is a method to promote preventive care provision, such as through educational programs for clinicians that are the sequelae from this current study, such steps should be taken. This would help optimize the care that individuals with intellectual disability receive in the community, and help address the disparities in health outcomes that individuals with intellectual disability experience.

Conclusions

The findings of this study revealed that, although attitudes may contribute to a primary care provider's decision whether or not to recommend cancer screening, the decision with respect to cancer screening for any patient may be better understood as a complex decision, with attitudes representing only one among many considerations. It is likely that, where primary care providers decide not to recommend cancer screening to any given patient with intellectual disability, multiple factors, including attitudes, play a role in contributing to the decision as to whether or not to recommend various cancer screening options.

While this study raises the possibility that primary care providers' attitudes towards people with intellectual disability influence their screening recommendations, it is probable that screening recommendations are complex. Further research is needed to further elucidate the factors contributing to their screening recommendations as part of routine practice, including the roles of attitudes and experience. Such research would help us to understand how these factors may be related to the cancer screening disparities experienced by individuals with intellectual disability, and to explore which other factors beyond primary care provider recommendations affect how this population obtains screening. If primary care providers can be encouraged to promote this form of preventive care to patients with intellectual disability in their practice, this will enhance the health care individuals with intellectual disability receive in the community.

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Table 1: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Breast Cancer Screening for a Female Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	95% CI for EXP(B)		Wald	P-value
		<u>Lower</u>	<u>Upper</u>		
<u>Model 1</u>					
Experience (physician)	-.150	.135	5.475	.025	.874
Gender (female)	1.378	.876	17.989	3.196	.074
Age (36-45)	.052	.148	7.509	.003	.958
Age (46-55)	19.588	.000	.000	.000	.998
Age (56-65)	-.089	.111	7.515	.007	.934
Age (older than 65)	20.199	.000	5.02	.000	.999
FamID ¹ (no)	.232	.279	.770	.090	.764
WorkID ² (no)	.338	.256	7.696	.151	.697
Constant	.740			.568	.451
<u>Model 2</u>					
Experience (physician)	-.091	.115	7.270	.007	.932
Gender (female)	1.694	.788	37.758	2.952	.086
Age (36-45)	1.887	.316	138.165	1.480	.224
Age (46-55)	21.222	.000	.000	.000	.998
Age (56-65)	.755	.139	138.165	.294	.558
Age (older than 65)	20.865	.000	32.628	.000	.999
FamID ¹ (no)	1.222	.529	21.086	1.600	.198
WorkID ² (no)	-.199	.103	6.48	.035	.851
CLAS-ID Empowerment	-1.680	.016	2.219	1.827	.176
CLAS-ID Exclusion	-2.617	.007	.735	4.934	.026
CLAS-ID Sheltering	-.230	.137	4.601	.066	.797
CLAS-ID Similarity	1.796	.173	209.733	.983	.321
Constant	3.289			.130	.718

*non-reference category in parentheses for dichotomous variable ¹ Has a family member or friend ² Has work experience with people with ID

Table 2: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Cervical Cancer Screening for a Female Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	95% CI for Exp (B)		Wald	P-value
		<u>Lower</u>	<u>Upper</u>		
<u>Model 1</u>					
Experience (physician)	.026	.275	3.825	.001	.969
Gender (female)	.509	.543	5.100	.794	.373
Age (36-45)	1.249	.612	19.859	1.978	.160
Age (46-55)	1.333	.603	23.853	2.021	.155
Age (56-65)	.559	.327	9.347	.428	.513
Age (older than 65)	.721	.242	17.499	.435	.509
FamID ¹ (no)	-.280	.254	2.251	.253	.615
WorkID ² (no)	-.411	.210	2.095	.491	.484
Constant	.694			.781	.377
<u>Model 2</u>					
Experience (physician)	-.017	.253	3.825	.001	.980
Gender (female)	.557	.559	5.453	.918	.338
Age (36-45)	1.197	.516	21.265	1.592	.207
Age (46-55)	1.275	.529	24.194	1.710	.191
Age (56-65)	.553	.529	10.978	.345	.557
Age (older than 65)	.754	.275	24.063	.370	.543
FamID ¹ (no)	-.325	.188	2.212	.324	.569
WorkID ² (no)	-.391	.236	2.160	.436	.509
CLAS-ID Empowerment	.290	.212	4.227	.244	.622
CLAS-ID Exclusion	-.441	.422	2.294	.462	.497
CLAS-ID Sheltering	.213	.181	3.252	.188	.665
CLAS-ID Similarity	-1.138	.471	1.984	1.497	.221
Constant	5.304			.934	.334

*non-reference category in parentheses for dichotomous variables ¹ Has a family member or friend ² Has work experience with people with ID

Table 3: Results of a Multiple Logistic Regression Analysis to Predict Participants' Ratings of their Anticipated Likelihood of Recommending Colorectal Cancer Screening for a Female Patient with an Intellectual Disability presented in a Vignette (N=95)

	Beta-coefficient	95% CI for EXP(B)		Wald	P-value
		<u>Lower</u>	<u>Upper</u>		
<u>Model 1</u>					
Experience (physician)	-1.163	.033	2.968	1.026	.311
Gender (female)	1.338	.720	20.150	2.477	.116
Age (36-45)	-.203	.087	7.646	.032	.859
Age (46-55)	1.034	.167	47.388	.514	.473
Age (56-65)	.236	.114	14.034	.037	.848
Age (older than 65)	1.094	.141	6.503	.492	.483
FamID ¹ (no)	-.137	.166	4.577	.026	.871
Work ID ² (no)	1.258	.675	18.347	2.232	.135
Constant	1.418			1.583	.208
<u>Model 2</u>					
Experience (physician)	-1.787	.007	3.890	1.240	.265
Gender (female)	1.513	.580	35.513	2.078	.149
Age (36-45)	2.261	.141	653.595	1.101	.294
Age (46-55)	2.176	.248	313.086	1.426	.232
Age (56-65)	1.371	.108	143.920	.557	.455
Age (older than 65)	2.308	.111	910.168	1.007	.316
FamID ¹ (no)	.266	.189	9.009	.073	.788
WorkID ² (no)	2.2093	.891	73.827	3.451	.063
CLAS-ID Empowerment	.581	.213	14.999	.286	.593
CLAS-ID Exclusion	-3.314	.003	.484	6.298	.012
CLAS-ID Sheltering	.113	.134	9.365	.011	.917
CLAS-ID Similarity	-2.122	.003	4.204	1.366	.242
Constant	5.304			1.911	.167

*non-reference category in parentheses for dichotomous variables ¹ Has a family member or friend ² Has work experience with people with ID