Perception and experience of primary care physicians on Pap smear screening for women with intellectual disabilities: A preliminary findings

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Abstract

This study aims to establish evidence-based data to explore the perceptions and experience of primary care physicians in the Pap smear screening provision for women with intellectual disabilities (ID), and to analyze the associated factors in the delivery of screening services to women with ID in Taiwan. Data obtained by a cross-sectional survey by a structured questionnaire (12 perceptional issues) was posted to all primary care settings (N=168) where providing Pap smear tests for women with ID in Taichung and I-Lan counties in Taiwan, Republic of China in 2009. The vital primary care physician of each healthcare setting was the main respondent of the questionnaire. Finally, there were 69 valid questionnaires returned, giving a response rate of 41.7%. The main findings showed that 72.5% medical care settings provide Pap smear services and 51.5% have practical experience on conducting the tests for women with ID. Among the respondents, nearly ninety percent primary care physicians expressed that women with ID need Pap smear test regularly. With regard to the associated factors in the delivery of Pap smear screening services to women with ID. The study found that experienced healthcare settings in Pap smear tests for women with ID were more likely to be in public healthcare settings, felt confident in providing screening tests, having a rapid screening program and having a reminding follow-up system. Those respondents felt necessity in Pap smear test for women with ID were more likely to express it is needed to set up a special screening clinic for this group of women. The present study suggests that women with ID need thoughtful, well-coordinated care from primary care physicians, to increase access to health care providers may be helpful in improving Pap screening tests for this population.

Key words: Intellectual disability, Pap smear, perception, primary care physician, preventive health

1. Introduction

People with ID is one of the most vulnerable populations among the disabled, they are more likely to have poorer health and accompanied with comorbidities, require more preventive health interventions than the general population (Hsu et al., 2009; Lin et al., 2009a; Lin et al., 2009b; Lin, Lin, Yen, Loh, & Chwo, 2009; Yen, Lin, Loh, Shi, & Hsu, 2009; Lin et al., 2007). Many studies have made it clear that people with intellectual disability (ID) have considerable primary health care needs (Beange 1996; Lennox & Kerr 1997; Martin 2000; Lin, Wu, & Yen, 2004; Lin, Yen, Loh, Chow, Wu, & Tung, 2005). However, Grabois, Nosek, and Rossi (1999) pointed out that a substantial portion of primary care physicians were unable to serve their patients with disabilities in the previous year for reasons. Among preventive health services, several previous studies have identified that ID was always used as a reason for primary care physicians to remove women with ID from the screening list (Djuretic, Laing-Morton, Guy, & Gill, 1998; Pearson, Davis, Ruoff, & Dyer, 1998; Nightingale, 2000; Stein, 2000; Watts, 2008), even though they are eligible for screening in health authority guidance (NHSCSP, 2006). Therefore, access to primary care physicians and assumptions made by healthcare professionals about women with ID were vital factors that affect women with ID to access cervical screening (Watts, 2008).

However, Reynolds, Stanistreet and Elton (2008) expressed different conclusion, they found the reasons given for ceasing and/or not screening suggest that merely being coded as having an ID is not the sole reason for these actions. Wood and Douglas (2007) have similar findings which their results showed that the low uptake of cervical screening by women with ID does not appear to be primarily due to these women being excluded from invitation for screening. Generally, primary care professionals make pragmatic decisions when considering screening for women with ID unable to give informed consent, and are guided mainly by the presence or absence of behavioral consent. Finally, they suggested that primary care professionals need guidance and support to offer and provide screening appropriately to women with ID.

To ensure Pap smear screening right of women with ID, it is necessary to examine the perception and experience of primary care physicians in the screening service toward women with ID in health care system. However, evidence-based screening recommendations are lacking in this group of population (Wilkinson, Culpepper, & Cerreto, 2007). Therefore, the aims of the present study are to establish evidence-based data to explore the perceptions and experience of primary care physicians in the Pap smear screening provision for women with ID, and to analyze the associated factors in the delivery of screening services to women with ID in Taiwan.

2. Methods

In order to examine of primary care physicians' perception on Pap smear screening for women with ID, a number of questions were proposed in relation to 12 perceptional issues. Respondents were asked to express their opinions in the each question. The all twelve indicators were selected based on system approach – input, process and output of healthcare services. These 12 questions (yes/no answer) were: (1) Do you provide Pap smear screening for women with ID? (2) Do you have practical experience of Pap smear screening for women with ID? (3) Do you think it is necessary to accept Pap smear screening in women with ID? (4) Do you think it is necessary to provide special Pap smear clinic (environment or exam instrument) for women with ID or disabilities? (5) Is it adequate of provisional Pap smear screening program for women with ID? (6) Do healthcare professional capable to do Pap smear screening for women with ID? (7) Have you had participated trainings/conferences related to disability health care services? (8) Do you actively provide health information to ID individuals and their caregivers? (9) Do your healthcare setting meet the criteria of barrier-free-environment to provide health services for people with disabilities? (10) Do you have preferential policy of Pap smear screening for women with ID? (11) Do you have reminding policy for women with ID of the next Pap smear screening? (12) Do you have rapid service system for the vulnerable

populations (such as the disabled) on Pap smear screening? These questions were specifically designed and, to improve its validity, were reviewed by five experts in the field of medicine, public health, nursing and social welfare.

The key information survey, the study included all primary care settings (N=168) where provide Pap smear tests in Taichung County and I-Lan County in Taiwan (NHI, 2009). We employed a cross-sectional design by a mail-structured questionnaire that was completed for each healthcare setting by its vital primary care physician between June 12, 2009 and August 31, 2009. In an attempt to increase the response rate, the questionnaire sent to each respondent was accompanied by a gift to thanks for their cooperation. In addition, the researchers administering the study also phoned the key informants, reminding them to mail back the questionnaire by the deadline. Finally, there were 69 valid questionnaires returned, giving a response rate of 41.7%. Data were analyzed with SPSS 16.0.

3. Results

Table 1 presents the primary care physicians' perceptions on Pap smear screening for women with ID. The results showed that there were 72.5% medical care settings expressed that they were providing Pap smear services for women with ID while 51.5% have practical experience on serving the tests for this population. Among

these experienced medical care settings (N=35), even they reported many difficulties to conduct Pap smear tests, they were still felt capable to serve this group of women (N=28; 80%) and easily provided Pap smear information to them (N=29; 82.9%). However, there were 22 respondents (62.9%) expressed difficulty to do Pap smear follow-up for women with ID in the study.

Among the respondents, there were 61 (89.7%) primary care physicians expressed that women with ID need Pap smear test regularly. However, only 40 (58%) respondents agreed to set up a specific Pap smear clinic or program for women with ID. Generally, less than half of the respondents (N=31, 46.3%) felt the provisional Pap smear screening program for women with ID is adequate and 57.5% (N=39) physicians expressed that they were confident to provide Pap smear tests for this group of women. There were 47 (68.1%) respondents reported that they were actively provide health information to ID individuals and their caregivers as they use Pap smear tests in the clinics.

With regard to the in-job trainings of the primary care physicians, there were 18 (26.1%) respondents have ever accepted or participated trainings/conferences which focused on disability health services. Not many primary healthcare settings (N=26, 37.7%) met the standards of barrier-free-environment to provide health services for people with disabilities currently. There were 32 (47.1%) respondents expressed that

their settings have a preferential policy of Pap smear screening for women with ID and 29 (42.0%) have a rapid Pap smear service for this vulnerable population. However, there were only one-third healthcare settings (N=24, 34.8%) have had a reminding policy for women with ID of the next Pap smear screening in the study.

Table 2 presents the relation of having experience in providing Pap smear screening to other perceptions among the primary care physicians. The results showed that have experience in Pap smear tests for women with ID was statistical correlated to the ownership of healthcare setting, physicians' capability, a rapid screening scheme and reminding screening program in chi-square tests. The experienced healthcare settings in Pap smear tests for women with ID were more likely to be in public healthcare settings, felt confident in providing screening tests, having a rapid screening program and having a reminding follow-up system. Table 3 presents the relation of perceived need of Pap smear test for women with ID to other perceptions among the primary care physicians. The results showed that perceived need in Pap smear tests for women with ID was statistical correlated to the special Pap smear clinic for women with ID. Those respondents felt necessity in Pap smear test for women with ID were more likely to express it is needed to set up a special screening clinic for this group of women.

4. Discussion

Persons with disabilities constitute one of the largest and most diverse subpopulations in the society, their compliance with routine cancer screenings is essential to reducing morbidity and mortality because of cancer disease (Ramirez, Farmer, Grant, & Papachristou, 2005). However, Wei, Findley and Sambamoorthi (2006) found women with disabilities were less likely to receive mammography and Pap smears within the recommended intervals than the women without disabilities. This study aims to establish evidence-based data to explore the perceptions and experience of primary care physicians in the Pap smear screening provision for women with ID. The main findings showed that 72.5% medical care settings provide Pap smear services and 51.5% have practical experience on conducting the tests for women with ID. Among the respondents, nearly ninety percent primary care physicians expressed that women with ID need Pap smear test regularly.

With regard to the associated factors in the delivery of Pap smear screening services to women with ID. The study found that those healthcare settings where have experience in Pap smear tests for women with ID was statistical correlated to the factors of ownership of healthcare setting, physicians' capability, a rapid screening scheme and reminding screening program. Grabois, Nosek, and Rossi (1999) conducted a cross-sectional survey of primary care physicians, they found 63% of the

physicians supplied auxiliary aids and services to their patients with disabilities; the most common aid was printed materials. There were one-five of the physicians responded that they examined their patients with disabilities while the patients remained in their wheelchairs. Nearly forty percent had used or purchased an adjustable-height examination table and 37% had seen patients with disabilities in other locations. Additional factors that may contribute to limited access and may be amenable to change include low demand for screening from women with ID (Stein & Allen, 1999).

Another study conducted by Wilkinson and Cerreto (2008) found that the usual source of care and health insurance remained significant predictors of receipt of clinical preventive services across all types among women with disabilities. However, Wilkinson, Culpepper and Cerreto (2007) commented that abnormal Pap smears and cervical cancer are less common in adults with ID and screening recommendations should be individualized. They suggested physicians should individualize the interval for cervical screening to the patient's risks.

Coverage in the cervical cancer screening programme is markedly lower for women with ID than for the general female population (Stein & Allen, 1999). Women with ID who had a cervical smear test most often experienced pain and difficulty with the procedure (Broughton & Thomson, 2000). Smeltzer (2006) pointed out some lack

of access arises from obstacles in the physical environment. In addition, primary care physicians and their staffs have been described as either insensitive or overly sensitive about the disability and many women with disabilities described negative attitudes from healthcare providers (Becker, Stuifbergen, & Tinkle, 1997; Coyle & Santiago, 2002). To insure the rights of women with ID to access Pap smear screening service, health professionals will need to become more flexible and competent in the service that they provide (Lin et al., accepted). Therefore, women with ID need thoughtful, well-coordinated care from primary care physicians, to increase access to health care providers may be helpful in improving Pap screening tests for this population.

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Table 1. Perceptions on Pap smear screening for women with ID

Perceptional issues	Yes; N (%)	No; N (%)
1. Do you provide Pap smear screening for women with ID (N=69)	50 (72.5)	19 (27.5)
2. Experience of Pap smear screening for women with ID (N=68)	35 (51.5)	33 (48.5)
I. Difficulties during Pap smear screening (N=35)	28 (80.0)	7 (20.0)
II. Ability to do Pap smear screening (N=35)	28 (80.0)	7 (20.0)
III. Easily provide Pap smear information (N=35)	29 (82.9)	6 (17.1)
IV. Difficulty to do Pap smear follow-up (N=35)	22 (62.9)	13 (37.1)
3. It is necessary to accept Pap smear screening in women with ID (N=68)	61 (89.7)	7 (10.3)
4. It is necessary to provide special Pap smear clinic for women with ID (N=69)	40 (58.0)	29 (42.0)
5. It is adequate of provisional Pap smear screening program for women with ID (N=67)	31 (46.3)	36 (53.7)
6. Healthcare professionals are capable to do Pap smear screening for women with ID (N=68)	39 (57.4)	29 (42.6)
7. Experience to participate disability health service trainings/conferences (N=69)	18 (26.1)	51 (73.9)
8. Actively provide health information to ID individuals and their caregivers (N=69)	47 (68.1)	22 (31.9)
9. Barrier-free-environment to provide health services for people with disabilities (N=69)	26 (37.7)	43 (62.3)
10. Have a preferential policy of Pap smear screening for women with ID (N=68)	32 (47.1)	36 (52.9)
11. Have a rapid Pap smear service for the vulnerable populations (such as the disabled) on Pap smear screening (N=69)	29 (42.0)	40 (58.0)
12. Have a reminding policy for women with ID of the next Pap smear screening (N=69)	24 (34.8)	45 (65.2)

Table 2. Relation of providing Pap smear screening experience to other perceptions

Perceptional issues	No experience N (%)	Have experience N (%)	χ^2	p value
Healthcare setting ownership (N=68)			9.232	0.002
Public	4 (20.0)	16 (80.0)		
Private	29 (60.4)	19 (39.6)		
Healthcare setting (N=68)			0.19	0.663
Hospital	6 (54.5)	5 (45.5)		
Clinic	27 (47.4)	30 (52.6)		
Provisional screening program is adequate (N=65)			0.775	0.379
No	19 (54.3)	16 (45.7)		
Yes	13 (43.3)	17 (56.7)		
Health professional is capable (N=66)			3.97	0.046
No	18 (64.3)	10 (35.7)		
Yes	15 (39.5)	23 (60.5)		
Experience in disability service training (N=67)			0.228	0.633
No	25 (51.0)	24 (49.0)		
Yes	8 (44.4)	10 (55.6)		
Actively provide health information (67)			2.711	0.1
No	14 (63.6)	8 (36.4)		
Yes	19 (42.2)	26 (57.8)		
Barrier-free-environment is adequate (N=67)			0.82	0.365
No	22 (53.7)	19 (46.3)		
Yes	11 (42.3)	15 (57.7)		
Preferential screening policy for women with ID (N=66)			<0.001	0.988
No	17 (48.6)	18 (51.4)		
Yes	15 (48.4)	16 (51.6)		
Reminding screening policy for women with ID (N=67)			6.037	0.014
No	26 (60.5)	17 (39.5)		
Yes	7 (29.2)	17 (70.8)		
A rapid Pap smear service for the vulnerable populations (N=67)			5.635	0.018
No	24 (61.5)	15 (38.5)		
Yes	9 (32.1)	19 (67.9)		

Table 3. Relation of perceived need for Pap smear test to other perceptions

Perceptional issues	Necessary N (%)	Un-necessary N (%)	χ^2	p value
Healthcare setting ownership (N=68)			0.86	0.354
Public	19 (95.0)	1 (5.0)		
Private	42 (87.5)	6 (12.5)		
Healthcare setting (N=68)			0.884	0.347
Hospital	9 (81.8)	2 (18.2)		
Clinic	52 (91.2)	5 (8.8)		
Provide Pap smear screening for women with ID (N=69)			3.305	0.069
Yes	46 (93.9)	3 (6.1)		
No	15 (78.9)	4 (21.1)		
Experience of Pap smear screening for women with ID (N=68)			0.195	0.659
Yes	31 (91.2)	3 (8.8)		
No	29 (87.9)	4 (12.1)		
Difficulties during Pap smear screening (N=37)			0.121	0.728
Yes	25 (92.6)	2 (7.4)		
No	8 (88.9)	1 (11.1)		
Ability to do Pap smear screening (N=37)			1.091	0.296
Yes	24 (88.9)	3 (11.1)		
No	9 (100.0)	0 (0.0)		
Easily provide Pap smear information (N=36)			1.193	0.275
Yes	27 (96.4)	1 (3.6)		
No	6 (85.7)	1 (14.3)		
Difficulty to do Pap smear follow-up (N=37)			2.338	0.126
Yes	18 (85.7)	3 (14.3)		
N0	15 (100.0)	0 (0)		

Table 3. Relation of perceived need for Pap smear test to other perceptions (cont.)

Issues	Necessary N (%)	Un-necessary N (%)	χ^2	p value
Special Pap smear clinic for women with ID (N=68)			6.39	0.011
Yes	39 (97.5)	1 (2.5)		
No	22 (78.6)	6 (21.4)		
Provisional Pap smear screening program is adequate (N=66)			0.055	0.815
Yes	27 (90.0)	3 (10.0)		
No	33 (91.7)	3 (8.3)		
Actively provide health information (N=68)			2.191	0.139
Yes	43 (93.5)	3 (6.5)		
No	18 (81.8)	4 (18.2)		
Barrier-free-environment (N=68)			0.309	0.579
Yes	24 (92.3)	2 (7.7)		
No	37 (88.1)	5 (11.9)		
Preferential screening policy (N=67)			0.276	0.6
Yes	28 (87.5)	4 (12.5)		
No	32 (91.4)	3 (8.6)		
Reminding screening policy (N=68)			0.195	0.658
Yes	21 (87.5)	3 (12.5)		
No	40 (90.9)	4 (9.1)		
A rapid Pap smear service (N=68)			0.512	0.474
Yes	26 (92.9)	2 (7.1)		
No	35 (87.5)	5 (12.5)		

Appendix 1. Questions of healthcare provider's perception on Pap smear screening for women with ID

Issues of Pap smear screening for women with ID (Yes/No)
1. Do you provide Pap smear screening for women with ID?
2. Do you have experience of Pap smear screening for women with ID?
2a. Do you difficulties during Pap smear screening for women with ID?
2b. Are you capable to do Pap smear screening for women with ID?
2c. Is it easily to provide Pap smear information to ID individuals and their caregivers?
2d. Do you feel difficulty to do Pap smear follow-up for women with ID?
3. Do you think it is necessary to accept Pap smear screening in women with ID?
4. Do you think it is necessary to provide special Pap smear clinic (environment or exam instrument) for women with ID or disabilities?
5. Is it adequate of provisional Pap smear screening program for women with ID?
6. Do healthcare professional capable to do Pap smear screening for women with ID?
7. Have you had participated trainings/conferences related to disability health care services?
8. Do you actively provide health information to ID individuals and their caregivers?
9. Do your healthcare setting meet the criteria of barrier-free-environment to provide health services for people with disabilities?
10. Do you have preferential policy of Pap smear screening for women with ID?
11. Do you have rapid service system for the vulnerable populations (such as the disabled) on Pap smear screening?
12. Do you have reminding policy for women with ID of the next Pap smear screening?