Patients from across Europe have similar views on patient-centred care: an international multilingual qualitative study in infertility care

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BACKGROUND: International patient centredness concepts were suggested but never conceptualized from the patients’ perspective. Previously, a literature review and a monolingual qualitative study defined ‘patient-centred infertility care’ (PCIC). The present study aimed to test whether patients from across Europe value the same aspects of infertility care.

METHODS: An international multilingual focus group (FG) study with 48 European patients from fertility clinics in Austria, Spain, the UK and Belgium, with deductive content analysis.

RESULTS: All specific care aspects important to participants from all countries could be allocated to the 10 dimensions of PCIC, each discussed in every FG, including: ‘information provision’, ‘attitude of and relationship with staff’, ‘competence of clinic and staff’, ‘communication’, ‘patient involvement and privacy’, ‘emotional support’, ‘coordination and integration’, ‘continuity and transition’, ‘physical comfort’ and ‘accessibility’. Most specific care aspects (65%) were discussed in two or more countries and only a few new codes (11%) needed to be added to the previously published coding tree. Rankings from across Europe clearly showed that ‘information provision’ is a top priority.

CONCLUSIONS: The PCIC-model is the first patient-centred care (PCC) model based on the patients’ perspective to be validated in an international setting. Although health-care organization and performance differ, the similarities between countries in the infertile patients’ perspective were striking, as were the similarities with PCC models from other clinical conditions. A non-condition specific international PCC model and a European instrument for the patient centredness of infertility care could be developed. European professionals can learn from each other on how to provide PCC.

Key words: patient-centred care / health-care quality / infertility / qualitative research / international

Introduction

Patient centredness is one of the six dimensions of quality of care according to the ‘Institute of Medicine’ in the USA (Corrigan et al., 2001). However, the consensus on the most appropriate international conceptualization of patient-centred care (PCC) is lacking.

Several definitions and models for PCC, allied concepts (e.g. relationship-centred care) and components of PCC (e.g. patient-
centred communication) have been proposed. However, only few models for the concept of PCC were actually based on the patients’ perspective. Instead, most were based on the perspective of professionals. As advised by Stewart (2001), qualitative research on patients has the potential to capture the whole concept of patient centredness. Studies based on monolingual qualitative interviews exploring what is important to patients have provided condition-specific models for PCC for a number of healthcare domains, including care for hospitalized patients (Gerteis et al., 1993), physiotherapy for patients with low back pain (Cooper et al., 2008), infertility (Dancet et al., 2011a) and endometriosis care (Dancet et al., 2011b). We are aware of no previous qualitative study that has developed or validated a PCC model or definition based on the perspective of patients from different health-care systems and cultures, and speaking different languages. However, in 2001 Stewart (2001) first suggested international patient-centredness concepts, based on the strong agreement between a definition of ‘patient-centred communication’ developed by professionals from Canada and South Africa (Stewart et al., 1995) and the findings of an independent patient survey in the UK (Little et al., 2001).

An international and multilingual qualitative study on PCC is highly relevant and timely considering the importance of benchmarking for quality management, the added value of benchmarking internationally (Helgason, 1997) and the upcoming reimbursement for European patients of health care provided in different European member states (http://ec.europa.eu/health/cross_border_care/policy).

Infertility is an appropriate field to study the universality of PCC in Europe. First, infertility is an important health problem in Europe (estimated median 9% prevalence rate for 12 months infertility in developed nations; Boivin et al., 2007) and the demand for infertility treatment is expected to increase (Olsen et al., 1996). Second, European benchmarking is particularly important, as there is evidence that European infertile patients routinely cross their countries’ borders to receive infertility treatment (Pennings et al., 2009; Shenfield et al., 2010). Third, as for other conditions, infertile patients are known to value PCC (van Empel et al., 2011). This could partly be related to the emotional needs of infertile patients (Verhaak et al., 2007) resulting in a strong preference for patient centredness (Little et al., 2001). Fourth, there is a detailed model for ‘patient-centred infertility care (PCIC’; Dancet et al., 2011a) which is a good starting point for a multilingual qualitative study on PCC. This PCIC model was developed in two consecutive studies. A literature review, including studies on the infertile patients’ perspective on care (Dancet et al., 2010a), transformed the 8 dimensions of PCC for hospitalized patients (Gerteis et al., 1993) to the 10 dimensions of PCC for infertile patients. A topic list developed through this literature review guided a qualitative study with patients from the Netherlands and the Dutch-speaking part of Belgium that provided additional in-depth insight into the 10 dimensions of PCIC and the relationship between these 10 dimensions (Dancet et al., 2011a).

The present study aims to test whether patients originating from different European countries value the same aspects of infertility care.

**Methods**

An international, multicentre, multilingual focus group (FG) study was conducted to complement the monolingual FG study that led to the development of the model on PCIC (Dancet et al., 2011a). Ethical approval was sought per country, if this was required according to local regulations.

**Setting**

FGs were performed in four fertility clinics (two University-based and two private clinics, including two with and two without a previously expressed interest in patient centredness). The clinics were located in four European countries where four different languages are spoken, more specifically: the UK (English), Spain (Spanish), Belgium (French) and Austria (German).

**Participants**

Heterosexual patients diagnosed with infertility and/or treated with IUI, IVF and/or ICSI were eligible. No additional eligibility criteria were defined.

**Data collection**

Physicians invited consecutive eligible patients, who met the inclusion criteria, to participate in the study and provided them with study information. Afterwards, local researchers contacted invited patients by telephone.

Two 2-h FGs were organized in 2010 in each of the four countries. Each FG included four to eight participants. At the beginning of each FG, participants filled out an informed consent form and a questionnaire on demographic and medical characteristics.

The FGs were moderated in the local language by local researchers. All local researchers had previously followed the same interviewing training given by the international study coordinator (E.D.). This coordinator also observed all FGs to ensure a homogenous methodology across countries. Participants were asked to discuss their most positive and negative experiences with infertility care. Local interviewers asked additional open-ended questions in order to further explore the experiences shared by participants and to explore experiences related to other care aspects from a topic list based on literature review (Dancet et al., 2010a) and previous FGs (Dancet et al., 2010b). The topic list covered the following 10 dimensions of PCIC: ‘information’, ‘competence of clinic and staff’, ‘coordination and integration’, ‘continuity and transition’, ‘accessibility’, ‘physical comfort’, ‘communication’, ‘attitude of and relationship with staff’, ‘emotional support’ and ‘patient involvement and privacy’. FGs ended with participants individually drawing a ranked priority list with five self-formulated care aspects.

Reciprocal translation (Fumimoto et al., 2001) into the four local languages was carried out for all documents used during data collection, including study information for patients, informed consent form, questionnaire on characteristics and the topic list.

FGs were recorded digitally and transcribed verbatim in their respective languages.

**Analysis of the FG transcripts**

Multilingual deductive content analysis was performed as a structured matrix analysis (Elo and Kyngäs, 2008) based on the previously published English coding tree of the PCIC model (Dancet et al., 2011a), which was developed through inductive coding. Deductive coding goes from general to specific (Elo and Kyngäs, 2008), whereas inductive coding moves from specific to general. Deductive coding is the most appropriate analysis method for the purpose of retesting the existing PCIC model in a broader European multilingual context (Elo and Kyngäs, 2008). This was done, by examining whether patients from different European countries valued the same aspects of infertility care. The analysis focused both on data that fitted the matrix, as well as data that did not (Elo and Kyngäs, 2008). For the case where specific care aspects had not yet been addressed by the previously published coding tree, the need for the
development of a new dimension of PCIC was explored. Further, new detailed sub-codes were developed based on inductive coding (Hsieh and Shannon, 2005). Coding was performed independently by the international study coordinator (E.D. or V.N. for the Austrian FGs) and by the local researcher of the respective country. The local researchers first received training on deductive content analysis from the international study coordinator (E.D.), who is experienced in qualitative data analysis (Dancet et al., 2010a,b, 2011b). Disagreements were resolved using an established consensus process (Hill et al., 1997).

Analysis of the patient’s priority lists

Patient’s priority lists were analysed in their respective language (exception: German translated to English) by two researchers independently. A combination of content analysis (to assign specific care aspects to the dimensions of PCIC) and the allocation of scores to the dimensions of PCIC based on the patients’ ranking were used to calculate overall priorities per country and the overall priorities for all countries in combination.

The previously published (Dancet et al., 2011a) infertile patients’ priorities of the Netherlands and the Dutch-speaking part of Belgium are described below in more detail. Furthermore, they are taken into account for the calculation of the overall European priorities.

A Kendall’s coefficient of concordance (ranging between 0 for no agreement and 1 for complete agreement) was computed using the Statistical Package for Social Sciences (SPSS 19.0 for Windows, Chicago, IL, USA) to evaluate the agreement between all countries’ rankings. Kendall’s coefficient of concordance was also calculated between each individual European regions’ ranking and the overall European numeral ranking. A p < 0.05 was considered statistically significant. Additionally, the between-country similarities and differences were observed and named qualitatively.

Results

Participants

A total of 108 patients were informed about the study and 48 (44%) finally took part. Reasons for not taking part included: willing to take part but not available at the specific times of the FGs (n = 36), not willing to take part because of time constraints (n = 10) or hesitation to discuss fertility care in a group (n = 4).

Table I shows participants’ demographic and medical characteristics. Forty-eight heterosexual participants (i.e. the male and female partners of 24 couples) from Belgium (French-speaking region; n = 14), Austria (n = 16), Spain (n = 10) and UK (n = 8) took part. Participants had a mean age of 36.5 years and over half of the participants (n = 32/48) were childless. Child wish had been present for a median duration of 3 years and the vast majority (n = 42/48) had experienced at least one IUI or IVF/ICSI cycle. The experience of IVF/ICSI was most common (n = 40/48). The median number of experienced IUI or IVF/ICSI cycles was two.

The 10 European dimensions of PCIC

All 10 previously published dimensions of PCIC (Dancet et al., 2011a) were discussed in all FGs across all countries (see Table II). No new aspect of care was identified which called for the addition of a dimension to the 10 dimensions of PCIC (Dancet et al., 2011a). Agreement on coding among researchers was high, as can be expected for deductive coding. All researchers were unanimous on the fact that no extra dimension for PCIC was needed. The rare need for discussion

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Country</th>
<th>Spain</th>
<th>Austria</th>
<th>UK</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants</td>
<td>14</td>
<td>10</td>
<td>16</td>
<td>8</td>
<td>48</td>
</tr>
<tr>
<td>Mean age, range (years)</td>
<td>37.3 (31–47)</td>
<td>38.5 (33–46)</td>
<td>35.2 (29–39)</td>
<td>35 (30–40)</td>
<td>36.5 (29–47)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of females</td>
<td>7</td>
<td>5</td>
<td>8</td>
<td>4</td>
<td>24</td>
</tr>
<tr>
<td>Number of males</td>
<td>7</td>
<td>5</td>
<td>8</td>
<td>4</td>
<td>24</td>
</tr>
<tr>
<td>Parental status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of participants with childrena</td>
<td>10</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>16</td>
</tr>
<tr>
<td>Number of participants without children</td>
<td>4</td>
<td>10</td>
<td>12</td>
<td>6</td>
<td>32</td>
</tr>
<tr>
<td>Median duration of child wish in number of years (range)</td>
<td>5 (3–9)</td>
<td>3 (1–4)</td>
<td>3.5 (2–7)</td>
<td>2.5 (1–8)</td>
<td>3 (1–9)</td>
</tr>
<tr>
<td>Number of patients diagnosed with infertility but not yet treated with IUI nor IVF/ICSI</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Number of patients treated with IUI or IVF/ICSI</td>
<td>14</td>
<td>10</td>
<td>12</td>
<td>6</td>
<td>42</td>
</tr>
<tr>
<td>Median number of experienced cycles IUI and IVF (range)b</td>
<td>2.5 (2–7)</td>
<td>2 (1–6)</td>
<td>3 (1–7)</td>
<td>?</td>
<td>2 (1–7)</td>
</tr>
<tr>
<td>Number of patients who experienced IUI</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Number of patients who experienced IVF or ICSI</td>
<td>14</td>
<td>10</td>
<td>12</td>
<td>4</td>
<td>40</td>
</tr>
</tbody>
</table>

aAll participants were faced with infertility at the time of the FGs. If participants did already have children, they were all faced with secondary infertility and might have been previously faced with primary infertility.

bParticipants who had not yet started IUI or IVF/ICSI treatment (n = 6) were excluded from this calculation.

cExcept for patients in the UK because in that sample these data were not collected.
to resolve disagreements focused on new codes developed through inductive coding and their labelling and allocation to the coding tree.

According to what was valued by patients from across Austria, Spain, the UK and the French-speaking part of Belgium, the patient centredness of infertility care depended on 10 dimensions of PCIC that can be divided into system and human factors. The six system factors included (in order of importance as given by European patients in this study): ‘provision of information’, ‘competence of clinic and staff’, ‘coordination and integration’, ‘continuity and transition’, ‘physical comfort’ and ‘accessibility’. The four human factors included (in order of importance as given by European patients in this study): ‘attitude of and relationship with staff’, ‘communication’, ‘patient involvement and privacy’ and ‘emotional support’.

Striking similarities across European countries in the specific care aspects discussed

The detailed description per dimension of what is valued by patients differed little across Europe. Most codes (250/385; 65%) were discussed in two or more of the four countries. The following section describes per dimension all important specific care aspects discussed in at least one FG in each of the four countries on which patients agreed (e.g. staff optimism concerning achieving pregnancy was not addressed because patients did not agree whether this was a positive or negative staff attitude). In Table II an exemplifying FG quotation is given for each dimension.

Provision of information

Patients expressed the need for a clear plan of the complete treatment route and information on: medication, treatments’ success rates and differences between clinics. Patients wanted information on their own test results. They valued information given both by telephone, face-to-face and on media (e.g. paper, DVD). Information needed to be plentiful and detailed.

Attitude of and relationship with staff

Patients disliked certain staff attitudes and valued the following staff attitudes: being friendly, empathic, accessible, helpful, careful, respectful and engaged. Patients attached importance to a good relationship with staff.

Competence of clinic and staff

Patients wanted to be treated in expert clinics by experts providing a good medical follow-up.

Communication

Patients sought the opportunity to ask questions, requested time with staff and wanted to know the expected time schedule. Patients appreciated being informed spontaneously in an understandable way (language, level) and valued staff with skill in communicating bad news. Additionally, patients valued follow-up consultations to discuss extensively the results of interventions and treatments.

Patient involvement and privacy

Patients valued taking part in shared decision-making and valued attention paid to their input. Patients wanted their care to be individualized to their personal medical situation and wanted to be recognized as an individual (not a number). Couples wanted staff to explicitly involve the male partners (e.g. invitation to attend interventions and consultations) and respect their privacy.

Table II: The dimensions of PCIC and exemplifying quotations from FGs across Europe.

<table>
<thead>
<tr>
<th>Dimensions of PCIC</th>
<th>Exemplifying quotations*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of information</td>
<td>‘But you kind of like to know what’s going on, what’s coming next’. (UK, FG 1)</td>
</tr>
<tr>
<td>Attitude of and relationship with staff</td>
<td>‘I appreciate that all the staff, from the nurses who draw blood until the doctor, including the staff in the operating room, always address me in a very friendly, very caring way’ (Spain, FG 2)</td>
</tr>
<tr>
<td>Competence of clinic and staff</td>
<td>‘We contacted psychologists from outside the fertility clinic, but we quickly realized that these people know nothing of our problems and it was not worth continuing in that domain’ (Belgium, FG2)</td>
</tr>
<tr>
<td>Communication</td>
<td>‘Using day to day language, day to day life language, would be very good’. (UK, FG 2)</td>
</tr>
<tr>
<td>Patient involvement and privacy</td>
<td>‘When they realize who you are exactly on the phone, . . . That’s very important to me’ (Belgium, FG 2)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>‘The time after the transfer is psychologically heavy. Therefore, it would be good if more support is provided at that point, if you could consult a psychologist’. (Austria, FG 1)</td>
</tr>
<tr>
<td>Coordination and integration</td>
<td>‘The truth is that you are grateful for every quickly returned phone call, for when they do not waste any time. I had to wait for a phone call, and the difficulty is that I get terribly nervous when I am waiting for news or the results of an examination or oocyte aspiration’ (Spain, FG 1)</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>‘She always does the follow-up, in any case to us, it means the world’ (Belgium, FG1)</td>
</tr>
<tr>
<td>Physical comfort</td>
<td>‘Having to wait in a waiting room where I am confronted with people who do not have similar problems, makes me feel bad’ (Austria, FG 1)</td>
</tr>
<tr>
<td>Accessibility</td>
<td>‘Especially when you can’t get through anyway, because I remember when I was ringing up and you just think, you know, there’s no point’. (UK, FG 1)</td>
</tr>
</tbody>
</table>

*Quotations were chosen from FG transcripts because of their clarity and relevance to all countries. Care was taken to include quotations from all different countries.
Emotional support
Patients wanted both emotional support from clinical care providers (i.e. physicians, nurses) during their daily care (e.g. when receiving bad news) and the offer of a session with a counsellor. Patients reported especially requiring support, for instance, when they receive the negative result of a pregnancy test.

Coordination and integration
Patients disliked waiting times, both between interventions or treatments and in waiting rooms. Patients appreciated a smooth organisation and coordination of activities among staff. The clinic should take care that all financial costs charged to patients are justified.

Physical comfort
Patients from all countries requested waiting rooms shared only with other infertile patients and they valued comfortable accommodation.

Accessibility
Patients valued continuous accessibility to a clinic by telephone. They wanted to get in touch easily and wanted the opportunity to ask medical questions. Patients valued the possibility to undergo medical interventions outside the traditional 9 a.m. to 5 p.m. schedule.

Potential differences between European countries in the discussed specific care aspects
Compared with the previously published coding tree (Dancet et al., 2011a) 34 new specific care aspects (11% of the total 385 codes) were added. However, all were discussed in one country only. Half of these new specific care aspects, for example ‘availability of private hospitalization rooms’ and ‘provision of information on price differences between clinics’ were named by and characteristic of patients from private clinics who were paying for their own treatments. Many other aspects of care (n = 14/34) could be considered more detailed descriptions of other codes and were not striking. However, Spanish patients referred to the care aspects ‘showing interest in patients’ personal life’, ‘openness about staff’s own personal life’ and ‘a nearby/warm attitude’ that are closely related to other codes, such as ‘personalized care’, ‘engaged attitude’ and ‘friendly attitude’. Additionally, 29 (7.5%) specific care aspects discussed in the Dutch-speaking part of Belgium or the Netherlands and described in the previously published coding tree (Dancet et al., 2011a) were not discussed in the FGs in the current study.

Indication of priorities from patients from across Europe
All dimensions except one (‘physical comfort’ in the UK) were mentioned on patients’ priority lists by participants in every country, including the previously published FGs from the Dutch-speaking region of Belgium and the Netherlands (Dancet et al., 2011a).

Table III shows overall patients’ priorities for each individual country as well as an overall European ranking. The Kendall’s coefficient of concordance was 0.577 (P < 0.0001) demonstrating a moderate-to-good agreement between the individual countries’ rankings. This level of agreement indicates that the overall European ranking is an adequate, but not perfect representation of the rankings from all examined countries, including the previously published rankings from the Netherlands and the Dutch-speaking region of Belgium (Dancet et al., 2011a). The level of agreement between each individual European region and the overall European numeral ranking showed that the overall European numeral ranking most adequately represents the ranking from the Dutch-speaking region of Belgium (Kendall’s coefficient of concordance = 0.976; P < 0.0001) and least adequately represents the ranking from the French-speaking region of Belgium (Kendall’s coefficient of concordance = 0.748; P < 0.0001; Table III).

Some similarities between countries were observed. More specifically, the dimension ‘provision of information’ was ranked among the overall top-4 priorities in every country and the dimension ‘accessibility’ was ranked in the overall bottom-4 priorities in every country. However, between countries important differences were also observed. More specifically, the two dimensions ‘patient involvement and privacy’ and ‘emotional support’ were ranked both in countries’ overall top-3 and bottom-3 priorities.

Discussion
Principal findings
The 10-dimensional model for PCIC seems to be valid for Europe, as patients from five countries (including the Dutch and French-speaking regions of Belgium) across Europe have similar views on what is important in infertility care. All 10 dimensions were valued and no new dimensions were required. Per dimension the similarities across Europe regarding the valued specific care aspects were striking. Rankings of the dimensions differed between European countries but information provision is clearly a top priority for this group of European patients.

Methodological strengths and criticisms
This study is characterized by the following five strengths, which are discussed in more detail below: (i) it explored the universality of PCC, (ii) it provided in-depth insight into PCC, (iii) it coped successfully with the challenges set by multilingual qualitative data collection and data analysis, (iv) it was based on the patients’ perspective and (v) it is condition specific.

First, this is the first study explicitly aiming to explore the universality of PCC since Stewart (2001) first suggested the possibility of developing global definitions of patient centredness, which could be used across the world, in 2001.

Second, this study examined the universality of a previously published model (Dancet et al., 2011a). Models provide a deeper insight into PCC than definitions, which are useful for teaching but are known to fail to capture the indivisible whole of a healing relationship (Stewart, 2001). Additionally, for conceptualization, the broader concept of PCC was selected over concepts on components of PCC, such as ‘patient-centred communication’ (Wanzer et al., 2004;
### Table III  Overall priorities of patients by country and for Europe (1 is highest priority, 10 lowest priority).

<table>
<thead>
<tr>
<th>Dimensions of PCIC</th>
<th>Overall patients’ priorities by country</th>
<th>Overall European patients’ priorities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The Netherlands(^a)</td>
<td>Belgium</td>
</tr>
<tr>
<td>Provision information</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Attitude of and relationship with staff</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Competence of clinic and staff</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Communication</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Patient involvement and privacy</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Emotional support</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Coordination and integration</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Physical comfort</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Accessibility</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Kendall’s coefficient of agreement between individual region and overall European numeral ranking ((P &lt; 0.0001))</td>
<td>0.921</td>
<td>0.976</td>
</tr>
</tbody>
</table>

\(^a\)Previously published data: Dancet, van Empel et al., 2011.

\(^b\)Physical comfort was not addressed on priority lists of the FG in the UK.

\(^c\)Kendall’s coefficient of agreement across the six European regions, covering five European countries = 0.577 (\(P < 0.0001\)).
Epstein et al., 2005). Because patient centredness includes all health care (inter)actions and even the clinic’s infrastructure.

Third, this study coped successfully with the challenges set by multilingual qualitative research to maintain a homogenous data collection and analysis in four different settings and in four different languages. With respect to data collection, the following measures were taken, as recommended in the literature: sampling guidelines (Veenstra et al., 2010; Moretti et al., 2011), inclusion criteria (Revicki et al., 2008; Moretti et al., 2011) and allowing local researchers to moderate the FGs in the local languages according to the same interview guide (Bastiaens et al., 2007; Veenstra et al., 2010) after following an identical training (Bastiaens et al., 2007). With respect to data analysis, this process was also performed in the FGs’ original language. This has rarely been done in studies dealing with patients (Bastiaens et al., 2007) and helped to prevent certain nuances from getting lost in translation (Moretti et al., 2011). Deductive coding, the most appropriate analysis method for retesting a previously published model (with coding tree; Dancet et al., 2011a) in another, international context (Elo and Kyngäs, 2008), proved to simplify the multilingual coding process conducted by several researchers compared with inductive coding (Bastiaens et al., 2007). Although deductive coding was used, the specific patients’ perspective remained the starting point of analysis because the original coding tree was based on inductive coding of patient FGs (Dancet et al., 2011a).

Fourth, a further strength is that this study conceptualized PCC based on research on the patients’ perspective. There is little empirical evidence on models on patient centredness (Little et al., 2001). Yet the patients’ perspective is essential for conceptualizing PCC that should be responsive to patients’ preferences, needs and values (Corrigan et al., 2001; Davis et al., 2005; Robinson et al., 2008).

Fifth, another upside of the European model for PCIC is that it is condition specific, as a previous study indicated that different groups of patients value different aspects of care (e.g. depending on prognosis; Dowsett et al., 2000). Furthermore, because it is condition specific, the PCIC model is very specific and highly recognizable for infertility health-care providers. This enhances translation into clinical practice as it specifies what is important to the average patient.

This study has some limitations which should be taken into consideration by future research.

First, patients were not explicitly asked what ‘PCC’ meant to them. Instead patients discussed what they regarded as being important for them. This avoided a conceptual discussion and kept the focus on what patients valued. However, note that this strategy is in line with all four other studies that had conceptualized PCC for a specific condition based on qualitative (FG) interviews with patients (Gerteis et al., 1993; Cooper et al., 2008; Dancet et al., 2011a,b).

Second, it is possible that the perspectives of participants were conditioned by their specific experiences in a specific clinic. In order to compensate for only including one clinic per participating country, diverse types of European clinics were included: private and university clinics, both with and without a previously expressed interest in PCC.

Third, only 5 out of the 27 European countries were included. Countries spread around the European territory were initially targeted to be included in the study. However, limitations were set by language barriers. Therefore, regrettably, no Eastern European country was included but this will be considered in the future.

Fourth, the countries did not completely agree on the ranking of the 10 dimensions of PCIC for Europe. The overall European numeral ranking was an adequate but not perfect representation of the rankings of all countries. The ranking of the French-speaking region of Belgium was least adequately represented by the overall European numeral ranking. Only two consequently observed similarities were shared between countries: information provision is a top priority and accessibility is not. More research on larger samples of patients is needed in order to provide more insight into the similarities and differences in rankings between European countries.

Comparison to other conceptualizations of patient centredness

The European model for PCIC addresses all main aspects of patient centredness discussed in several types of previous studies.

First, the European PCIC model addresses two areas of focus from across published professional discussions on patient centredness based on practice and/or the literature (Laine and Davidoff, 1996; Stewart, 2001; Freeman et al., 2004; Wagner et al., 2005; Slow-Carroll et al., 2006; Shaller, 2007; Robinson et al., 2008; Saha et al., 2008; Berwick, 2009; Stange et al., 2010). More specifically, the focus on ‘the physician–patient interaction/communication’ is addressed by the two dimensions of the European PCIC model ‘communication’ and ‘attitude of and relationship with staff’. The focus on ‘patients’ involvement in decision-making’ is addressed by the PCIC dimension ‘patient involvement and privacy’. Interestingly, infertile patients often discussed interaction with staff other than physicians. Moreover, infertile patients wanted staff to involve both themselves and their partner in decision-making which is not surprising as both partners take part in assisted reproduction.

Second, the European PCIC model addresses the two themes that are similar (although formulated differently) across the two non-condition-specific patient-centredness models (Stewart et al., 1995; Mead and Bower, 2000) developed based on professionals’ practice and/or literature: the model for ‘patient centredness’ (Mead and Bower, 2000) and the model for ‘patient-centred consultation’ (Stewart et al., 1995). The two consistent themes concern ‘the whole patient’ and ‘building a patient–doctor relationship’ and are covered by the following dimensions of the European PCIC model: ‘communication’, ‘attitude of and relationship with staff’, ‘patient involvement and privacy’, ‘emotional support’ and ‘continuity and transition’.

Third, the European PCIC model is very similar to the other three models for PCC based on the patients’ perspective from other fields of health care, namely: care for hospitalized patients (Gerteis et al., 1993), physiotherapy for low back pain (Cooper et al., 2008) and endometriosis care (Dancet et al., 2011b). Besides differences in formulations, few content differences were found comparing the three most recent models (Cooper et al., 2008; Dancet et al., 2011a,b) with the oldest model of PCC for hospitalized patients (Gerteis et al., 1993). For fertility care (including the current study), endometriosis care and physiotherapy for low back pain, two dimensions covering ‘staff attitude’ and ‘competence’ were added (Cooper et al., 2008; Dancet et al., 2011a,b). The dimension ‘involvement of family and friends’ was not covered for physiotherapy for low back pain (Cooper et al., 2008) and infertile patients only wanted to involve their partner (Dancet et al., 2011a). The similarity across the
condition-specific models was surprising given the differences in the need for patient centredness according to clinical factors documented in the literature (Dowsett et al., 2000). Possibly the similarities can be explained by the fact that three of the four models addressed chronic non-life threatening conditions for which patients received ambulatory care.

Few data are available on differences between countries in the importance patients attach to aspects of care (Sitzia and Wood, 1997). To the best of our knowledge this has only been evaluated in health-care fields other than infertility (Grol et al., 1999; Groenewegen et al., 2005; Valentine et al., 2008). All concur with our finding that patients across countries (with and without the same condition) have many views in common. However, differences in rankings between countries were also found in all three studies (Grol et al., 1999; Groenewegen et al., 2005; Valentine et al., 2008) and convergence in rankings was stronger within than across countries (Valentine et al., 2008).

Implications for clinical practice and European policy

For infertility care, patients from different European countries value the same aspects of care. Therefore, it seems that there is no need for clinics to adapt their PCC for cultural differences for the many infertile patients that cross borders within Europe (Pennings et al., 2009; Shenfield et al., 2010).

The similarity across Europe in what is valued by patients indicates that health-care providers from different European countries can learn from each other how to provide PCC. Furthermore, since patients from across Europe value the same care aspects, they are likely to prefer the same kind of clinic, which is interesting for clinics that are striving to enlarge their national and international market share.

Nevertheless, the model of PCIC is not meant as ‘cookbook’ because we agree with others that rigidly adhering to the model would lead to ‘model-centred’ care instead of PCC (MacQueen, 2001). This model guides staff to focus on all dimensions of care important to patients while they adapt their care to the individual patient.

Given the observed remarkable similarity across PCC models based on the patients’ perspective for different conditions, the presented model may be useful for health-care fields other than infertility; in particular for ambulatory settings caring for patients with chronic non-life threatening conditions.

Although priorities seem to differ per country, information provision should be top of the list in all centres striving to provide PCC. Clinics are advised to provide plentiful and detailed information by telephone, face-to-face and on media, such as brochures, DVDs. Additionally, themes that should definitely be covered across all countries include a clear plan of the complete treatment route, information on administering medication, treatments’ success rates, differences between clinics (with respect to treatment possibilities, success rates and patients’ experiences/satisfaction), and patients’ own test results. Besides these general targets, a validated tool to identify clinic specific patient-centred improvement targets for European fertility care needs to be developed.

Additionally, strategies to improve the patient centredness of care need to be developed. Our group divided the 10 dimensions of PCIC into human (e.g. communication) and system (e.g. information) factors, which is informative for improvement as human factors need to be improved at a staff level (Reason, 1995; Dancet et al., 2011a; e.g. staff training can improve communication; Lenzi et al., 2011) and system factors need to be improved at an organizational level (Reason, 2000; Dancet et al., 2011a; e.g. a new patient information brochure can improve information provision; Dancet et al. 2010b). Improving the patient centredness of care will require an (initial) investment. Currently, our group is conducting an RCT to evaluate the clinical and cost-effectiveness of patient-centred improvement projects in infertility care (Huppelschoten et al., 2011). In other fields RCTs proved that individualized PCC can be clinically and cost-effective (Hietasalo et al., 2009; Olsson et al., 2009).

The similarity of patients’ valued infertility care aspects across Europe is remarkable in view of the variability in legal frameworks, health care and reimbursement systems, health-care performance assessed by patients between European countries (Grol et al., 2000; Coulter and Cleary, 2001; Wensing et al., 2002; Kerssens et al., 2004; Groenewegen et al., 2005; Schoen et al., 2007; Koch et al., 2010), on the one hand, and the often expected and documented (Groenewegen et al., 2005) positive association between people’s reported experiences and what they find important, on the other hand.

In the preparations of the directive arranging the reimbursement of European cross-border care, policy-makers stated that the same standards of care needed to be met across countries (http://www.euro.par.europa.eu/sides/getDoc.do?pubRef=/-//EP//TEXT+TA+P6-TA-2009-0286+0+DOC+XML+V0//EN). Our study is a first indication that the same method for monitoring the quality dimension ‘patient centredness’ can be used across Europe.

Implications for future research

In order to further develop a global model for PCC that can be used across geographic borders and across conditions, it is important to document if the Western-European PCC model for infertility also applies to infertile patients from other European and non-European countries and to patients with other clinical conditions (both chronic and acute). Furthermore, it would be interesting to further explore the differences across countries in patients’ ranking of the dimensions of PCIC (especially ‘patient involvement and privacy’ and ‘emotional support’) and the differences across countries between the detailed sub-codes. For these purposes quantitative research seems better suited.

Our study included patients receiving fertility treatments using their own gametes. It would be interesting to examine whether the PCIC model also applies to donors and recipients taking part in third-party reproduction. This should be carried out in an international setting because gamete donation is a common reason for crossing borders for fertility treatment (Shenfield et al., 2010).

This study provides enough international qualitative evidence to develop a PCIC survey instrument to examine the 10 dimensions of PCIC quantitatively. Such an instrument can subsequently be used for international benchmarking. However, the cultural differences in ‘importance ratings’ should be taken into account. Therefore, data should be collected on both importance and performance during all international assessments, in contrast to similar national surveys (e.g. infertility; van Empel et al., 2010) for which only questioning importance during questionnaire validation and not during future assessments is recommended (Sixma et al., 2008).
Conclusions

The PCIC model is the first PCC model based on the patients’ perspective that has been validated in an international setting. Although health-care organization and performance are known to differ, the similarities in the patients’ perspective on important care aspects across countries and (based on literature review) across different condition-specific PCC models are striking. The evidence from this study further suggests that it is possible to develop a non-condition-specific international model for PCC and a European assessment and benchmarking instrument for the patient centredness of infertility care.

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Authors’ roles

E.D., T.D., J.K., W.N. and W.S. initiated and designed the study, more specifically, the aim, the data collection and data analysis process. E.D., T.D. and J.K. monitored data collection for the whole study and drafted and revised the paper. They are guarantors. H.Z., D.K., W.N. and E.D. implemented the study in Austria and W.N. and D.K. analysed the Austrian data. D.S.C., J.G.V. and E.D. implemented the study in Spain and D.S.C. and E.D. analysed the Spanish data. C.W., E.D. and N.K. implemented the study in the French-speaking part of Belgium and E.D. and N.K. analysed the data from the French-speaking part of Belgium. L.N., M.B. and E.D. implemented the study in the UK and E.D., L.V. and M.B. analysed the UK data. T.D., J.K., W.N., W.S., E.D. and L.V. integrated the international data in one data set and conducted the final analysis. All authors read the manuscript and revised the paper. All authors approved the final version of the manuscript to be published.

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Conflict of interest

None declared.

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Views of patients across Europe on patient-centred care


