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Patient centred care in infertility health care: Direct and indirect associations with wellbeing during treatment

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ABSTRACT

Objective: To investigate whether different dimensions of patient centred care (PCC) were directly associated with wellbeing or indirectly, via lower concerns about medical procedures and/or increased tolerability of treatment.
Methods: Cross-sectional study with 322 women and 111 men undergoing fertility diagnosis or treatment recruited online and in clinical setting. Participants completed questionnaires that assess PCC (PCQ-Infertility), individual (BSI Anxiety and Depression subscales) and relational wellbeing (FertiQoL Relational Domain), treatment concerns (CART Procedural Concerns scale) and tolerability (FertiQoL Tolerability Domain) and they filled a socio-demographic and fertility data file.
Results: All dimensions of PCC were positively associated with better wellbeing except for organization of care. Information provision and continuity of care were indirectly associated with better individual wellbeing, the first via lower treatment concerns and the second via higher treatment tolerability. Competence, accessibility, continuity and communication were indirectly associated with better relational wellbeing via higher treatment tolerability.
Conclusions: Patient centred care promotes wellbeing during treatment. PCC is directly associated to wellbeing but also indirectly. The mode of action of the different PCC dimensions on wellbeing varies.
Practical implications: To promote patients' wellbeing during treatment clinics should provide treatment related information and allow patients to establish a stable clinical relationship with a trustworthy and competent physician.

1. Introduction

Around 9% of the worldwide childbearing population suffers from infertility and 56% of these seek fertility care to conceive [1]. Fertility clinics have mainly been concerned with maximizing chances of success for patients but more recently several infertility specialists have called attention to delivery of care to improve quality of life (QoL) [2], treatment compliance [3–5] and overall patient wellbeing during treatment [6]. Patient centred care (PCC) refers to care that is respectful of and responsive to individual patient preferences, needs and values [7,8]. Research has shown that PCC is related to higher QoL and lower anxiety and depression [9]. However, it has yet to investigate which specific dimensions of PCC are relevant and the processes through which they can influence wellbeing.

In infertility care there is a growing conviction that patient evaluations of the care received should be considered alongside other typical treatment outcome indicators such as pregnancy or live birth rates [8]. One of the reasons for this is that pregnancy or birth rates only measure quality of care indirectly, as they are affected by many other factors such as the patient lifestyle or prognosis [10]. Process indicators that focus on the patients' treatment experience such as PCC are considered to be more direct measures of quality of care [11] and provide useful information to improve care [12]. Patients themselves express the wish for PCC [13,14], are willing to trade-off a higher success rate for patient-centredness and indicate that PCC is an important criterion when selecting fertility clinics in hypothetical trade-off scenarios [15].

At the interpersonal level PCC can be conceptualized as the characteristics that health professionals should have when relating to patients (e.g., communication skills, respect) whereas at the organizational level it is the characteristic that should be present in the health system (e.g., accessibility to treatment, organization of care) [16]. The Picker Institute developed one of the most comprehensive approaches to PCC at the organizational level that also integrates interpersonal aspects of care [17]. Through focus

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group methodology and literature review eight dimensions of care were identified: accessibility; respect for patients' values, preferences and needs; information, communication and education; involvement of family and friends; continuity and transition; coordination and integration of care; physical comfort; and emotional support and alleviation of fear and anxiety [17–19]. Recently, Dancet et al. replicated the Picker Institute methodology to generate a detailed description of PCC in infertility care that is based on the patient perspective [13,14]. Results from this work provided empirical support for the Picker Institute framework and identified a further two dimensions: competence of clinic and staff as well as attitude of and relationship with staff. This model of PCC was subsequently validated in an international sample of 48 patients from four European countries using focus groups [20].

This body of work has been extremely valuable to increase awareness about the importance of PCC in infertility care and to reach higher precision in the definition and operationalization of this construct. However, to better organize infertility care to promote patients' wellbeing during treatment we need to know which specific PCC dimensions are more strongly associated with it and how. Fig. 1 depicts how the different dimensions of PCC may be associated with patients' wellbeing during treatment. First, there may be a direct relationship between PCC and wellbeing (shown by solid bold line in Fig. 1). One study sampling 427 female patients from 29 Dutch fertility clinics already showed that PCC is directly associated with better QoL and psychological wellbeing (anxiety and depression) [9]. However, the study used an overall score of PCC and did not differentiate between the different PCC dimensions, so it is still not known which specific PCC dimensions are directly associated with wellbeing. Second, PCC may be indirectly associated with wellbeing (shown by dotted and dashed lines in Fig. 1). In broad terms, more positive experiences regarding interpersonal aspects of PCC may be indirectly associated with wellbeing via lower patients' concerns about treatment (see dashed arrows in Fig. 1). Research shows that patients experience distress due to treatment procedures (e.g., injections for hormonal stimulations) [21], the uncertainty of the outcome [22] and the experience of failure [23]. Aspects of communication, information provision and patient involvement in decision-making could decrease patients' concerns and address misconceptions about treatment [3], thus possibly contributing to better wellbeing. Third, more positive experiences regarding organizational aspects of PCC may be indirectly associated with wellbeing via higher tolerability of treatment (see dotted lines in Fig. 1). Infertility medical exams and treatments are technically complex and involve repeated monitoring (e.g., through ultrasound scans) and regular visits to clinics. As such they often result in significant disruptions to the daily routine and professional lives of patients [24,25]. Perfecting organizational aspects of care could improve wellbeing by minimizing onerous demands of treatment.

In this study we investigated whether dimensions of PCC were directly associated with patients' individual and relational wellbeing during treatment. In addition, we investigated if the dimensions of PCC were indirectly associated with wellbeing, by being associated with patients' concerns about treatment procedures and/or tolerability of treatment, which in turn were associated with wellbeing.

2. Materials and methods

2.1. Study participants

A total of 222 questionnaires were submitted online but nine duplicates (same email address provided) were excluded. At the clinic setting 233 participants filled and returned questionnaires (response rate 49%).

The final sample consisted of 322 (74.4%) women and 111 (25.6%) men. Table 1 shows socio-demographic and clinical characteristics of the sample. Women were in their early thirties and men in their mid-thirties. Participants were with their partners for about seven years and were trying to conceive for about four years. Current medical engagement was in 28% diagnostic testing, 18% medication to induce ovulation, 7% Intra-Uterine Insemination, 15% waiting list for Assisted Reproductive Technologies (ART) and 32% ART. Participants recruited online were more educated (mean = 14.94 years, SD = 3.47 versus mean = 11.33, SD = 3.37, $t(348) = 9.819$, $p < .001$), had a higher socioeconomic status ($\chi^2[433,3] = 46.873$, $p < .001$), more frequently lived in urban areas ($\chi^2[433,1] = 78.990$, $p < .001$), were at more advanced treatment stages ($\chi^2[433,4] = 16.195$, $p < .01$) and had done more ART cycles (mean = 1.21, SD = 1.53 versus mean = 0.52, SD = 0.87, $t(417) = 5.644$, $p < .001$) than participants recruited at the clinic.

2.2. Measures

Participants completed a questionnaire pack that included the following measures. Socio-demographic information included

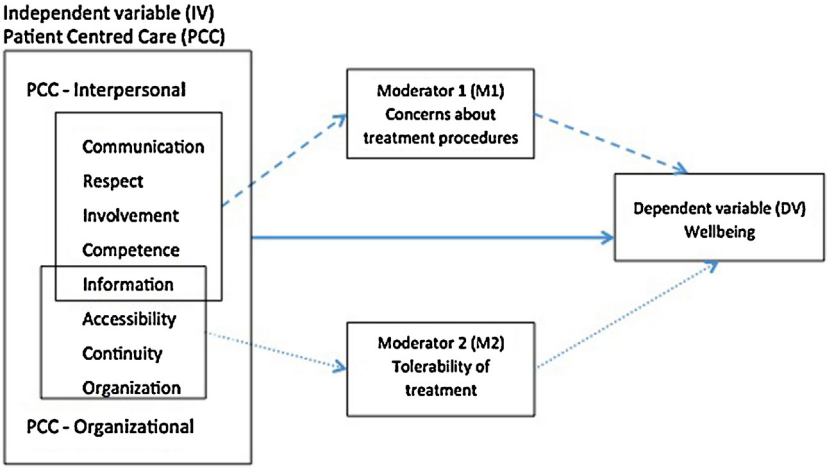

Fig. 1. Direct and indirect associations hypothesized between the independent variable (IV) patient centred care (PCC) and the dependent variable (DV), wellbeing. The study hypotheses were that all PCC dimensions would be directly associated with wellbeing (full arrow); PCC dimensions that capture interpersonal aspects of care would be indirectly associated with wellbeing (dashed arrows), via concerns about treatment (Moderator 1, M1); and PCC dimensions that capture organizational aspects of care would be indirectly associated with wellbeing (dotted arrows), via tolerability of treatment (Moderator 2, M2).