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Predictors of caregiver supportive behaviors towards reproductive health care for women with intellectual disabilities

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ABSTRACT

Although many previous studies have begun to address the reproductive health needs of women with intellectual disabilities; however, the supportive behaviors of caregivers to assist their reproductive health is not well understood. Data from a cross-sectional survey of "*2009 National Survey on Reproductive Health Care Needs and Health Education Strategies for Women with Intellectual Disabilities in Taiwan*" were analyzed. Study sample consisted of 1152 caregivers who working in 32 disability institutions have been analyzed in the study. The results showed that the caregiver did not have adequate supportive behaviors towards reproductive health care for women with ID (mean score was 29.84 out of 60), particularly in the arrangement of preventive reproductive health services. We analyzed the potential significant variables in a multiple linear regression model to examine the factors which affect the caregiver's supportive behaviors of reproductive health for women with ID. The model revealed that the factor of respondent's gender, job category, working years in disability setting, helping experience of reproductive health for women with ID, perception of reproductive health knowledge, in-job training of reproductive health, perceived adequacy of public reproductive health service for the client, scores of reproductive health knowledge and reproductive health attitude were significantly correlated to their supportive behavioral score of reproductive health for women with ID. These factors can explain 23.6% of the variation of supportive behavioral score. The present study suggests the reproductive health interventions need to take into account the perspectives of health workers, caregivers and women, as well as the constraints they face in providing and receiving services, respectively.

1. Introduction

Women with disabilities encounter various social, attitudinal and physical barriers to accessing safe motherhood and reproductive health services in society (Smith, Murray, Yousafzai, & Kasonka, 2004). Bremer, Cockburn, and Ruth (2010) investigated the reproductive health experiences among women with physical disabilities in Cameroon of Canada. They found this group of women had limited understanding of reproductive health and many had not received basic reproductive health education. Furthermore, Mele, Archer, and Pusch (2005) revealed that women with physical disabilities face both financial and nonfinancial barriers to access that may result in delayed detection and increased risk of poorer outcomes from

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breast cancer. Both of the above studies concluded that women with disabilities need greater education on reproductive health and improved access to health care, and the health service providers require education about working with women with disabilities.

In general, disabled women do not get the appropriate information and treatment regarding reproductive health care, they rarely get information about sexuality, birth control, sexually transmitted diseases or pregnancy and motherhood from mainstream health care facilities. If disabled women get these services at all, they get them from friends and from the disability community (Degener, 2000). In modern society, although health professionals have begun to address the health needs of women with disabilities, representation of women with ID in health research and health-care practice remains inadequate. The health policy requires more information about their health concerns, and appropriate health services and options (Brown & Gill, 2002).

Women with intellectual disabilities (ID) are not likely to marry or to enact gender roles as the other people. They are often lacking key sources of informal support and care in later life. While caregivers play an important part in development and wellbeing of adults with ID across the life span (Walsh, 2002). Among the reproductive health issues, women with ID may not able to describe pain or discomfort often associated with the menstrual cycle, peri- or post menopause and thus depends on caregivers to assist in identifying causes of anxiety and distress (McCarron & Service, 2002). However, little is known about the real extent and function of the caregivers. Therefore, the present study aims to explore the profile and predictors of caregiver supportive behaviors towards reproductive health care for women with ID.

2. Method

The present study was one of the results of "2009 National Survey on Reproductive Health Care Needs and Health Education Strategies for Women with Intellectual Disabilities in Taiwan". Data were collected by a cross-sectional and a mail-structured questionnaire that was completed by the institutional staff working in these registered disability welfare institutions in Taiwan. A total of 1152 response questionnaires (response rate = 71.87%) collected from 32 welfare institutions have been analyzed in the study. The survey questionnaire included a consent letter, caregiver's demographic characteristic, their perceptions and supportive behaviors of reproductive health for women with ID. We divided supportive behaviors of reproductive health into four domains: menstrual, menopause, sex education, and help the clients to accept the reproductive health services. Each domain has five issues (questions), the range of each issue was 0–3 score (answers from low to high score: never, seldom, often and always) and the total sum score of each domains was 0–15. The questionnaire was specifically designed and, to improve its validity, was reviewed and revised by five experts in the field of clinical medicine, public health, nursing, special education, and welfare institutional manager. As receiving questionnaires, the data were entered into a database and analyzed using SPSS 16.0 software. We used number and percentage to describe caregiver supportive behavioral scores towards reproductive health care for women with ID. Chi-squares were conducted to examine the relation of participant's personal characteristics and supportive behavioral scores. Finally, a multiple linear regression method was used to predict the score of caregiver's supportive behaviors for women with ID.

3. Results

The demographic characteristics of the respondents showed that most of the respondents were first-line workers who cared for people with ID in disability institutions. Table 1 present the caregiver supportive behaviors which include menstrual, menopause, sex education, and help the clients to accept the reproductive health services for women with ID. In menstrual behaviors, the respondents were always or were often aware of the client's menstrual cycle (69.4%), and teaching how to express discomfort during menstrual cycle (64.0%). In the supportive behaviors in menopause of women with ID, the respondents were always or often encouraging the clients to take high calcium food (64.0%) and providing consultation in weight management during the client's menopause (62.0%). Services in sex education, the issues of "how to avoid private contact and personal protection (77.7%)", "sexual harassment and assaults (66.1%)" and "seeking for help, in case of sexual problems (65.7%)" were always or often provided for women with ID. Those services in preventive health utilization, the respondents were always or often helping the clients on "preventive care arrangement (57.3%)", but seldom or never to teach the client of breast self-exam (69.2%), and to arrange pap smear test for the client (64.9%).

With regard to the caregiver supportive behavioral scores towards reproductive health care for women with ID, Table 2 presents the mean score was 29.84 ± 15.52 (range: 0–60). Supportive behavioral scores in four domains were the following (Mean $\pm$ S.D.): menstrual issues = 8.03 ± 3.98; sex education = 8.18 ± 4.14; menopause issues = 7.81 ± 4.61, and preventive health services = 6.07 ± 4.64.

Table 3 presents the relation of caregiver's personal characteristics and supportive reproductive health behaviors score for women with ID. Respondent's gender ($p < 0.001$) and age ($p < 0.001$), marital status ($p < 0.001$), educational level ($p < 0.001$), job category ($p < 0.001$) and working years in current setting ($p < 0.001$) or disability setting ($p < 0.001$) were significantly different in their supportive behavioral score for the client's reproductive health care in bivariate Chi-square analyses. Table 4 analyzed the relation of caregiver's previous health experience characteristics and supportive reproductive health behavioral score for women with ID, results expressed that behaviors of "helping experience of reproductive health for women with ID" ($p < 0.001$), "perception of reproductive health knowledge" ($p < 0.001$), "in-job training of reproductive health" ($p < 0.001$), "perceived adequacy of public reproductive health service for the client" ($p = <0.046$), scores of