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Do infertile women and government staff differ in evaluation of infertility-related websites?

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ABSTRACT

Objective: To investigate the evaluation of local government Web sites carrying information on infertility by infertile women and by government staff. In particular, the study investigated whether the women and staff differed with respect to the information they rate as important and their self-reported satisfaction with the Web sites. **Design and Sample:** Cross-sectional descriptive study. Sixty-two local government staff members, of whom 46 were public health nurses managing subsidy programs for infertility treatment in the Hokuriku region of Japan, and 84 infertile women attending local clinics. **Measures:** We measured the level of satisfaction with the local government Web sites and perceptions about the importance of each type of content. Data were descriptively analyzed, as well as by factor analysis and multiple regression analysis. **Results:** Local government Web sites were analyzed with respect to information about the treatment, details of the subsidy program, psychological support, and procedures for making a subsidy application. **Conclusions:** The women rated information on the treatment and details of the subsidy programs as important. There was no difference of satisfaction with the Web sites between the infertile women and the staff. Local government staff need to provide reliable data for women who are seeking information on infertility treatment.

Key words: health provider support, infertile women, Japan, survey, Web sites.

Background

According to Internet World Stats (2007), about two thirds of the inhabitants of the United Kingdom are current Internet users. Among those who access the World Wide Web, about 60–80% obtain information on health care from Web sites (The Harris Polls, 2007). When they choose treatment, this choice is affected to some extent by information that is obtained through the Internet (Marriott et al., 2008). Access to information can empower patients to make better informed decisions about health-related issues and more actively participate in health care practice (Berland et al., 2001; Ford, 2000). In addition, online contact with other patients, patient organizations, and health care providers can offer comfort and support (Epstein, Rosenberg, Grant, & Hemenway, 2002). However, the use of the Internet for health care has inherent difficulties, since not all of the information is reliable and some Web sites have readability problems (Berland et al., 2001; Impicciatore, Pandolfini, Casella, & Bonati, 1997; Okamura, Bernstein, & Fidler, 2002; Suarez-Almazor, Kendall, & Dorgan, 2001). Thus, patients may make decisions about their treatment based on unreliable information obtained from Web sites. The infertile couple is no different from other “e-health users” (Marriott et al., 2008). Worldwide, about 80 million people suffer from involuntary childlessness (Boivin, Bunting, Collins, & Nygren, 2007). An increasing percentage of patients undergoing in vitro fertilization (IVF) use the Internet to obtain information, with 42–54% of these patients currently accessing information on the Internet (Haagen et al., 2003; Weissman, Gotlieb, Ward, Greenblatt, & Casper, 2000). A Canadian study of 100 infertile couples revealed that about half of them used the Internet to gather information, and two thirds of the women in these couples took information found on the Internet into consideration when selecting a medical institution for their treatment (Huang, Al-Fozan, Tan, & Tulandi, 2003). This suggests that the Internet has become a vital source of information for people with infertility (Tuil, Verhaak, De Vries Robbe, & Kremer, 2008). The Internet can no longer be left out of consideration in the modern medical world (Cousineau et al., 2008; Jadad, 2004; Marriott et al., 2008; van Empel et al., 2010). The sources of information on fertility services and facilities have changed remarkably during the past 10 years (van Empel et al., 2010). To reduce the economic burden placed on infertile couples by IVF and intracytoplasmic sperm injection (ICSI), the Japanese Ministry of Health, Labour and Welfare has provided subsidies for fertility treatment since 2004, administering the program through prefectures, designated cities, and major cities. The staff involved have to manage the subsidy programs for infertility treatment and provide information on Web sites. In Japan, the use of the Internet varies among regions (Masuya, Aoki, &

Kubota, 2008), which is reflected in the differences in the content provided on Web sites about subsidy programs for infertility treatment (Shimada, 2008). It is a responsibility of local governments to provide people with information on public services, including such subsidies.

Research questions

Our literature search yielded no Japanese studies about the relation between the Web sites of local governments and the needs of infertile women. Therefore, we investigated: (1) What types of information do infertile women and local government staff rate as important? (2) How satisfied are such women and staff with the information available on Web sites? (3) Do such women and staff differ with respect to self-reported satisfaction with these Web sites? (4) Is the level of satisfaction with the Web sites related to ratings of the importance of information, and does the relationship differ between women with infertility and local government staff? (5) Which categories are significantly related to satisfaction among women and staff? Establishment of this baseline information could provide the impetus for developing a method of evaluating local government Web sites. If certain discrepancies or inadequacies are detected, addressing these areas should contribute to the improvement of Web sites so as to better meet the needs of women undergoing infertility treatment.

Methods

Design and sample

There were 27 designated medical institutions offering subsidy programs for infertility treatment in the three prefectures of the Hokuriku region of Japan (as of April 2006). The results of a search of the Web sites of each medical institution revealed that 11 institutions with Web sites focused on the treatment of infertility or the results of treatment. These institutions were invited to participate and six institutions agreed, including one public hospital from prefecture B and five private infertility clinics. Also, a convenience sample of 120 women (40 from each prefecture) was invited to participate. The sample accounted for 14% of 863 women who used the subsidy programs for infertility treatment in these three prefectures of the Hokuriku region from April 2006 to March 2007.

The director of each institution gave approval for the distribution of between 10 and 40 envelopes (total: 120) to women attending the institutions. During routine consultations, a doctor or a midwife explained to each woman the purpose of the study, that participation was voluntary, and that refusal to participate or withdrawal from the

study would not affect any future treatment. Their participation would remain anonymous and the data would be kept confidential. Then the women were given an envelope containing a written explanation of the study's purpose and the policy for protection of participants, a confirmation form, the questionnaire, and two stamped self-addressed envelopes (one for the confirmation form and one for the questionnaire). To enroll staff, the first author (C. T.) contacted the head of each of the 90 offices in the Hokuriku region responsible for implementing the subsidy program, explaining in person or over the telephone the aims of the study and the policy regarding protection of participants. The first author then asked for the cooperation of the staff member who was managing the subsidy program for infertility treatment. Envelopes, containing the same materials as those given to the women were then mailed out to the 90 participating offices.

A total of 210 participants were issued questionnaires between September 10 and October 10, 2006, including 120 women and 90 staff members. Of these, 85 (71%) women and 64 (71%) staff members returned the questionnaire, for a total of 149 responses (71% response rate). Three questionnaires (one woman, two staff members) were excluded because of missing data.

Of the 146 remaining responses (70%), 84 (70%) were from women and 62 (69%) were from staff members.

The Ethics Committee of the Kanazawa University Graduate School of Medical Sciences approved this study. All of the participants gave informed consent to the study. It was emphasized that refusing to participate in this study would not affect each woman's management or treatment at any time. We also provided assurance regarding the confidentiality of the data.

Measures

When preparing the questionnaire, we sought information about the various programs for infertility.

We referred to the Ministry of Health, Labour and Welfare's guidelines regarding the implementation of infertility treatment subsidies (Ministry of Health, Labour and Welfare, 2007) and the Web sites of 94 subsidy programs for infertility treatment throughout Japan (43 prefectures, 16 designated cities, and 35 core cities). Our literature review of the assistance or support services offered by prefectural and local governments focused mainly on the areas of maternal nursing and public health nursing. Five midwifery researchers validated the content of the questionnaire, while a pretest with four women undergoing infertility treatment and four staff members

established face validity.

The questionnaire had 32 items related to the local government Web sites: 9 items related to the content provided by all prefectural and local government Web sites, 18 items related to the content provided by some programs, and 5 items related to content that women wanted according to our literature search, although it was not provided by any program as of April 2006. All 32 items are listed in Appendix A. The background variables included the age, occupation, and parity. We also included the duration of infertility treatment, whether or not the women knew about the subsidy programs, whether or not the women had accessed the Web sites about the subsidy programs for infertility treatment, and the workplace and occupational description of the staff members.

To determine the level of satisfaction with the Web sites provided by local governments, we asked all participants the question: "Do you think that the website provided by your local government for women undergoing infertility treatment satisfies their needs?" They responded on a 3-point Likert scale: 35satisfied, 25neither satisfied nor dissatisfied, or 15dissatisfied. To determine the importance of each Web site, we asked, "How important do you think the following types of websites are to women undergoing infertility treatment?" for each of the 32 types of content provided by the local governments. This question was scored on a 4-point Likert scale: 45extremely important, 35important, 25more-or-less important, or 15not important.

Analytic strategy

First, for the questions relating to the importance of the 32 Web sites items provided by the local governments, we deleted those that showed a ceiling effect and a floor effect; in other words, restrictions in the range of responses whereby distinctions disappeared and invalidated the responses. For the remaining questions, we performed exploratory factor analysis (principal factor method with promax rotation: hereafter, factor analysis) and deleted questions with a factor loading ≤ 0.4 . We repeated the factor analysis and chose factors with an Eigenvalue > 1.0 . Second, differences between the women and the staff were examined with the unpaired t test, based on the average score for each factor and the rate of satisfaction with the Web sites of the local governments. Third, Pearson's correlations were calculated between each factor and the rate of satisfaction with the Web sites of the local governments reported by each woman and staff member. Finally, we carried out separate multiple regression analyses (backward elimination method) for the women and the staff members, using each factor as an independent variable and satisfaction with the Web sites as the dependent variable. Analyses were carried out

using the SPSS statistical package, version 14.0 for Windows (SPSS, Chicago, IL), and significance was set at $p < 0.05$.

The validity of the structural concept of the questions about public support services was examined by factor analysis. Internal consistency was assessed from the overall Cronbach's α and the α index for each factor.

Results

Demographic profile

The average age of the 84 women was 35 years (standard deviation [SD] 54.5, range 26–45 years) and nearly three quarters (73%) of them were employed. More than half of the women (58%) had received infertility treatment for 43 years, with the average duration being 43 months (SD 536.1). Just over three quarters of them (76%) were undergoing IVF or ICSI at the time of the survey and 21% had given birth previously. Seventy-nine women (94%) knew that subsidies for infertility treatment were provided by the prefectural and municipal governments. Fifty-four women (64.3%) had accessed the Web sites.

Of the 62 staff members, 49 (79%) were health care workers and 13 (21%) were office workers. Among the 49 health care workers, 46 (94%) were public health nurses. Overall, 22 (35%) staff members worked at prefectural public health centers or core city public health centers, 21 (34%) worked at local government health centers, 16 (26%) worked at local government offices, and 3 (5%) worked at prefectural government offices.

Factor analysis of the perceived importance of Web sites information

Of the 32 items in the questionnaire, the following five questions were deleted because of a ceiling effect: amount of the subsidy, type of treatment covered by the program, terms and conditions, duration of the subsidy, and the list of contacts. None of the questions had a floor effect. We carried out factor analysis of the remaining 27 items and deleted four questions (reception by health care workers rather than office workers) with a factor loading < 0.4 . We then repeated the factor analysis with the remaining 23 items and selected the four factors that had Eigenvalues > 1.0 and factor loadings > 0.4 for all items, which together accounted for 60.3% of the variance.

Validity and reliability

The first factor with five items (Cronbach's $\alpha = 0.88$) was information about treatment,

including the details of infertility treatments such as costs. The second factor with seven items (Cronbach's α 0.84) was details of the program, including questions about the application procedure. The third factor with seven items (Cronbach's α 0.82) was related to psychological support and self-help groups. The fourth factor with four items (Cronbach's α 0.82) was the application procedure and the necessary documents (Table 1).

The factors were clearly classified, the Eigenvalue was 41.0 when a factor was adopted, and the factor names closely reflected the factor items, and so construct validity was confirmed. The overall Cronbach's α was .90 and the α index for each factor was 0.82–0.88, which meant that internal consistency was confirmed. The average score for satisfaction with the Web site was 1.85 for the women and 2.02 for the staff. There was no significant difference in the level of satisfaction between the women and the staff. However, regarding the perceived importance of items on the Web site, the women gave higher average scores for treatment information and details of the program than the staff, and the difference was significant ($p < 0.001$) (Table 2). Table 3 shows the Pearson's correlation coefficients for the relations between the factors and the satisfaction of the women and the staff. Among the women, a positive correlation ($r = 0.34$ – 0.60) was observed between “psychological support” and “treatment information,” and between “details of the program” and “the application procedure.” None of the other factors showed a significant correlation. Among the staff, a positive correlation ($r = 0.27$ – 0.50) was observed between all of the factors, except for “treatment information” and “the application procedure,” while a negative correlation was observed between satisfaction with the Web site and “treatment information” or “details of the program” (both $r = -0.26$).

Multiple regression analysis was conducted with the factors as independent variables and the level of satisfaction as a dependent variable. None of the factors showed a significant relation with the level of satisfaction (Table 4).

Discussion

The most important consideration for Web sites with information on the treatment of infertility is accuracy (Jain & Barbieri, 2005). A study performed in the United Kingdom showed that infertile women are dissatisfied with the information that they can obtain about treatment (Souter, Penney, Hopton, & Templeton, 1998). Although this study was conducted about 10 years ago, the situation has not changed, and couples are still disappointed with information on their treatment options (Porter & Bhattacharya, 2008). A questionnaire survey of 1,499 couples in the Netherlands revealed that

information provided in accordance with the national infertility guideline did not satisfy the couples and needed to be improved (Mourad et al., 2009). In Japan, local governments provide information on their Web sites about medical institutions that are performing infertility treatment, but the amount of information on such Web sites differs from region to region (Shimada, 2008). Our study shows that infertile women want information about the treatment of infertility. Interestingly, although the purpose of the Web sites run by local governments in Japan is to provide information about the subsidy programs rather than information on treatment itself, the women who access these Web sites are searching for information on treatment more than information on subsidies.

Thus, infertile women in Japan also want more information about their available treatment options.

There is a significant cost for couples in Japan to undergo IVF or ICSI (Kubo, 2005; Matsubayashi et al., 2004; Niino & Okai, 2008; Shimamoto, 2007; Tokuchin, 2008), as is also true for couples in other countries (Collins, 2001; Pratt, 2004; Redshaw, Hockley, & Davidson, 2007; Shahin, 2007). Subsidy programs for infertility treatment are designed to alleviate this economic burden. Local governments should take responsibility for providing information on these programs to the couples who need it. A study in Brazil reports that information on the availability of public sector infertility services is not sufficient (Makuch, Petta, Osis, & Bahamondes, 2010). Our study revealed that the staff supporting this program in Japan considered it more important to explain application procedures, rather than explaining the details of the subsidy program. The main purpose of psychological support is to alleviate anxiety and distress the infertile couples may feel. It has been reported that infertile women suffer from various stresses (de Klerk et al., 2008; Matsubayashi, Hosaka, Izumi, Suzuki, & Makino, 2001; Newton, Sherrard, & Glavac, 1999; Niino & Okai, 2008; Verhaak et al., 2007) and need psychological support (Igarashi, Fujii, Kimura, & Mizunuma, 2008; Lechner, Bolman, & van Dalen, 2007; Niino & Okai, 2008; Slade, O'Neill, Simpson, & Lashen, 2007). Studies performed in Canada, the United States, and Australia have shown that infertile women are dissatisfied with the information available about how to become a parent (e.g., by adoption) (Halman, Abbey, & Andrews, 1993; Hammerberg, Astbury, & Baker, 2001; Sabourin, Wright, Duchesne, & Belisle, 1991; Schmidt, 1998; Schmidt, Holstein, Boivin, Sa°ngren et al., 2003; Schmidt, Holstein, Boivin, Tjornhoj- Thomsen et al., 2003). Many local governments in Japan introduce consultation centers about infertility on their Web sites, but seldom provide information about self-help groups or adoption and foster parenting groups. Our study showed that both the infertile women and the local

government staff who considered information about the details of infertility treatment and the subsidy programs to be important also rated information on psychological support as important. However, there was no difference between the women and the staff with respect to satisfaction with the Web sites. The information provided by these Web sites may differ from region to region, but all local governments have the responsibility to provide reliable information.

The respondents were a convenience sample from the Hokuriku region of Japan and the staff worked for local governments in that region. Therefore, generalization of our results to the rest of Japan should be carried out with caution. The women in the study cohort with childbearing experience who were undergoing treatment for infertility had some differences in the perception of their local government support services compared with nulliparous women. In addition, some women in the study population had not accessed the Web sites themselves and it is possible that the Web sites were evaluated differently by women who had accessed them versus those who had not. Future studies would be needed to clarify the differences of these two cohorts. Furthermore, the 32 items comprising our questionnaire might not have covered all the available types of Web site content, for example, some women may prefer to access data via e-mail. Finally, we measured the level of satisfaction regarding support services provided by local governments with one question that used a 3-point scale. Additional questions about satisfaction, a wider response range, and a larger, more representative sample could have improved the validity of our data.

Our study revealed how information provided on the Internet about financial assistance for infertility treatment is perceived by infertile women and the staff running the program in Japan. Our questionnaire can be used to evaluate the effectiveness of Web sites and to identify problems. The satisfaction of women using the sites may be improved if local governments actively provide more information about treatment, the details of the program, self-help groups, and adoption and foster parenting. Thus, our study has identified areas that can be addressed by the local governments in Japan to improve their Web sites and facilitate their operation. The Ministry of Health, Labour and Welfare has recently increased the level of the subsidy and relaxed the income conditions for this program. Since 2006, the number of participating medical institutions designated by the local governments has also been increasing. Many studies have already been conducted regarding support for infertile women (Boivin et al., 2007; Cousineau et al., 2008; Makuch et al., 2010; Marriott et al., 2008; Mourad et al., 2009; Porter & Bhattacharya, 2008; Tuil et al., 2008; van Empel et al., 2010). If a patient is unaware that the information provided is incomplete and has no reason to be

critical, he/she is likely to be content with the information received. It is important to realize that assessment of patient satisfaction is only an indirect, and therefore inadequate, method of monitoring current practice (Mourad et al., 2009). In the future, it will be important to evaluate changes to the Web sites run by local governments and changes in the evaluation of these Web sites by the women using the sites and the staff providing services. Such a study should include more evidence-based evaluation of actual performance.

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APPENDIX I

Questionnaire about the importance of web site information

How important do you think the following are to women undergoing infertility treatment?
(Extremely important/Important/Somewhat important/Not important)

1. Providing information about infertility itself (△)
2. Introduction to infertility consultation centers (○)
3. Providing information about consultation (△)
4. Providing information about investigations and treatments for infertility (△)
5. Providing information about the costs of investigations and treatments for infertility (△)
6. Providing information about the unexpected effects of treatment (△)
7. Providing the latest information about infertility treatments (×)
8. Providing information about the treating doctors at the designated medical institutions (×)
9. Providing information about counseling at the designated medical institutions (△)
10. Providing advice for daily life (△)
11. Providing information about self-help groups (△)
12. Data on the general outcome of infertility treatment (×)
13. Providing information about groups that help with adoption and foster parenting (×)
14. Purpose of the subsidy programs for infertility treatment (○)
15. Introduction to infertility consultation programs (△)
16. Amount of subsidy (○)
17. Types of treatment covered by the program (○)
18. Terms and conditions of eligibility (○)
19. Procedures to follow from application to receiving the subsidy (△)
20. Duration of the subsidy (○)
21. How to pay medical costs at the medical institution (△)
22. Documents required for making an application (○)
23. Downloading the application form (△)
24. List of designated medical institutions (○)
25. Addresses and telephone numbers of the designated medical institutions (△)
26. Method of selecting and designating the medical institutions (×)
27. List of medical institutions providing IVF and/or ICSI (△)
28. List of contacts (○)
29. Addresses and telephone numbers of the contacts (△)
30. Names of the staff members in charge of assistance (△)
31. Method for calculating the income of the couple (△)
32. Frequently asked questions and answers about the application process (△)

○ Provided by all prefectural and local government programs

△ Associated with infertility and infertility treatment

× Although our literature search revealed that women would like to receive such information, it was not provided by any program as of April 2006.