

ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction—a guide for fertility staff†

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STUDY QUESTION: Based on the best available evidence in the literature, what is the optimal management of routine psychosocial care at infertility and medically assisted reproduction (MAR) clinics?

SUMMARY ANSWER: Using the structured methodology of the Manual for the European Society of Human Reproduction and Embryology (ESHRE) Guideline Development, 125 recommendations were formulated that answered the 12 key questions on optimal management of routine psychosocial care by all fertility staff.

WHAT IS ALREADY KNOWN: The 2002 ESHRE Guidelines for counselling in infertility has been a reference point for best psychosocial care in infertility for years, but this guideline needed updating and did not focus on routine psychosocial care that can be delivered by all fertility staff.

STUDY, DESIGN, SIZE, DURATION: This guideline was produced by a group of experts in the field according to the 12-step process described in the ESHRE Manual for Guideline Development. After scoping the guideline and listing a set of 12 key questions in PICO (Patient, Intervention, Comparison and Outcome) format, thorough systematic searches of the literature were conducted, evidence from papers published until April 2014 was collected, evaluated for quality and analysed. A summary of evidence was written in a reply to each of the key questions and used as the basis for recommendations, which were defined by consensus within the guideline development group (GDG). Patient and additional clinical input was collected during the scoping and the review phase of the guideline development.

PARTICIPANTS/MATERIALS, SETTING, METHODS: The guideline group, comprised psychologists, two medical doctors, a midwife, a patient representative, and a methodological expert, met three times to discuss evidence and reach consensus on the recommendations.

MAIN RESULTS AND THE ROLE OF CHANCE: The guideline provides 125 recommendations that aim at guiding fertility clinic staff in providing optimal evidence-based routine psychosocial care to patients dealing with infertility and MAR. The guideline is written in two sections. The first section describes patients' preferences regarding the psychosocial care they would like to receive at clinics and how this care is associated with their well-being. The second section of the guideline provides information about the psychosocial needs patients experience across their treatment pathway (before, during and after treatment) and how fertility clinic staff can detect and address these. Needs refer to conditions assumed necessary for patients to have a healthy experience of the fertility treatment. Needs can be behavioural (lifestyle, exercise, nutrition and compliance), relational (relationship with partner if there is one, family friends and larger network, and work), emotional (well-being, e.g. anxiety, depression, quality of life) and cognitive (treatment concerns and knowledge).

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LIMITATIONS, REASONS FOR CAUTION: We identified many areas in care for which robust evidence was lacking. Gaps in evidence were addressed by formulating good practice points, based on the expert opinion of the GDG, but it is critical for such recommendations to be empirically validated.

WIDER IMPLICATIONS OF THE FINDINGS: The evidence presented in this guideline shows that providing routine psychosocial care is associated with or has potential to reduce stress and concerns about medical procedures and improve lifestyle outcomes, fertility-related knowledge, patient well-being and compliance with treatment. As only 45 (36.0%) of the 125 recommendations were based on high-quality evidence, the guideline group formulated recommendations to guide future research with the aim of increasing the body of evidence.

STUDY FUNDING/COMPETING INTEREST(S): The guideline was developed and funded by ESHRE, covering expenses associated with the guideline meetings, with literature searches, and with the implementation of the guideline. The GDG members did not receive payment. S.G., E.D., C.d.K., M.E., U.V.d.B., C.L.-J. and N.V. report no conflicts of interest. J.B. reports grants from Merck & Co, consulting fees from Merck Serono S.A. and Speaker's fees from Merck Serono S.A. P.T. reports consulting fees from the German government and being the Chair of the German Society for Fertility Counselling. C.V. reports consulting fees from Merck Serono S.A. C.M.V. reports being adviser in projects for Merck Serono S.A. and Ferring S.A. on patient educational material. T.W. reports speaker's fees from Repromed, DGPM, Breitbach, DAAG, fiore, LPTW, MSD, salary/position funding at TAB-beim-Bundestag, BZgA, and being the Vice-chair of the German Society for Fertility Counselling.

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Introduction

The European Society of Human Reproduction and Embryology (ESHRE) guideline 'Routine psychosocial care in infertility and medically assisted reproduction—A guide for fertility staff' offers evidence-based best practice advice to all fertility clinic staff (doctors, nurses, midwives, counsellors, social workers, psychologists, embryologists and administrative personnel) on how to incorporate psychosocial care in routine infertility care. Psychosocial care is defined as care that enables couples, their families and their health care providers to optimize infertility care and manage the psychological and social implications of infertility and its treatment (*Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs, 2008*).

Psychosocial care is important in infertility care because most patients experience emotional distress during treatment (Verhaak et al., 2007a,b; Knoll et al., 2009; Karatas et al., 2011), ~23% discontinue prematurely because of the perceived burden of treatment (Brandes et al., 2009) and one-third of patients end treatment without achieving pregnancy (Pinborg et al., 2009) and experience difficulties in adjusting to unmet parenthood goals (Verhaak et al., 2007a,b; Johansson et al., 2010; Wischmann et al., 2012; Gameiro et al., 2014). Even when a pregnancy is achieved, it is experienced with increased anxiety about the viability and health of the foetus (Hammarberg et al., 2008). Psychosocial care should support patients in achieving their parenthood goals and managing all the implications of successful or failed treatment. By offering psychosocial care in combination with medical care during routine practice, fertility clinic staff can ensure that care is accessible for all patients and addresses their most common needs. For these reasons, psychosocial care should be the responsibility of all staff members that have contact with patients.

Scope

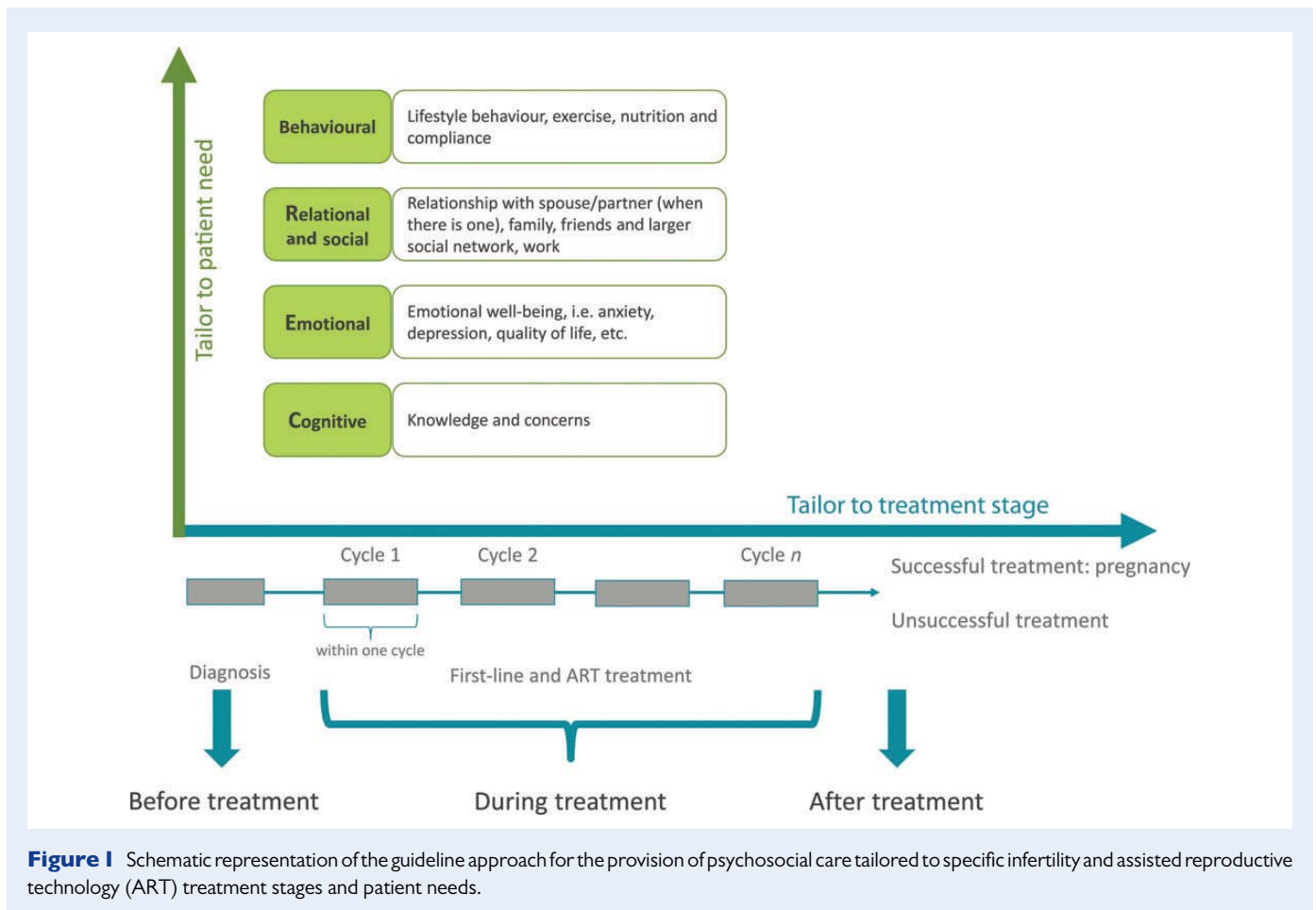
The ESHRE guideline provides information about two main issues. First, about the preferences of patients regarding the psychosocial care, they would like to receive at clinics and how this care is associated with

their well-being. This information is considered useful to raise staff awareness about patient preferences for psychosocial care. Second, about the psychosocial needs that patients experience across their treatment pathway, and how staff can detect and address these needs. Thus, the guideline describes patients' needs, informs about risk factors for specific psychosocial needs and tools to detect these and lists evidence-based psychosocial interventions that can be delivered by members of staff without specialised training in mental health care and do not require the active intervention of mental health professionals (e.g. specialist counsellors, psychologists and psychiatrists).

The guideline is organised according to a horizontal 'time' axis and a vertical 'needs' axis with the aim of tailoring care to the different psychosocial needs patients experience across time at different treatment stages. This approach is depicted in Fig. 1. The time axis includes three stages: before, during and after treatment. The needs axis refers to conditions assumed necessary for patients to have a healthy experience of the fertility treatment. Needs can be behavioural (i.e. lifestyle, exercise, nutrition and compliance), relational (i.e. relationship with partner, family, friends and larger network, and work), emotional (i.e. anxiety, depression, quality of life) and cognitive (i.e. treatment concerns and knowledge).

Methods

The guideline was developed according to the Manual for ESHRE Guideline Development (Nelen, 2009). All details on the methodology can be found in the full version of the guideline available at www.eshre.eu/Guidelines. In short, the guideline development group (GDG) defined 12 key questions structuring psychosocial care in fertility clinics. The questions were defined in PICO format (Patient, Intervention, Comparison and Outcome), and for each question, the best available evidence was searched in PUBMED/MEDLINE, PsychInfo and the Cochrane library and included studies published between January 1990 and April 2014. The evidence was extracted into evidence tables, and the quality of all manuscripts was assessed. Three 2-day meetings were organized to discuss the evidence for each question, in order to reach consensus about the final formulation of the



recommendations. For each recommendation, a grade (A–C) was assigned based on the strength of the supporting evidence (Scottish Intercollegiate Guidelines Network, 2010). In case of the absence of evidence, the GDG offered good practice points (GPP), based on expert opinion.

After finalization of the guideline draft, stakeholders were invited to review and comment on the guideline. The chair of the GDG (SG) and the methodological expert (NV) processed all comments received, by adapting the content of the guideline and/or by replying to the reviewer. The review process is summarized in the review report, published on the ESHRE website. The guideline will be considered for update 4 years after publication.

Key questions and recommendations

The current document summarizes the key questions and the recommendations for clinical practice. Further background information and the supporting evidence for each recommendation can be found in the full version of the guideline available at <http://www.eshre.eu/Guidelines-and-Legal/Guidelines/Psychosocial-care-guideline.aspx>.

Psychosocial care: patients' preferences and well-being

Which aspects and components of psychosocial care are important to patients? Fertility staff should be aware that patients value:

- how staff relate to them (Ryan, 1999; Schmidt *et al.*, 2003; Dancet *et al.*, 2010; van Empel *et al.*, 2010, 2011). [A];
- staff showing understanding and paying attention to the emotional impact of infertility (Schmidt *et al.*, 2003; Dancet *et al.*, 2010; van Empel *et al.*, 2010). [A];
- that both partners are involved in the treatment process (Dancet *et al.*, 2010). [A];

- being involved in decision-making (Dancet *et al.*, 2010). [A];
- receiving psychosocial care from sensitive and trustworthy staff members (Dancet *et al.*, 2010; van Empel *et al.*, 2010). [A];
- receiving attention to their distinct needs related to their medical history (Karatas *et al.*, 2010). [B].
- minimal waiting times, not being hurried in medical consultations, and continuity of care (Ryan, 1999; Dancet *et al.*, 2010). [A];
- the professional competence of fertility staff and receiving personalized care (Dancet *et al.*, 2010). [A];
- the provision of opportunities for contact with other patients (Dancet *et al.*, 2010). [A];
- being in a clinic dedicated to infertility care (Dancet *et al.*, 2010). [A];
- the offer of specialized psychosocial care (infertility counselling or psychotherapy) before, during and after IVF treatment (Dancet *et al.*, 2010). [B].

The GDG recommends fertility staff to be aware that:

- patients expressing a need for emotional support value the offer of specialized psychosocial care (infertility counselling or psychotherapy). [GPP];
- patients may value the presence of a chaperone during medical examinations. [GPP];
- men value rooms designated for producing sperm samples. [GPP].

Which routine psychosocial care components are important to patients?

Fertility staff should be aware that patients value:

- written treatment-relevant information (Schmidt *et al.*, 2003; Dancet *et al.*, 2010; Mourad *et al.*, 2011). [C];
- explanations about treatment results and treatment options (Schmidt *et al.*, 2003). [C];

understandable and customized (i.e. personally relevant) treatment information (Schmidt et al., 2003; Dancet et al., 2010; Mourad et al., 2011). [C]; the provision of information about psychosocial care options (e.g. contact details of support groups, online support options, access to infertility counselling or psychotherapy) (Schmidt et al., 2003; Cousineau et al., 2008; Dancet et al., 2010; Sexton et al., 2010). [B].

Fertility staff should be aware that IVF patients equally prefer in-person or telephone consultation to discuss their treatment results and future plans (Stewart et al., 2001). [C]

Which characteristic of fertility staff and clinics are associated with patients' well-being?

Fertility staff should be aware that:

receiving patient-centred care is associated with better patient well-being (Aarts et al., 2012; Gameiro et al., 2013a,b). [C]; positive staff characteristics (communication, respect, competence, involvement and information) are associated with better patient well-being (Aarts et al., 2012; Gameiro et al., 2013a,b). [C]; positive clinic characteristics (information, competence of clinic and staff and continuity) are associated with better patient well-being (Aarts et al., 2012; Gameiro et al., 2013a,b). [C].

Fertility staff should be aware that offering the currently available interactive complex interventions (complex interventions integrate several psychosocial components (e.g., information provision, training in coping or relaxation strategies.) is not likely to affect patient individual and relational well-being (Shu-Hsin, 2003; van Zyl et al., 2005; Gürhan et al., 2007; Mori, 2009). [B]

Fertility staff should provide preparatory information about diagnostic procedures because it decreases infertility-specific anxiety and stress (Pook and Krause, 2005). [C]

Fertility staff should be aware that:

tailored online psycho-educational interventions may improve infertility-specific stress and self-efficacy, and the sexual and social concerns of particular groups of patients (Cousineau et al., 2008). [C]; providing IVF patients with access to an internet-based personal health record is not likely to promote their emotional well-being (depression, anxiety and self-efficacy) (Tuil et al., 2007). [C].

Psychosocial care before treatment

The 'before treatment' period refers to the period that begins at the first visit to the clinic until the start of the first treatment cycle, being it either first-line treatment such as intrauterine insemination (IUI) or assisted reproductive technology (ART) treatment.

What are the needs of patients before treatment?

Behavioural needs

Fertility staff should be aware that:

one in 10 patients referred for fertility treatment chooses not to start treatment (Brandes et al., 2009). [C]; the reasons patients state for not starting any type of recommended fertility treatment are: rejection of treatment (due to ethical objections, concerns about and lack of interest in treatment), personal reasons, relational problems, financial issues and psychological burden of treatment (Gameiro et al., 2012). [B]; the reasons patients on the waiting list to start ART treatment state for not starting recommended ART treatment are: relational problems, psychological burden of treatment, personal reasons, clinic-related problems and financial issues (Gameiro et al., 2012). [B]; a considerable number of patients have lifestyle behaviours that may negatively affect their general and reproductive health (Klonoff-Cohen et al., 2001; Freizinger et al., 2010; Schilling et al., 2012). [C].

Relational/social needs

Fertility staff should be aware that:

patients starting first-line or ART treatments do not have worse marital and sexual relationships than the general population (Slade et al., 1997; Edelmann and Connolly, 2000; Verhaak et al., 2001, 2005a,b). [B]; patients in fertility workup do not present higher prevalence rates of sexual dysfunctions than the general population (Shindel et al., 2008). [C].

Emotional needs

Fertility staff should be aware that:

before the start of IVF treatment, patients are not more depressed than the general population or matched controls (Verhaak et al., 2007a,b; Lintsen et al., 2009; Lewis et al., 2013). [B]; evidence about whether before the start of a first IVF cycle patients are more anxious (state and trait anxiety) than the general population is inconsistent (Verhaak et al., 2007a,b; Lintsen et al., 2009; Lykeridou et al., 2009; Kumbak et al., 2010; Turner et al., 2013). [B]; before first-line or ART treatment, women do not show more psychiatric disorders or general psychopathology than the general population (Edelmann and Connolly, 2000; Salvatore et al., 2001; Dhaliwal et al., 2004; Van den Broeck et al., 2010; Zaig et al., 2013). [C].

How can fertility staff detect the needs of patients before treatment?

The GDG recommends that fertility staff:

offer patients the opportunity to have their needs assessed and be informed about their emotional adjustment before the start of treatment. [GPP]; use the tools listed in [Supplementary Data](#) when assessing patients' needs. [GPP].

Behavioural needs

Fertility staff should:

be aware that currently there are no reliable pre-treatment tools or predictors to identify patients who are not likely to start recommended fertility treatment (Gameiro et al., 2012). [B]; not assume that patients fully self-report on risk factors for reduced fertility (e.g. eating disorders) (Freizinger et al., 2010). [C]; be aware that risk factors (e.g. smoking, alcohol use and diet) for reduced fertility can be assessed with self-administered online tools (Landkroon et al., 2010). [C].

The GDG recommends that fertility staff consider explicitly screening risk factors (e.g. drug use, eating disorders) for reduced fertility (Freizinger et al., 2010). [GPP].

Relational and social needs

Fertility staff should be aware that:

women experience higher social and sexual infertility-specific stress than men (Slade et al., 1997; Newton et al., 1999; Peterson et al., 2007, 2008, 2014; Donarelli et al., 2012). [C]; the ways patients deal with their fertility problems are associated with infertility-specific relational and social distress: the use of meaning-based coping (e.g. thinking about the fertility problem in a positive light, finding other goals in life) seems to be associated with lower fertility-specific marital and social distress; the use of avoidance coping strategies (e.g. avoiding being among pregnant women) seems to be associated with higher fertility-specific marital and social distress (Peterson et al., 2008). [C]; in couples, the way one partner reacts to the infertility condition/diagnosis is associated with how the other partner reacts (Peterson et al., 2008, 2014). [C]; couples who have different views on the importance of parenthood and social concerns may show lower relationship satisfaction than those who have similar views (Peterson et al., 2003). [C].

Emotional needs

Fertility staff should be aware that:

women have higher levels of depression and infertility stress than men (Slade *et al.*, 1997; Newton *et al.*, 1999; Edelman and Connolly, 2000; Peterson *et al.*, 2003, 2014; Reis *et al.*, 2013). [C];

patients with a lower occupational status experience higher infertility stress and anxiety than patients with a medium or high occupational status (Lykeridou *et al.*, 2009, 2011). [C];

women whose partner has male factor infertility experience higher anxiety than women with female factor, mixed or unexplained infertility, whereas the type of infertility diagnosis is not related to depression (Lykeridou *et al.*, 2009). [C];

the way patients deal with their fertility problems is associated with their infertility distress: the use of passive coping (e.g. rumination, withdrawal) seems to be associated with higher levels of infertility distress. The use of active coping (e.g. goal-oriented problem-solving, thinking rationally about the problem) seems to be associated with lower infertility distress (Van den Broeck *et al.*, 2010). [C];

individuals who perceive their partner to be available and responsive experience lower infertility stress than individuals who perceive their partner to be avoidant and non-responsive (Van den Broeck *et al.*, 2010; Donarelli *et al.*, 2012). [C];

in couples, each partner's depressive symptoms are associated with their own and their partner's infertility-specific distress (Peterson *et al.*, 2014). [C]; the SCREENIVF is an infertility-specific validated tool designed to be used before the start of treatment, to assess risk factors for emotional problems after a treatment cycle (Verhaak *et al.*, 2010; Van Dongen *et al.*, 2012). [B].

The GDG recommends that fertility staff use the SCREENIVF before the start of each treatment cycle to assess patients' risk factors for emotional problems after the cycle. [GPP].

How can fertility staff address the needs of patients before treatment?

The GDG recommends that fertility staff refer patients at risk of experiencing clinically significant psychosocial problems to specialized psychosocial care (infertility counselling or psychotherapy). [GPP].

Behavioural needs

Fertility staff should:

provide preparatory information about medical procedures because it promotes compliance (Pook and Krause, 2005; Lykeridou *et al.*, 2009, 2011). [B];

be aware that weight-loss programmes based on diet and exercise offered pre-ART treatment may be effective in reducing weight and BMI (Clark *et al.*, 1998; Moran *et al.*, 2011). [B].

The GDG recommends that fertility staff:

consider providing patients with information about lifestyle behaviours that may negatively affect their general and reproductive health. [GPP];

support patients in changing lifestyle behaviours that negatively affect their general and reproductive health, as well as their chances of treatment success. [GPP].

Relational and social needs

The GDG recommends that fertility staff:

offer additional psychosocial care to patients at risk of experiencing increased infertility-specific relational and social distress. [GPP];

actively involve both partners of the couple in the diagnosis and treatment process. [GPP].

Emotional needs

Fertility staff should provide preparatory information about medical procedures because it decreases infertility-specific anxiety and stress (Pook and Krause, 2005). [C].

The GDG recommends that fertility staff:

refer patients identified by the SCREENIVF as being at risk of emotional problems to specialized psychosocial care (infertility counselling or psychotherapy). [GPP];

actively involve both partners of the couple in the diagnosis and treatment process. [GPP].

Cognitive needs

Fertility staff should provide preparatory information about medical procedures because it increases patient knowledge (Hope and Rombauts, 2010). [C].

Psychosocial care during treatment

The 'during treatment' period refers to time that encompasses any treatment cycle, being it either first-line treatment such as IUI, or ART cycles.

What are the needs of patients during treatment?

Behavioural needs

Fertility staff should be aware that:

around 1 in 12 patients and 1 in 5 patients do not comply with first-line and ART treatment, respectively (Brandes *et al.*, 2009; Gameiro *et al.*, 2013a,b). [A];

the reasons patients state for discontinuing recommended first-line treatment are: postponement of treatment (i.e. stopping treatment for at least 1 year), logistics and practical reasons, rejection of treatment, perception of poor prognosis and the psychological burden of treatment (Gameiro *et al.*, 2012). [A];

the reasons patients state for discontinuing recommended treatment after one failed IVF/ICSI cycle are: financial issues, the psychological and physical burdens of treatment, clinic-related reasons and organizational problems, postponement of treatment (or unknown), and relational problems (Gameiro *et al.*, 2012). [A];

the reasons patients state for discontinuing a recommended standard ART treatment programme of three consecutive cycles are: postponement of treatment, the psychological burden of treatment, the physical and psychological burdens of treatment, and personal problems (Gameiro *et al.*, 2012). [A].

Relational and social needs

Fertility staff should be aware that:

relational satisfaction of patients does not change from before they start an IVF/ICSI cycle to after the pregnancy test (Verhaak *et al.*, 2001). [B];

women report more intimacy with their partner during an IVF/ICSI cycle than during a normal menstrual cycle, in particular at the retrieval and transfer days of the cycle (Boivin and Takefman, 1996). [B];

women experience lower sexual satisfaction after the pregnancy test than before the start of an IVF/ICSI cycle (Verhaak *et al.*, 2001). [B];

women report lower social support from significant others in the period between the oocyte retrieval and the embryo transfer of an IVF/ICSI cycle than during the equivalent period in a normal menstrual cycle (Boivin and Takefman, 1996). [B];

during an IVF/ICSI cycle, 6 in 10 patients report treatment-related absences from work and, on average, patients miss 23 h of work (Bouwman *et al.*, 2008). [C].

Emotional needs

Fertility staff should be aware that

patients' emotional stress fluctuates during an IVF/ICSI cycle, with peaks at the oocyte retrieval, the embryo transfer and the waiting period before the pregnancy test (Boivin and Takefman, 1996; Boivin et al., 1998; Knoll et al., 2009; Turner et al., 2013). [B];

women's positive affect decreases during an IVF/ICSI cycle (Knoll et al., 2009; Boivin and Lancaster, 2010). [B];

anxiety and stress are higher when patients are anticipating results (e.g. in the waiting period before the pregnancy test, between oocyte retrieval and embryo transfer) (Boivin and Takefman, 1996; Boivin et al., 1998; Verhaak et al., 2007a,b; Knoll et al., 2009). [B];

patients experience high emotional distress when they are informed that the treatment was unsuccessful (Verhaak et al., 2007a,b). [B];

when they are informed that the treatment was unsuccessful, 1 to 2 in 10 women experience clinically significant levels of depressive symptoms (Verhaak et al., 2007a,b). [B];

after receiving the pregnancy test for their IVF/ICSI treatment, 1 in 4 women and 1 in 10 men have a depressive disorder. One in 7 women and 1 in 20 men have an anxiety disorder (Volgsten et al., 2008, 2010). [B].

Cognitive needs

Fertility staff should be aware that patients report moderate-to-high concerns about achieving pregnancy with a healthy live birth, which do not decrease across treatment (Klonoff-Cohen et al., 2007). [C]

How can fertility staff detect the needs of patients during treatment?

The GDG recommends the fertility staff use the tools listed in [Supplementary Data](#) when assessing patients' needs. [GPP].

Behavioural needs

Fertility staff should be aware that currently there are no reliable tools or predictors to identify patients not likely to comply with recommended treatment (Gameiro et al., 2012). [B].

Relational and social needs

Fertility staff should be aware that:

at the start of ovarian stimulation, at oocyte retrieval and after the pregnancy test, men report lower perceived support than women (Agostini et al., 2011). [C];

men report higher social isolation than women during an IVF/ICSI treatment cycle (Boivin et al., 1998). [C];

patients with lower education level or physical or emotional complaints due to IVF/ICSI may take more treatment-related hours off work (Bouwman et al., 2008). [C].

Emotional needs

Fertility staff should be aware that:

women are more likely to experience anxiety, depression, stress and/or psychiatric morbidity than men (Boivin et al., 1998; Berghuis and Stanton, 2002; Verhaak et al., 2005a,b; Montagnini et al., 2009; Chiaffarino et al., 2011). [B];

the number of previous treatment cycles is not associated with depression, anxiety or incidence of psychiatric disorders for men and women undergoing treatment (Khademi et al., 2005; Volgsten et al., 2010; Chiaffarino et al., 2011; Newton et al., 2013; Turner et al., 2013). [C];

patients undergoing mild stimulation IVF/ICSI (as opposed to standard stimulation) are more likely to experience negative emotional reactions at oocyte retrieval but less likely to experience these reactions during hormonal stimulation and after a treatment cycle cancellation or failure (de Klerk et al., 2006). [C];

patients with a previous history of vulnerability to mental health disorders are more likely to experience depression, anxiety and/or psychiatric morbidity during treatment (Zaig et al., 2013). [C];

the ways women deal with their fertility problems are associated with infertility-specific distress; the use of avoidant coping (e.g. avoiding being among pregnant women) is associated with higher infertility-specific distress; the use of emotional expressive coping (e.g. expressing feelings to significant others) is associated with lower infertility-specific distress (Panagopoulou et al., 2006). [C];

patients with low acceptance of infertility and childlessness are more likely to experience anxiety and depression when they are informed that the treatment was unsuccessful (Verhaak et al., 2005a,b). [C];

patients who experience high helplessness regarding infertility and its treatment are more likely to experience anxiety and depression when they are informed that the treatment was unsuccessful (Verhaak et al., 2005a,b). [C];

in couples, the way one partner reacts to infertility and its treatment is associated with how the other partner reacts (Berghuis and Stanton, 2002; Knoll et al., 2009). [C].

Cognitive needs

Fertility staff should be aware that currently there are no reliable methods or information about predictors of the concerns patients have about treatment (Klonoff-Cohen et al., 2007). [C]

How can fertility staff address the needs of patients during treatment?

The GDG recommends that fertility staff refer patients at risk of experiencing clinically significant psychosocial problems to specialized psychosocial care (infertility counselling or psychotherapy). [GPP].

Behavioural needs

The GDG recommends that fertility staff offer patients the opportunity to discuss uptake or not of recommended treatment and receive decisional support to deliberate their choice. [GPP].

Relational and social needs

Fertility staff should be aware that:

offering the currently available interactive complex interventions (complex interventions integrate several psychosocial components (e.g., information provision, training in coping or relaxation strategies.) is not likely to improve patient interpersonal relationships or sexual concerns (Shu-Hsin, 2003). [B];

providing IVF/ICSI-patients with access to an internet-based personal health record is not likely to improve their social support (Tuil et al., 2007). [B].

The GDG recommends that fertility staff:

offer additional psychosocial care to patients with specific characteristics associated with social isolation or absence from work. [GPP];

actively involve both partners of the couple in the treatment process. [GPP].

Emotional needs

Fertility staff should be aware that:

offering the currently available complex interventions is not likely to improve patients' depression levels (Shu-Hsin, 2003; van Zyl et al., 2005; Gürhan et al., 2007). [B];

providing IVF/ICSI-patients with access to an internet-based personal health record is not likely to improve their emotional well-being (anxiety, depression and self-efficacy) (Tuil et al., 2007). [B].

The GDG recommends that fertility staff:

offer additional psychosocial care to patients with specific characteristics associated with negative emotional reactions. [GPP];

actively involve both partners of the couple in the treatment process. [GPP].

Cognitive needs

Fertility staff should be aware that providing IVF/ICSI-patients with access to an internet-based personal health record is not likely to increase their knowledge about infertility and its treatment (Tuil *et al.*, 2007). [B].

The GDG recommends that fertility staff offer patients the opportunity to discuss and clarify their treatment-related concerns. [GPP].

Psychosocial care after treatment

The 'after treatment' period refers to the period starting 1 year after patients undergo their last treatment cycle, and the section differentiates between people who did not conceive with treatment (i.e. unsuccessful treatment) and people who did (i.e. successful treatment that results in live birth).

What are the needs of patients after treatment?

After unsuccessful treatment

Relational and social needs

Fertility staff should be aware that ~2 years after unsuccessful IVF/ICSI treatment, patients are generally satisfied with their marital relationship (Sydsjo *et al.*, 2005; Johansson *et al.*, 2009). [C]

The evidence about the behavioural and emotional needs of patients after unsuccessful IVF treatment is too limited for supporting recommendations (Verhaak *et al.*, 2007a,b; Johansson *et al.*, 2009). No evidence was found on patients' cognitive needs.

Pregnancy after treatment

Behavioural needs

Fertility staff should be aware that women who achieve pregnancy with fertility treatment practice lifestyle behaviours that are similar to women who conceive spontaneously (Fisher *et al.*, 2013). [C]

Relational and social needs

Fertility staff should be aware that the way patients relate to their foetus is similar whether the foetus is conceived with ART treatment or spontaneously (Hammarberg *et al.*, 2008; Hjelmsstedt and Collins, 2008; Karatas *et al.*, 2011). [C]

Emotional needs

Fertility staff should be aware that:
 women who conceived with IVF/ICSI do not experience more symptoms of depression, worse self-esteem or worse mental health during pregnancy than women who conceive spontaneously (Hammarberg *et al.*, 2008; Vilska *et al.*, 2009; McMahon *et al.*, 2011). [A];
 women who conceived with IVF/ICSI may experience more pregnancy-specific anxiety than women who conceived spontaneously (Hammarberg *et al.*, 2008). [B].

Cognitive needs

Fertility staff should be aware that women with multiple pregnancies after IVF/ICSI may have higher maternal expectations than women with spontaneous multiple pregnancies (Baor and Soskolne, 2010). [C].

How can fertility staff detect the needs of patients after treatment?

After unsuccessful treatment

The GDG recommends that fertility staff use the tools listed in [Supplementary Data](#) when assessing patients' needs. [GPP].

Behavioural needs

Fertility staff should be aware that former patients who remain childless 5 years after unsuccessful IVF/ICSI treatment may use more sleeping

pills, smoke more often and consume more alcohol than former patients that become parents via adoption, or spontaneously (Johansson *et al.*, 2009). [C]

Relational and social needs

Fertility staff should be aware that former patients that remain childless 5 years after unsuccessful IVF/ICSI treatment are three times more likely to separate than former patients that become parents via adoption, or spontaneously (Johansson *et al.*, 2009). [C]

Emotional needs

Fertility staff should be aware that:

women who remain childless 10 years after unsuccessful IVF/ICSI treatment are not more likely to develop psychiatric disorders than women of the same age who never underwent fertility treatment (Yli-Kuha *et al.*, 2010). [C];

women with a persistent desire for pregnancy 3 to 5 years after unsuccessful treatment may experience more anxiety and depression than women who find new life goals or women who become mothers (Verhaak *et al.*, 2007a,b). [C].

No evidence was available on detection of cognitive needs of patients after unsuccessful fertility treatment.

Pregnancy after treatment

Emotional needs

Fertility staff should be aware that:

women who experienced multiple failed ART cycles or high stress during treatment may be more likely to experience symptoms of anxiety during pregnancy (Hammarberg *et al.*, 2008). [C];

patients with multiple pregnancies after ART are not more likely to experience poorer mental health than patients with a single ART pregnancy (Vilska *et al.*, 2009). [C].

To our knowledge, there are no studies assessing predictors of the behavioural, relational or cognitive needs of patients after treatment.

How can fertility staff address the needs of patients after treatment?

After unsuccessful treatment

The GDG recommends that fertility staff:

refer patients who, when ending unsuccessful treatment, experience or are at risk of experiencing (in the short or long term) clinically significant psychosocial problems to specialized psychosocial care (infertility counselling or psychotherapy). [GPP];

offer additional psychosocial care to patients who, when ending unsuccessful treatment, are at risk of increased infertility-specific psychosocial distress. [GPP];

offer patients the opportunity to discuss the implications of ending unsuccessful treatment. [GPP].

Pregnancy after treatment

The GDG recommends that fertility staff:

refer patients who experience or are at risk of experiencing clinically significant psychosocial problems after successful treatment to specialized psychosocial care (infertility counselling or psychotherapy). [GPP];

offer additional psychosocial care to patients at risk of increased infertility-specific psychosocial distress after successful treatment. [GPP];

offer patients the opportunity to discuss their worries about pregnancy achieved with fertility treatment. [GPP].

These GPPs were decided by consensus, as no studies were found on interventions that can be delivered by staff to address the needs of patients who underwent unsuccessful or successful fertility treatment.

Conclusion

This is the first guideline offering evidence-based and good practice recommendations to all fertility staff about how to implement routine psychosocial care at fertility clinics. It was developed based on the Manual for ESHRE Guideline Development (Nelen, 2009). All recommendations were resulted from consensus within the GDG and were submitted to an extensive transparent review by relevant stakeholders.

During the development of this guideline, it became clear that the evidence available to fully answer many key questions was either non-existent, scarce or of low quality. Indeed, many issues could not be resolved based on the available literature. Of the 125 recommendations, 45 (36.0%) are based on high-quality evidence (grade A or B), 51 (40.8%) on moderate (grade C) and 29 (23.2%) formulated as a GPP based on expert opinion. Future projects should endeavour to perform high-quality research to address: (i) patient preferences about staff and clinic characteristics, and psychosocial components; (ii) the impact of staff and clinic characteristics and psychosocial care on patient well-being; (iii) the needs of patients before, during and especially after fertility treatment; (iv) development, validation and process evaluation of psychosocial interventions that can be delivered by staff or self-administered by patients (e.g. provision of information, supporting patients after unsuccessful treatment, anxiety management during the 2-week waiting period, etc.); (v) the needs of patients undergoing first-line treatments; (vi) the needs of men undergoing treatment; (vii) the influence of ethnic, religious, societal and cultural factors on the needs of patients; (viii) how to identify patients at risk of non-compliance with recommended treatment and at risk of maladjustment after unsuccessful treatment.

Beyond the recommendations listed in the previous sections, four main conclusions can be taken from the evidence reviewed in this guideline. First, patients have clear preferences about the care they receive. Fertility staff should know these preferences and incorporate them in service delivery. Second, fertility staff must inform themselves of the specific needs patients experience at different treatment stages and tailor psychosocial care accordingly. Third, some patients are more vulnerable to the demands of treatment and need additional psychosocial care or specialized mental-health services (i.e. infertility counselling or psychotherapy). Fertility staff must be informed about risk factors for increased psychosocial needs and should consider using the SCREENIVF before the start of fertility treatment to identify patients at risk of developing emotional problems. Finally, the most effective way to start implementing psychosocial care is by providing preparatory information because it is expected to be simpler and more feasible to implement compared with other reviewed interventions and shown to be efficacious in addressing many patient needs.

Supplementary data

Supplementary data are available at <http://humrep.oxfordjournals.org/>.

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Authors' roles

S.G. chaired the GDG and hence fulfilled a leading role in collecting the evidence, writing the manuscript and dealing with reviewer comments. N.V., as methodological expert, performed all literature searches for the guideline, provided methodological support and was overall coordinator of the guideline production. All other authors, listed in alphabetical order, as guideline group members, contributed equally to the manuscript, by drafting key questions, synthesizing evidence, writing the different parts of the guideline and discussing recommendations until consensus within the group was reached.

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Conflict of interest

S.G., E.D., C.d.K., M.E., U.V.d.B., C.L.-J. and N.V. report no conflicts of interest. J.B. reports grants from Merck & Co, consulting fees from Merck Serono S.A. and Speaker's fees from Merck Serono S.A. P.T. reports consulting fees from the German government and being the Chair of the German Society for Fertility Counselling. C.V. reports consulting fees from Merck Serono S.A. C.M.V. reports being adviser in projects for Merck Serono S.A. and Ferring S.A. on patient educational material. T.W. reports speaker's fees from Repromed, DGPM, Breitbart, DAAG, fiore, LPTW, MSD, salary/position funding at TAB-beim-Bundestag, BZgA and being the Vice-chair of the German Society for Fertility Counselling.

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This section compiles a list of available tools that all fertility staff can use to assess the needs of patients before, during and after fertility treatment. These tools were either developed specifically for assessing patients facing infertility (i.e. fertility-specific) or are generic tools that are applicable to infertile patients. Although not necessary, fertility staff may consider asking mental health professionals for support in the interpretation of the data obtained by using the tools.

Tool	Fertility specific	Need(s) assessed					Reference/link
		Behavioural	Relational and social	Emotional	Cognitive	Other	
Beck Depression Inventory (BDI)	No			✓			(Beck and Beamesderfer, 1976)
Concerns of Women Undergoing Assisted Reproductive Technologies (CART)	Yes				✓		(Klonoff-Cohen <i>et al.</i> , 2007)
Cardiff Fertility Knowledge Scale (CFKS)	Yes				✓		(Bunting <i>et al.</i> , 2013) www.fertilityknowledge.com
Fertility Quality of life (FertiQoL)	Yes	✓	✓	✓		Quality of treatment	(Boivin <i>et al.</i> , 2011) www.fertiqol.com
Fertility Status Awareness Scale (FertiSTAT)	Yes	✓					(Bunting and Boivin, 2010) www.fertistat.com
General Health Questionnaire (GHQ)	No			✓			(Goldberg, 1978)
Hospital Anxiety and Depression Scale (HADS)	No			✓			(Zigmond and Snaith, 1983)
Mental Health Inventory-5 (MHI-5)	No			✓			(Florian and Drory, 1990)
Patient-centred care questionnaire (PCQ)	Yes					Experiences of patient-centeredness	(van Empel <i>et al.</i> , 2010)
Quality of care from patient perspective—specific to IVF treatment (QPP-IVF)	Yes					Quality of care	(Holter <i>et al.</i> , 2014)
SCREENIVF	Yes		✓	✓	✓		(Verhaak <i>et al.</i> , 2010)
World Health Organization Quality of Life Tool (WHOQOL-BREF)	No			✓			(Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group, 1998)

✓ Indicates that the tool can be used to assess this need.

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