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Reproductive knowledge and patient education needs among Indonesian women infertility patients attending three fertility clinics

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ABSTRACT

Objective: This study investigated the reproductive knowledge and patient education needs of 212 female Indonesian infertility patients.
Methods: A cross-sectional survey was conducted from July to September 2011 by married women, 18 to 45 years old, seeking infertility care from clinics in Jakarta, Surabaya and Denpasar. Participants were literate, the sample was highly educated, predominantly urban and primarily middle class or elite.
Results: Infertility consultants were cited as the most useful source of information by 65% of respondents, 94% understood that infertility results from male and female factors, 84% could distinguish between infertility and sterility, and 70% could identify their fertility window. However, demand for further knowledge of reproduction and infertility was expressed by 87%. Patients' knowledge of the causes and treatment of infertility was extremely poor. Two key causes of infertility, advanced age and untreated sexually transmissible infections, were not named. Only 19% of patients had received written information.
Conclusion: The study revealed the need for expanded infertility patient education among women patients accessing fertility care in Indonesian clinics.
Practice implications: Opportunities for education should be maximized within infertility consultations. A standardized infertility patient education curriculum should be developed, incorporating patients' priorities, as well as gaps in existing knowledge.

1. Introduction

Provision of patient education has long been recognized as key responsibility of health care providers and as fundamental to patient empowerment. Ensuring that patients are adequately informed is essential to safeguarding minimum standards of care [1], promoting the highest quality of care [2] and providing patient-centered care [1]. The flow-on effects include ensuring patients' ability to give informed consent, greater understanding of and participation in medical decision making and often better health outcomes [3]. Moreover, patient education has been found to be a key aspect of patient satisfaction with infertility care [4–6].

While there is widespread acknowledgement of the importance of patient education within the infertility field, there is limited research into what knowledge infertility patients actually possess and how they gain infertility related information in resource poor settings where health literacy is typically low. Most research on the knowledge levels and needs of infertility patients has been conducted in Western industrialized settings [1,7], often focusing on patients' use of the internet for accessing information [8]. The current gap in understanding of fertility patients' knowledge in non-Western and developing country settings is enormous. This article reports on the first study that has investigated Indonesian infertility patients' reproductive knowledge, information sources and education needs.

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Estimates of infertility in Indonesia vary depending on whether they are extrapolated from the number of patients seeking biomedical care or whether they are derived from demographic health surveys. The lowest rate quoted is 10% and the highest is 22% [9]. Regardless of the difficulties in establishing accurate infertility rates in Indonesia the significance of infertility in terms of the real numbers affected cannot be understated. Based on the current population of women of reproductive age, a conservative 10% female infertility rate translates into a sub-population of around four million women experiencing infertility in their life time [9]. Enormous social suffering stems from childlessness in Indonesia, and impacts upon women to a greater extent than men due to centrality of motherhood for female identity [10].

Biomedical fertility care and assisted reproductive technologies (ART) have been available in Indonesia since 1987. However, the past five years has seen unprecedented expansion in the capacity of infertility clinics. In 2009 there were nine registered fertility clinics operating across the country compared to a total of 23 clinics in 2013, and in 2012 the number of IVF cycles performed was 3581 compared with 987 cycles recorded for 2009, representing an increase of around 400%. This escalation in the number of Indonesians accessing infertility care and seeking to explore the option of ART amplifies the responsibility of the Indonesian infertility field to ensure that these patients are adequately educated.

Debates over the rationale for and against the provision of ART in developing countries have often raised concerns over ensuring quality of care in relation to high-tech treatments [11,12]. Considering that the infrastructure of Indonesian fertility clinics can be described as state of the art, and that the technical expertise of ART clinicians in Indonesia is closely monitored by government and professional bodies, concerns over technical competence are somewhat misplaced. Rather, it is the interpersonal communication between clinicians and infertility patients that requires investigation. As Dyer et al. have asserted in relation to infertility patients in South Africa; “the need for information is of such importance both to the individual patient and to the advancement of reproductive health . . .that information and counseling should be accessible even in the absence of other treatment options” [13]. This research represents an important contribution toward establishing the evidence required for developing a comprehensive education strategy for Indonesian infertility patients.

2. Methods

This study aimed to investigate Indonesian infertility patients’ reproductive knowledge, information sources and education needs. The data was generated by the “Survey of Indonesian infertility patients’ reproductive knowledge and health seeking behaviour,” conducted between July and September 2011. This article reports on data from the knowledge and education components of the survey, as findings on patterns of health seeking have been published previously [9]. Our respondents were 212 infertile Indonesian women recruited through three infertility clinics in the cities of Jakarta, Surabaya and Denpasar. As funding was adequate only for the inclusion of three clinics, we selected clinics in hospitals with differing models and client bases. The Jakarta based clinic is in an elite private hospital that typically attracts patients of very high socio-economic status. The Surabaya based clinic sits within a university teaching hospital that tends to attract mid to lower income patients, while the Denpasar clinic is attached to a regional public hospital that primarily services those who cannot afford to pay for private services. Despite being recruited in these three cities, only 46% of the sample resided within the city or district where they were accessing fertility care, which is indicative of the high degree of mobility exercised by Indonesian infertility patients in seeking biomedical care [9].

Invitations to participate were posted in waiting rooms, inviting patients to contact clinic reception staff for information sheets. Information sheets provided details of the study and participation requirements and invited interested parties to contact survey interviewers by text message if they wanted to participate. No treating doctors were involved in recruitment to avoid potential feelings of obligation among patients. The sample was a self-selected convenience sample. The sample size constituted over 50% of women patients attending these clinics in between July and September. An exact response rate is impossible to verify as we were unable to know what proportion of patients actually read the invitation flyer, and we were careful to ensure that recruitment was via self-selection. The criteria for participation was that women be married, aged between 18 and 45 years, and seeking biomedical infertility treatment. Single women were not recruited because infertility care is only legally available to married couples in Indonesia. Women undergoing IVF programs were excluded to avoid any stress-related impact on their treatment that could stem from participation. Surveys were administered via face-to-face interviews conducted by a team of 14 female interviewers, all of whom were doctors, and who were trained in research ethics and interviewing techniques. None of the interviewers were the treating doctors of participants.

The proportion of respondents recruited was relatively even across the three sites—35% from Jakarta, 36% from Surabaya, and 29% from Denpasar. The sample was highly indicative of the privileged sub-population of Indonesians who have the easiest access to infertility care due to their affluence, proximity to services and higher education. The sample was comprised of 78% urban residents, with the remaining 22% living rurally or in poor urban fringe communities. The ages of respondents ranged between 18 and 45 years and the median age was 31. All respondents were literate and 86% had completed senior high school or some form of tertiary education, and 60% possessed a tertiary degree. Thus, the educational attainment of women in the sample was very high and not indicative of Indonesia’s overall population. Monthly household incomes among our respondents were skewed toward higher socioeconomic groups with 50% being classified as middle class or elite on the basis of their monthly household income. See Table 1 below for additional description of sample characteristics. In sum, our sample was well educated, affluent and predominantly urban. This confirmed our presumption that women with lower incomes, less education and those living in more remote areas would be less likely to access infertility clinics, and subsequently would be less likely to be recruited.

The distinct nature of this affluent and highly educated sample reflects the fact that only around 10% of Indonesia’s population fall within an income band where they could pay for fertility care out of their expendable income without relying on loans or savings. The high socio-economic status of the sample limits the generalizability of findings to other Indonesian women experiencing infertility who do not access biomedical care due to their relatively poor socio-economic status or remote location. This convenience sample therefore provides insight relevant only to the experiences and needs of a specific sub-population of infertility patients who are in a position to access and pay for biomedical infertility care available only in large cities.

The sample size for analysis was 212 and descriptive and categorical analysis was performed by two statisticians using STATA. Below we present our findings on a number of themes which are: sources of information about infertility, knowledge of reproduction and infertility, knowledge of the causes and treatment of infertility, written information provided to patients and requested information. These five thematic clusters of survey