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The patients' perspective on (quality of) subfertility care

A systematic review

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- Introduction
- Objective
- Methodology systematic review
- Results:
 - Samples and settings
 - Methodology
 - Scope
 - Findings: The patients' perspective on (the quality of) subfertility care

Introduction (1):

The importance of the pts' perspective on care

- Until now quality of care mainly from professionals' (doctors) perspective
- Patient is important stakeholder
- High quality care > result (live birth)

High quality care = result,

no complications,
patient-centered
care,...



Introduction (2): The nurse/midwife as a bridge

EBM



daily
practice

Introduction (3): The nurse/midwife as a bridge

Gynecologists,
Doctors,
Scientists,
Embryologists



Patients

Objective

‘How do patients with fertility problems in developed countries perceive and evaluate subfertility care?’

First: ‘what (amount + quality) has already been published on this subject?’

Methodology: Systematic review (1)

- Highest level of evidence
- Synthesizing what is published on a subject
- Tasks: review question, protocol, conduct the review, reporting the findings
- Systematic steps (-> to ensure reproducibility)
 - Search strategy
 - Selection of studies (content)
 - Quality assessment
 - Data extraction
 - Meta-synthesis

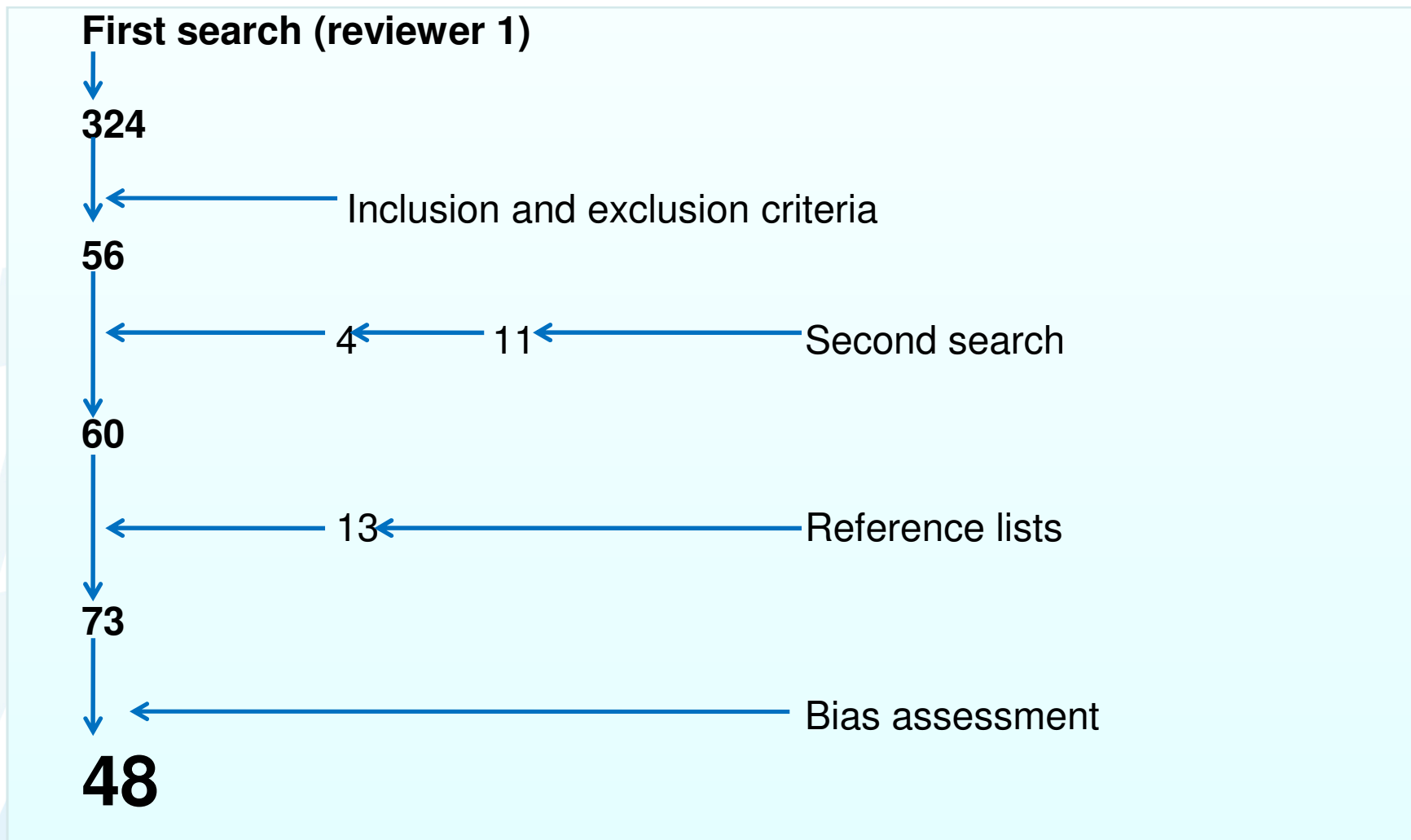
Methodology: Systematic review (4)

- Quality assessment (=assessment of risk of bias)
2 reviewers (Kappa statistic)
Quality criteria for non-intervention studies (Sheperd et al, 2006)
 - (i) An explicit account of theoretical framework and/or the inclusion of a literature review which outlined a rationale for the intervention
 - (ii) Clearly stated aims and objectives
 - (iii) A clear description of context which includes detail on factors important for interpreting results
 - (iv) A clear description of sample
 - (v) A clear description of methodology, including systematic data collection methods
 - (vi) Analysis of the data by more than one researcher
 - (vii) The inclusion of sufficient original data to mediate between data and interpretation

Cut-off point: 4/7

Methodology: Systematic review (5)

Selection of studies



Results

- Setting and sample



Implications for interpretation of findings

- Methodology



Implications for interpretation of findings

- Scope 


- Findings:

*'The patients' perspective on
(the quality of) subfertility care'*

Results: setting and sample (1)

- Setting: 
- Country:
 - Europe: n= 31 (UK, Netherlands, Denmark,..)
 - VS: n=10
 - Other: n= 7 (Australia, Canada,...)
- Datacollection
 - Monocentric: n= 30
 - Multicentric: n= 7
 - Other: n= 11 (pt organisation, national sample, ...)

Results: setting and sample (2)

- Sample: 
- Size
mean: 100 (min: 16, P25: 50, P75: 260, max: 1934)
- Respondents
 - couples: n=14
 - women: n=21
 - men: n=2
 - women and men: n=11
- Patients with positive treatment result
 - included: n= 13
 - excluded: n= 22
 - not specified: n= 13

Implications for interpretation of findings

- Setting and sample -> generalisibility

Results: Methodology (1)

- Primary aim
- Evaluated aspect of pts' perspective (outcome)
- Design:
 - Qualitative research (n=7)
 - Combination interview and single quantitative question (n=4)
 - Single quantitative question (n=9)
 - Questionnaire (n=28)

Results: Methodology (2)

- Primary aim
Examining the patients' perspective on
(quality of) subfertility care: n= 28
(mostly questionnaires)
Other: n= 20



Results: Methodology (3)

- Evaluated aspect of pts' perspective (outcome)
 - Experience/evaluation: n= 22
 - Satisfaction: n= 10
 - Preference: n=3
 - Experience/evaluation and satisfaction: n= 8
 - Satisfaction and preference: n= 3
 - Experience/evaluation and satisfaction and preference: n=2



Results: Methodology (4)

- Qualitative research (n=7)
 - Interviews (one on 1-2)
 - 1/7 by telephone, others live
 - Data-analysis



Results: Methodology (5)

- Combination interview and single quantitative question (n=4)
 - Datacollection
 - Data-analysis



Results: Methodology (6)

- Single quantitative question (n=9)
 - Datacollection: Type of question, scale
 - Data-analysis



Results: Methodology (7)

- Questionnaire (survey) (n=28)

- Datacollection

- 5/28 used existing nonspecific Q, 23/28 developed Q

- Only 6/23 developed Q on the basis of research into the pts' perspective

- Only 4/23 (partial) validation phase

- Type of question: open, closed, open/closed

- Data-analysis



Implications for interpretation of findings

- Methodology -> trustworthiness of results of studies

Results: scope (1)

- Examined care processes
- Examined dimensions of patient centeredness



Results: scope (2)

Examined care processes

- Entire process of subfertility investigation and treatment (n=10)
- Two aspects of care (n=5)
- One aspect of care (n=33)

Results: scope (3)

Examined care processes

- Popularity of care processes:
 - pain medication during oocyte retrieval (n=7),
 - counseling (n=6),
 - subfertility treatment (not specified) (n=4),
 - online information provision (n=4),
 - information provision (n=4),
 - consultations (n=3),
 - the transition primary-secondary care (n=3),
 - mode of stimulation in IVF-treatment (n=2),
 - care at end of treatment (n=2),
 - Communication (n=2).
 - Other (n=1) (subfertility treatment (specified IUI), subfertility treatment (specified IVF), subfertility investigation (specified HyCoSy, HSG), surgical sperm retrieval, pain medication during sperm retrieval, decision-making process, treatment preference IUI-IVF.

Results: scope (4)

Examined dimensions of patient centeredness

- Concept patient centeredness (Picker Institute) + self developed dimension
 - Access to care
 - Respect for patient's values, preferences, needs
 - Coordination and integration of care
 - Information, communication and education
 - Physical comfort
 - Emotional support and alleviation of fear and anxiety
 - Involvement of family and friends
 - Transition and continuity
 - Professionals



9 dimensions of patient centeredness



Results: scope (5)

Examined dimensions of patient centeredness

- Number of assessed dimensions per study
 - 1 dimensions (n= 20)
 - 2 dimensions (n= 5)
 - 3 dimensions (n= 3)
 - 4 dimensions (n= 5)
 - 5 dimensions (n= 2)
 - 6 dimensions (n= 6)
 - 7 dimensions (n= 1)
 - 8 dimensions (n= 1)
 - 9 dimensions (n= 1)**
(unclear, only overall satisfaction reported: 4)

Results: scope (6)

Examined dimensions of patient centeredness

- Popularity of dimensions
 - Information, communication and education (n=21)
 - Emotional support and alleviation of fear and anxiety (n=17)
 - Professionals (n=17)
 - Respect for patient's values, preferences, needs (n=14)
 - Physical comfort (n=14)
 - Access to care (n=13)
 - Transition and continuity (n=13)
 - Coordination and integration of care (n=7)
 - Involvement of family and friends (n=6)

Implications for interpretation of findings

- Scope -> the care processes on which we have knowledge
 - > the completeness of the picture on the patient centeredness of care

Results: findings (1)

what is the pts' perspective

- Per dimension of patient centeredness: important aspects
- Citation from patients in focusgroups on the patients' perspective on care

Results: findings (2)

what is the pts' perspective

- Access to care
 - waiting time during treatment
 - waiting time in the waiting room
 - distance
 - Importance of access
 - Timing referral
 - waiting time for first appointment
 - possibility of telephone consultation
 - Appointment options
 - concept of pre-clinic request
 - costs
 - Telephone accessibility

‘And I’ve asked a few times if it was possible to communicate by email and they’ve already given me two emailaddresses, on which this is possible. That is also just to dubble check it when you see it in writing’. (B, FGG2, p7, r, Resp A)

Results: findings (3) what is the pts' perspective

- Respect for patient's values, preferences, needs
 - Individualized/personalized care
 - Involvement in decision-making
 - Respect
 - Taken seriously
 - Preference

‘I also think it is great when... Well I’ve been treated here for a while now, but they recognize me straight away... Well, it is not easy for them of course to remember everyones namen because we are so many patients, but they act like ‘Oh, you’re that person’ and they know straight away where to go...’ (B, FGG2, p3, r, Resp L)

Results: findings (4) what is the pts' perspective

- Coordination and integration of care
 - Duration of consultation
 - Frequency of appointments
 - Administrative failures
 - Front-line: welcoming

All those papers and forms... You get your envelop, you just take that envelop with you when you need to be here for the pick-up or the transfer and then after the pick-up or transfer you just sign everything and then... I think that it is easy when you can do it here. I don't really bother when I'am at home, we know anyway that we can do it here...' (B, FGG2, p13, r, Resp A)

Results: findings (5) what is the pts' perspective

- Information, communication and education (1)
 - Importance of information
 - Information on diagnosis
 - Information on treatment options
 - Personal information provided on internet
 - Info on procedure
 - Communication
 - Written information
 - Information sperm quality
 - Information costs
 - Information on nature fertility problem

Results: findings (6) what is the pts' perspective

- Information, communication and education (2)
 - Information on alternatives
 - Information prognosis
 - Known plan
 - Sufficiency of information/ Ask all questions
 - Info on helping themselves
 - Quality of information
 - Understandability
 - Time for discussion
 - Information on side effects
 - Information on lifestyle

*‘they really talk about apples and pears...
Yes it is really ‘languages of the
people’. Some other doctors can really
talk in a way that makes you feel like,
oké... and now in Dutch please? And
out here.... I really really like that.’ (B,
FGG2, p6, r, Resp K)*

Results: findings (7) what is the pts' perspective

- Physical comfort
 - Accommodation
 - Type of clinic
 - Pain medication PU
 - Comparing expected and experienced pain

‘Not really because the last treatment....I had a transfer and we were there with some 4 patients, I think. And that was fun, we laughed, we talked about television shows, it was really pleasant. And at times like that it is nice to have some distraction. So, I mean, yeah... ..’(B, FGG2, p15, r, Resp K)

Results: findings (8) what is the pts' perspective

- Emotional support and alleviation of fear and anxiety
 - Personal need for counseling
 - Need for center to provide counseling
 - Timing counseling
 - support group
 - Importance of counseling
 - Evaluation of counseling
 - Emotional support of professionals during (medical) care

'that time with my extra-uterine pregnancy, that was really nice here... that was really well taken care of and they gave me a pat on the back, or she gently squeezed my leg when I was laying there... because it took a long time before they had found it, I often needed to come back... Yes, when they called me, they were like good luck and this and that... and then they send me some files by post and added a small note with 'we wish you fresh courage'... and that really helps... It is nice when the people really understand you, because with the general population this does not always work out... here, where you really need it,... they do so... I do appreciate that' (B, FGG 1, p19, r13-14, resp. E1)

Results: findings (9) what is the pts' perspective

- Involvement of family and friends
 - Importance of involving partner
 - Source of support



‘They are also very considerate about the time to telephone me with the treatment result, because my husband works in shifts; if he has to leave for a late shift at one, then I ask, if possible, to call me earlier... and they have called me at 11h15 in the morning... in order to make sure that I am not alone when they give me the news; also when he works in an early shift, they’ve called me after 15h00... I mean it is so nice to not be alone when you receive the news. Even being with your mum is not the same as with your partner.’ (B, FGG2, p7, r, Resp K)

Results: findings (10) what is the pts' perspective

- Transition and continuity
 - Continuity
 - Poor organizational aspects
 - Care after end of treatment
 - Communication with extern physicians
 - Fragmentized care (physician complete picture)

‘and then we wanted to start a new treatment and they were like, aha Dr X has already prepared this in your file. Then we were like, the doctor did say that, I cannot imagine that, and then, I took a look and we were like, yes he did make remarks in our file. And then we took our time to explain how we wanted it, and we thought we would need to call back in order to make an appointment or something like that, but no our file was already completed.’ (B, FGG2, p35, r, Resp F)

Results: findings (11)

what is the pts' perspective

- Professionals
 - Sensitivity of professionals
 - Attitude: staff (general)
 - Attitude: doctor
 - Attitude nurses
 - Trust in professionals
 - Attitude Office staff
 - Relationship with professionals
 - Competence of professionals
 - Attitude reception staff
 - Helpfulness

‘Yes, then I mentioned friendliness and concernedness, yes, if they would pull a long face when I arrive in the morning, than I would go straight back home, but I’ve never ever experienced this here’ (B, FGG2, p33, r, Resp L)

Conclusion (1)

- The patients' perspective on care has been studied in the past

But important shortcomings

methodology

scope

→ implications for interpretation

Conclusion (2)

- Need for an instrument (questionnaire) to evaluate the patients' perspective on quality of care that:
 - is developed based on research into the patients' perspective
 - assesses all the dimensions of patient centeredness
 - has it as a primary aim
 - assesses a specific (grounded) aspect of the pts' perspective
 - is validated
 - is globally applicable

Conclusion (3)

- Fertility patients want patient centered care:
 - Access to care;
 - Respect for patient's values, preferences, needs;
 - Coordination and integration of care;
 - Information, communication and education;
 - Physical comfort;
 - Emotional support and alleviation of fear and anxiety;
 - Involvement of family and friends;
 - Transition and continuity;
 - Good professionals.

Focusgroups

- What are focusgroups?
- Focus: The patients' experience -> the patients' perspective on (quality of) care
- Priority listing (how was score calculated)

Focusgroups: priority listing

- Information, communication and education (73)
- **Professionals (62)**
- Emotional support and alleviation of fear and anxiety (20)
- Access to care (14)
- Respect for patient's values, preferences, needs (14)
- Transition and continuity (13)
- **Medical expertise (13)**
- Coordination and integration of care (11)
- Physical comfort (1)
- Involvement of family and friends (0)

Thank you for your attention
Any questions?

