Papanicolaou smear screening of women with intellectual disabilities: A cross-sectional survey in Taiwan

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Abstract

Although little is known about the incidence of cervical cancer in women with intellectual disabilities (ID), Pap smear screening is an effective public health program to prevent cervical cancer to this group of people. The purposes of this study were to identify and evaluate the factors regarding the utilization of the Pap smears in women with ID seen in the preventive health screening program. We employed a cross-sectional survey "*2009 National Survey on Preventive Health Use and Determinants among People with Disabilities"*, with the study sample 508 women with ID (aged ≧15 years) participated in the research in Taiwan. Results showed that there were 22.1% women with ID had ever used Pap smear screening previously and mean age of the first screening was nearly forty years old. Comparing to the general population in Taiwan, the ID women at age group <35 years was less likely to use screening and the age group ≧35 years was more likely to use Pap smears than did the general women. Finally, a logistic regression analysis showed that marital status and had experience of accepted tubal ligation surgery were two factors which predicted Pap smear test use in the study. Those women with ID who had marital status were 8.99 times (95% CI=1.65-49.15) more likely than those had not marital status to use Pap smear test. Women with ID had experience on tubal ligation surgery were 10.48 times (95% CI=1.40-78.26) more likely to use Pap smear test than their counterparts. This study highlights that to acknowledge 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.

Key words: Intellectual disabilities, Papanicolaou (Pap) smear, women's health, preventive health

1. Introduction

A Papanicolaou (Pap) smear is a test that collects cells from the cervix and used to check for abnormal cells, inflammation, infection, and pre-cancerous cells that cause cervical cancer. Although little is known about the incidence of cervical cancer in women with intellectual disabilities (ID), the evidence exists that they were less likely to receive Pap smears within the recommended intervals than for the general female population (Stein & Allen, 1999; Wei, Findley, & Sambamoorthi, 2006). Women with disabilities were always encountering many obstacles during preventive health screenings. Mele, Archer and Pusch (2005) found that women with disabilities always described poor transportation, heavy doors, and inaccessible exam tables and bathrooms affected all of their health care services such as cancer screening services. They felt devalued by their providers and believed that their symptoms were often overlooked and these financial and nonfinancial barriers to access that may result in delayed detection and increased risk of poorer outcomes from cancer. Similar results found in Watta's (2008) study which reviewed literature written in English from 1990 to October 2007, she concluded that factors to prevent women with ID from accessing Pap smear screening fell into the following categories: administration errors; access to a GP; assumptions made by healthcare professionals about women with ID; perceived difficulties obtaining consent; attitudes of caregivers; the beliefs and experiences of women themselves; lack of accessible information; and physical difficulties.

Naturally, people with ID experience problems in expressing their own health needs (van Schrojenstein Lantman-de Valk, Metsemakers, Haveman, & Crebolder, 2000). They were more likely to have more ill-health and accompanied with multiple morbidities,

require more preventive health interventions than the general population (Hsu et al., 2009; Lin et al., 2006; Lin et al., 2007; Lin et al., 2009; Lin et al., in press; Lin, Lin, Yen, Loh, & Chwo, 2009; Lin, Yen, Li, & Wu, 2005; Yen, Lin, Loh, Shi, & Hsu, 2009; Lin, Wu, & Lee, 2004). The Pap smear screening problem among women with ID often results from multiple factors that need coordinate and multifaceted interventions. The health authority should adopt preventive comprehensive approach to develop the health care plan for this group of people. However, lack of comprehensive health plan for people with ID in Taiwan is a reflection of the health provision in Taiwan (Lin, Wu, & Yen, 2004; Lin, Chow, Yen, Wu, & Chu, 2004). It is needed to provide evidence-based information to health authority to initiate appropriate health policy, to improve quality of preventive health care for people with ID. Therefore, the purposes of this study were to identify and evaluate the factors regarding the utilization of the Pap smears in women with ID seen in the preventive health screening program in Taiwan.

2. Methods

This study employed a cross-sectional survey "*2009 National Survey on Preventive Health Use and Determinants among People with Disabilities"*, with the study population composed of 3,283 women with ID aged more than 15 years who were officially registered as having an ID in Taichung and Yilan counties in Taiwan. Because most of women with ID in the study had communication and writing difficulties, the main informants for the mail-structured questionnaire were the primary caregivers who could understand and provide information on the Pap smear use of women with ID under their care. The data collection covered two-month period from May to June, 2009. We

designed the questionnaire to consider demographics, reported use and perception of Pap smear use among women with ID and their caregivers. To increase the validity of the study's outcomes, the questionnaire was reviewed by 5 experts who work in the field of disability, public health, family medicine, social welfare, and academia. Finally, there were 508 women with ID (response rate was 16.3%) participated in the study. As the questionnaire responses, data were analyzed with SPSS 14.0. We used number, percentage and chi-square method to describe the subject's characteristics and analyzed their association with Pap smear use. Multivariate analysis of logistic regression method, odds ratio (OR) and 95% confidence interval (CI) were used to evaluate the potential associated factors related to Pap smear use in women with ID.

3. Results

Table 1 and table 2 present the characteristics of ID individuals and their primary caregivers in this study. The response ID subjects, the average age was 33.96±14.44 years, 58.1% had married and most of them were junior high school or less educational level. There were 59.8% ID subjects were ID solely while 49.2% were ID accompanied with other disabilities (multiple disabilities). In term of disability level, most of the women with ID in this study belonged to the moderate (38.6%) and mild level of disability (31.1%) respectively. With regard to ID occurrence among their relatives, the study found that nearly thirty percent of their relatives also have ID cases in their families. The caregiver data showed that there were 56.6% were the parents, 72.1% were female, and the average age of the caregivers was 46.19±15.27 years. There were 50.8% caregivers were unemployed, 47.3% were junior high school or less education level, 42.0% of the

families' monthly household income was less than 20,000 New Taiwan Dollars (NTD) and 46.9% of the families reported their household economic were under deficit status. .

Pap smear and cervical health use among women with ID, table 3 showed that there were 7.6% women with ID had accepted hysterectomy and 19.7% had accepted tubal ligation surgery. There were 22.1% women with ID had ever used Pap smear screening and mean age of screening was 39.75±14.30 years. Among Pap smear users, 61.2% reported they accepted the screening within one year and 44.3% expressed they used the Pap smear screening regularly. With regard to the medical care settings to the Pap smear test, 46.4% women with ID were reported that they had ever received the screening letter to remind them to accept Pap smear test regularly.

Table 4 and table 5 analyzed the relationship between Pap smear use and subjects' characteristics in the bivariant chi-square tests. The results showed the factors of women with ID in marital status, age, educational level, living with parent, ID occurrence in the relatives, accepted hysterectomy or tubal ligation surgery were significantly correlated to use Pap smear test. The primary caregivers' characteristics such as relationship with ID individual, age, have religion belief, household income or household economic balance status were factors to affect ID individual to accept Pap smear test than their counterparts.

Finally, a logistic regression analysis was employed to assess the significance of variation in across different predisposing groups and to measure the enabling and need factors which associated with the use of Pap smear test among women with ID (Table 6). Model 1 analyzed the effects of predisposing factors, model 2 tested the predicted effects of predisposing and enabling factors, and Model 3 integrated all the factors which included predisposing, enabling and need factors to predict the use of Pap smear among

the subjects. Model 1 and model 2 gave essentially the same results, showing that the factors – age and marital status of women with ID correlated with the use of Pap smear test. In model 1, after adjusting for other predisposing factors, the aged group more than 35 were more likely to accept Pap smear test than aged less than 35, the odds ratio (OR) of the group was 8.09 (95% CI=1.20-54.61). Those women with ID who had married were 4.97 times more likely to accept Pap smear test than those women did not married (95% CI=1.19-20.79). The model 2 also indicated the same results, age (OR=14.18, 95% CI=1.56-128.77) and marital status (OR=6.94, 95% CI=1.51-31.89) were factors to affect the use of Pap smear in the study subjects. Model 3 showed that marital status and accepted tubal ligation surgery were factors which predicted the use of Pap smear test in the study. Those women with ID who had marital status were 8.99 times (95% CI=1.65-49.15) more likely than those had not marital status to use Pap smear test. Women with ID had experience on tubal ligation surgery were 10.48 times (95% CI=1.40-78.26) more likely to use Pap smear test than their counterparts.

4. Discussion

In general, Ramirez, Farmer, Grant and Papachristou (2005) found that women with disabilities were 17% more likely than women without disabilities to report noncompliance with cervical cancer screening guidelines, and women with disabilities had a lower likelihood of receiving a screening recommendation. Although little information about the incidence of cancer in people with ID, researchers of Sullivan, Hussain, Threlfall and Bittles (2004) found the age-standardized incidence of all cancers in people with ID was not significantly different from the general population in Western

Australia. They suggested that more proactive health promotion campaigns may be needed for people with ID, who are likely to be poor users of screening services.

The present study one of the main aims was to examine the Pap smears use in women with ID in Taiwan. Results showed that there were 22.1% women with ID had ever used Pap smear screening and mean age of the first screening was nearly forty years old. Comparing to the general population, the ID women at the age group <35 years was less likely to use screening and age group ≧35 years was more likely to use Pap smears than did the general women in Taiwan (Table 7). Our data was either higher than or different from the other countries studies, Stein and Allen (1999) found 13% of the UK adult women with ID had a record of a smear test in the previous five years, no significant differences in mean age were seen between women screened and those not screened. Reynolds, Stanistreet and Elton (2008) compared 267 women's records with the records of 534 women without ID in UK, they found women with ID had an odds ratio (OR) of 0.48 of receiving a cervical screening test; an OR of 2.05 of being ceased from screening; and an OR of 0.14 of being a non-responder of a screening invitation compared to age and practice matched women without ID.

In term of the factors regarding the Pap smears use in women with ID, our results found that the predisposing factors – marital status of women with ID, and need factors - tubal ligation experience were significantly correlated to their screening uses. The results provide the vital information to the further health policy initiation to increase the screening rate of this vulnerable population. Other studies also found many factors to affect the Pap smear screening in women with ID, such as Broughton and Thomson (2000) found the factors that influenced whether women with ID had a smear test included:

sexual activity; number of sexual partners; pregnancy; and a past history of smoking. Women with ID who had a cervical smear test most often experienced pain and difficulty with the procedure. Rasaratnam, Crouch and Regan (2004) found a significant association between relationship of the caregiver to people with ID and overall positive or negative attitude towards health care. They suggested more work needs to be done with family caregivers than with professional caregivers to improve compliance with medication. Wood (2007) explored the primary care professionals' views about, providing cervical screening to women with ID in two areas of Edinburgh. She found that many practices lack robust mechanisms to identify their patients with ID; practices vary in how they adapt the process of cervical screening to meet the needs of women with ID; and unable to give informed consent. Furthermore, Reynolds, Stanistreet and Elton (2008) concluded that 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. There are training needs among smear takers regarding appropriate reasons not to screen and providing screening for women with ID.

Wilkinson, Culpepper, and Cerreto (2007) used the US Preventative Service Task Force guidelines to suggest that abnormal Pap smears and cervical cancer are less common in adults with ID and screening recommendations should be individualized. However, women with ID have the same right as other women to access cervical screening. To acknowledge the rights of women with ID to access this service, health professionals will need to become more flexible in the screening service that they provide (Watta, 2008). Particularly in the competent of health care professionals, as Grabois, Nosek, and Rossi (1999) found 18% of the primary care physicians were unable to serve their patients with

disabilities in the previous year for reasons. To solve this problem, an important part in making this happen is changing the attitudes of health professionals towards women with ID, to acknowledge that they have the same sexual health needs as other women (Watta, 2008). In addition, the primary care professionals need guidance and support to offer and provide screening appropriately to women with ID (Wood, 2007).

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Table1. Characteristics of women with ID in the study

Variable	N	%
Age (N=469)		
Mean±S.D.	33.96±14.44	
Marital status (N=482)		
Married	280	58.1
Unmarried	202	41.9
Educational level (N=501)		
Junior high school and less	314	62.7
Senior high school and more	187	37.3
Multiple disabilities (N=508)		
No	304	59.8
Yes	204	40.2
Disability level (N=495)		
Mild	54	31.3
Moderate	95	38.6
Severe	191	19.2
Profound	155	10.9
ID occurrence in the relatives (N=501)		
No	352	70.3
Yes	149	29.7

Table 2. Characteristics of the primary caregivers

Variable	N	%
Age (N=446)		
Mean±S.D.	46.19±15.27	
Gender (N=481)		
Female	347	72.1
Male	134	27.9
Relation to ID individual (N=484)		
Parent	274	56.6
Other	210	43.4
Marital status (N=484)		
Married	330	68.2
Other	154	31.8
Educational level (N=486)		
Junior high school and less	230	47.3
Senior high school and more	256	52.7
Employment (N=476)		
No	242	50.8
Yes	234	49.2
Religion status (N=490)		
Yes	375	76.5
No	115	23.5
Household income monthly (N=424)		
<20000 NTD	178	42.0
≧20000 NTD	246	58.0
Household economic balance (N=375)		
Good (surplus)	199	53.1
Poor (deficit)	176	46.9

Table 3. Pap smear use among women with ID

Variable	N	%
Hysterectomy (N=487)		
Yes	37	7.6
No	450	92.4
Tubal ligation (N=478)		
Yes	94	19.7
No	384	81.3
Use of Pap smear (N=448)		
No	394	77.9
Yes	99	22.1
Age of Pap smear screen (N=67)		
Mean±S.D.	39.75±14.30	
Use Pap smear within one year (N=98)		
Yes	60	61.2
No	38	39.8
Pap smear use regularly (N=99)		
Yes	43	44.3
No	56	55.7
Pap smear notice by hospital/clinic (N=98)		
Yes	45	46.4
No	54	53.6

Table 4. Relation of Pap smear use and characteristics of women with ID

Variable	Pap smear use		χ^2	p value
	No; N (%)	Yes; N (%)		
Marital status (N=429)			20.017	<0.001
Married	220 (85.6)	37 (14.4)		
Unmarried	116 (67.4)	56 (32.6)		
Age (N=414)			76.787	<0.001
< 35	210 (94.2)	13 (5.8)		
≧35	111 (58.1)	80 (41.9)		
Educational level (N=443)			38.28	<0.001
Junior high school and less	184 (67.9)	87 (32.1)		
Senior high school and more	160 (93.0)	12 (7.0)		
Living setting (N=436)			0.371	0.543
Family	309 (77.8)	88 (22.2)		
Disability institution	32 (82.1)	7 (17.9)		
Living with parents (N=430)			73.607	<0.001
Yes	281 (89.5)	33 (10.5)		
No	60 (51.7)	56 (48.3)		
Multiple disabilities (N=448)			1.888	0.169
Yes	143 (81.3)	33 (18.7)		
No	206 (75.7)	66 (24.3)		
Disability level (N=436)			0.42	0.936
Mild	108 (76.1)	34 (23.9)		
Moderate	133 (78.2)	37 (21.8)		
Severe	62 (79.5)	16 (20.5)		
Profound	37 (78.7)	10 (21.3)		
ID occurrence in the relatives (N=444)			6.752	0.009
Yes	94 (70.1)	40 (29.9)		
No	252 (81.3)	58 (18.7)		
Hysterectomy (N=438)			8.882	0.003
No	326 (79.9)	82 (20.1)		
Yes	17 (56.7)	13 (43.3)		
Tubal ligation (N=432)			77.135	<0.001
No	308 (86.8)	47 (13.2)		
Yes	32 (41.6)	45 (58.4)		
Cervical cancer (N=437)			0.612	0.434
No	318 (78.5)	87 (21.5)		
Yes	27 (84.4)	5 (15.6)		

Table 5. Relation of Pap smear use and characteristics of the primary caregivers

Variable	Pap smear use		χ^2	p value
	No; N (%)	Yes; N (%)		
Gender (N=426)			1.518	0.218
Male	86 (74.1)	30 (25.9)		
Female	247 (79.7)	63 (20.3)		
Relationship (N=425)			56.679	<0.001
Parent	224 (91.4)	21 (8.6)		
Other	110 (61.1)	70 (38.9)		
Age (N=392)			24.842	0.002
< 45	114 (66.3)	58 (33.7)		
≧45	192 (87.3)	28 (12.7)		
Educational level (N=426)			0.016	0.9
Junior high school and less	160 (78.4)	44 (21.6)		
Senior high school and more	173 (77.)	49 (22.1)		
Career (N=418)			0.002	0.962
No	171 (78.1)	48 (21.9)		
Yes	155 (77.9)	44 (22.1)		
Married status (N=424)			0.269	0.604
Married	230 (78.8)	62 (21.2)		
Other	101 (76.5)	31 (23.5)		
Religion (N=430)			4.186	0.041
No	73 (70.9)	30 (29.1)		
Yes	263 (80.4)	64 (19.6)		
Pap smear setting (N=421)			0.63	0.427
NHI contract setting	317 (78.1)	89 (21.9)		
Not NHI contact setting	13 (86.7)	2 (13.3)		
Household income (N=373)			6.009	0.014
<20000 NTD	117 (74.5)	40 (25.5)		
≧20000 NTD	183 (84.7)	33 (15.3)		
Household economic balance (N=328)			4.371	0.037
Good (surplus)	107 (84.9)	19 (15.1)		
Poor (deficit)	152 (75.2)	50 (24.8)		

Table 6. Logistic regression of Pap smear utilization among people with ID (N=81)

Variables	Model I	Model II	Model III
Predisposing factors	OR (95% CI)	OR (95% CI)	OR (95% CI)
Caregiver's age (aged≧45 vs. < 45)	0.61 (0.17-2.24)	0.57 (0.15-2.22)	0.40 (0.08-2.07)
Age of women with ID (aged≧35 vs. < 35)	8.09 (1.20-54.61)	14.18 (1.56-128.77)	9.61 (0.84-110.42)
Marital status of ID individual (married vs. unmarried)	4.97 (1.19-20.79)	6.94 (1.51-31.89)	8.99 (1.65-49.15)
Education level of ID individual (senior high and more vs. junior high and less)	1.25 (0.17-9.20)	2.10 (0.25-18.07)	1.41 (0.15-13.33)
ID occurrence in the relatives (yes vs. no)	2.24 (0.57-8.76)	2.27 (0.52-10.00)	2.13 (0.45-10.10)
Caregiver's status (parent vs. other)	0.65 (0.07-5.95)	0.52 (0.05-5.63)	0.28 (0.01-4.70)
Understanding to ID individual (good vs. poor)	1.70 (0.33-8.67)	1.16 (0.22-6.11)	1.28 (0.23-7.22)
Perception of medical care quality (good vs. poor)	0.77 (0.14-4.24)	0.92 (0.16-5.44)	0.47 (0.06-3.58)
Enabling factors			
Religious status of caregiver (yes vs. no)		3.10 (0.61-15.83)	4.02 (0.62-26.07)
Household income (>20000 vs.≦20000 TWD)		0.84 (0.22-3.16)	1.06 (0.20-5.68)
Household economic balance (no vs. yes)		0.38 (0.09-1.55)	0.63 (0.12-3.25)
Need factors			
Hysterectomy (yes vs. no)			0.03 (0.01-1.42)
Tubal ligation (yes vs. no)			10.48 (1.40-78.26)
Importance of pap smear (yes vs. no)			0.20 (0.01-3.49)
Encouraged by friends or relatives(yes vs. no)			1.80 (0.38-8.47)

Table 7. Comparison of Pap smear use between general women and women with ID in Taiwan

Age	Women with ID		General women		χ^2	p value
	N	%	N	%		
20-34 years					10.54	0.001
No	167	88.8	8,938,879	79.2		
Yes	21	11.2	2,344,549	20.8		
≧35 years					28.57	<0.001
No	78	53.1	4,198,619	72.7		
Yes	69	46.9	1,576,473	27.3		