Version 01. Feb. 2022

EUROPEAN
FERTILITY
SOCIETY

Fertility Patients Care Guidance

EFS Fertility Patients Care Guidance Development Group

The European Fertility Society is an evidence based society that gives tools, support and education to patients and fertility clinics.

www.europeanfertilitysociety.com

The European Fertility Society C.I.C.
2 Lambseth Street, Eye, England, IP23 7AG
Email: info@europeanfertilitysociety.com

Follow us!

FERTILITY PATIENTS CARE GUIDANCE

Authors

Giuliana Baccino, Sarah Banks,
Andrew Coutts, Bola Grace, Sandra Greenbank,
Karin Hammarberg, Dimitris Kavakas,
Veronica Montgomery, Olivia Montuschi,
Julie Morgan, Mandy Rodrigues,
Stephanie Toulemonde, Andreia Trigo,
Ana Oliveira Pereira, Karenna Woods,
Jakub Dejewski.

With the collaboration of:

www.temos-worldwide.com
www.prideangel.com
www.masola.org

EFS
EUROPEAN
FERTILITY
SOCIETY

Table of Contents

EFS | EUROPEAN FERTILITY SOCIETY

Introduction

Foreword

It has been almost half a century since Sir Robert Edwards and his team performed the first successful in vitro fertilization (IVF) procedure. Successive generations of scientists and researchers, clinicians and embryologists have made this method widely used and brought the joy of parenthood to people around the world. In Europe alone, nearly 1 million treatment cycles were performed in 2017. However, despite the tremendous progress in this field of medicine, the road to fertility is still often winding, painful and long.

The European Fertility Society was created to support fertility patients by making their fertility journey more friendly and care-based. However, helping patients would not be possible without fertility clinics' development. That's why The European Fertility Society supports fertility clinics through teaching and training its health and patient care staff, setting patient care guidance, recommendations and certification of their processes.

Fertility Patients Care Guidance is a practical tool for fertility clinics that not only presents knowledge but also provides practical guidelines for use in daily practice at every level of management. The responsibility of the European Fertility Society does not end with the publication of this document. We regard it as a foundation of support for clinics and their medical and non-medical staff. Based on the standards and practices it contains, the European Fertility Society offers training and webinars to develop and effectively implement good practice in patient care. We do it because we want all patients' fertility journeys to be the best possible. We care.

— Jakub Dejewski
Chairman
EFS

Introduction

Fertility patients need specific, dedicated care. Regardless of whether or not they are infertile, all of them are pursuing the same goal = to become parents sooner rather than later, with the support of fertility professionals and state-of-the-art technology to make it happen.

Unlike decades ago when only health professionals had the opportunity to produce and disclose information to patients, nowadays information is available everywhere. Patients are eager to be involved in their treatment and in every decision-making process alongside a sensitive, dedicated fertility team.

Patients compare clinics and discuss their treatment with others. They expect more than a good outcome. Indeed, they expect to have a positive experience throughout their fertility journey.

The European Fertility Society therefore decided to produce a unique and practical patient care guide to improve the overall treatment experience for patients and reduce stress and treatment drop-out at the same time.

A group of experts and former fertility patients from different continents produced and oversaw two versions of the guide - a short version with highlights and recommendations, and an extended version corroborated by evidence-based literature.

At the European Fertility Society we are convinced that if this guide is correctly implemented by clinics, patient satisfaction will substantially increase. This will bring added value to the daily practice adopted by clinics to improve patients' lives.

— Giuliana Baccino, PhD
Coordinator of the Guidance Development Group

Chapter 1

The value of care

Karin Hammarberg
Andrew Coutts
Mandy Rodrigues

Abstract

Patient-centred care is respectful of and responsive to the preferences, needs and values of patients and those supporting them. The widely accepted dimensions of such care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care. This chapter will describe what patient-centred care means in the context of ART (Assisted Reproductive Technology), how it can be implemented and monitored, and the value of it for patients, staff and the clinic. Central to patient-centred care is access to transparent and evidence-based information at all stages of treatment. This chapter will also investigate how clinics can meet patients' information needs.

Introduction

In the context of assisted reproductive technology, person-centred care is care which, regardless of treatment outcome, leaves everyone feeling that they were given the best chance to have a baby whilst experiencing the best possible care.

Optimal patient-centred care should also account for the unique challenges faced by those who are infertile, including the impact of infertility on relationships, the financial costs of treatment, and the grief associated with failed cycles and decisions to end treatment without a child.

In this chapter we will discuss the value of patient-centred care in ART and how it can be measured and monitored to ensure that it meets patients' needs. Not only will be present evidence of the merits of good patient care, but we will also show how it adds value to staff and clinics' bottom line per se. Last but not least, we will discuss the importance of providing accessible and evidence-based information on all aspects of ART to patients before and during their IVF journey.

1.1

The importance of a patient care system in ART

Patient-centred care is a complex and constantly evolving concept. It is highly subjective and measurement thereof has been fiercely debated since its origins in the 1960s when the term 'person-centred' was first used in the field of psychotherapy. It remains a concept which lacks a universally agreed definition as it depends on the needs and experiences of the person receiving care, the environment in which it is given, and the individuals charged with its delivery. A number of dimensions or principles of 'patient-centred care' have been offered and these are considered and applied to the unique needs and challenges presented by patients in assisted reproductive technology settings in this chapter. Put simply, patient-centred care places the patient at the very centre of the care process. However, such an apparently simplistic concept continues to fuel academic and practitioner debate with the complexity of the relationship between patient and care provider being identified as a major obstacle in the development of a single, universally accepted definition.

Patient-centred care is far easier to define for the recipient. Regardless of why we are receiving care and in whatever context, we want to be looked after, treated with respect, supported where necessary, and cured where possible. The definition of patient-centred care from a provider's perspective appears to be more contentious, however, as its meaning may vary from one provider to the next, and from one environment to another (1). For instance, a doctor undertaking a one-off face-to-face consultation with a patient may consider patient-centred care in an entirely different light than a nurse delivering care to a ward-based patient over a significant period of time. Despite the absence of a universally agreed definition, there is no doubt that patient-centred care is something that providers should strive for and attempt to deliver in the most appropriate form for the person in their care. It has become an internationally recognised and accepted goal for all healthcare providers (2).

Principles of patient-centred care

Patient-centred care plays a central role in ensuring that the emotional and physical needs of the fertility patient are identified and satisfied. While the ultimate aim of ART is to offer the patient effective and successful treatment, the quality of fertility care is far more than the efficacy of one treatment or another. Patient-centred care encompasses a number of principles which, taken together, can enhance the patient experience as well as potentially contribute towards treatment efficacy.

The Picker Institute, an international not-for-profit organisation, which promotes a patient-centred approach in the delivery of health and social care, has developed a useful framework which identifies eight dimensions or principles of patient-centeredness. The dimensions illustrate the elements required for optimal patient-centred care.

- Access to care (includes physical access, waiting times, and transport)
- Respect for patients' values and needs (includes the patient's active involvement in decision-making, where possible)
- Coordination and integration of care (includes front line and support care)
- Information, communication and education (includes details of clinical aspects of care such as prognosis and treatment)
- Physical comfort (includes pain management and help with daily needs)
- Emotional support and alleviation of fear and anxiety (includes that related to clinical aspects)
- Partner involvement (includes supporting partners and ensuring that they are involved in the care process)
- Continuity and transition (involves care, treatment and support after discharge)

Patient-centeredness in the fertility care setting

Parenthood is viewed in all societies as a rite of passage - the moment when we leave an indelible mark on the world by passing our genes on to the next generation. It is a moment promoted and reinforced by societal norms advocating that parenthood is the pinnacle for which we all should strive. However, for an increasing number of people this gold standard of achievement is often difficult, and sometimes impossible to attain.

For the 10% to 15% of us of reproductive age who struggle with infertility, the inability to achieve this 'natural' process is often associated with feelings of depression, anxiety, anger, frustration and isolation which invariably negatively affect our relationships, wellbeing and self-worth. Infertility is so much more than the physical inability to achieve conception at a drop of a hat. Indeed, the link between infertility and a multitude of negative emotional and psychological issues cannot be understated (3-5).

In the context of fertility care and treatment, person-centred care must therefore appreciate the highly specific physical and psychological needs of the fertility patient. It must not narrowly treat the physical condition without an awareness of the influence that infertility can have on relationships, the financial impact of treatment costs, the grief associated with unsuccessful treatment and the utter devastation that the decision to stop treatment without a child has on the patient(s).

One of the most wide-ranging pieces of research into the experiences of fertility patients was undertaken in 2014 (6). The research, which involved nearly 400 patients, highlighted a number of specific needs and desires identified by the patients themselves and showed an apparent gap between these and the assumptions held by treatment providers. These included:

- When searching for fertility care, patients valued the physicians' attitude most of all, followed by success rates, distance from home to the fertility centre, physician continuity throughout the treatment period and type of fertility centre.
- Fertility care providers, on the other hand, considered success rates (effectiveness) to be the most important factor when recommending a fertility centre.
- Fertility patients and care providers had significantly different views on the value of treatment effectiveness, physician attitude and physician continuity.
- Fertility care providers in the study significantly underestimated the importance of patient-centeredness to fertility patients.
- To deliver optimal care to fertility patients, care providers need to understand the importance of patient-centred care, such as a friendly attitude, sympathy for the patients' plight, respect for the patients' right to informed consent and a transparent treatment process.

Implementing patient-centeredness in fertility care

It is important that patient-centred care co-exists with clinical effectiveness if it is to successfully contribute to improving the quality of healthcare. It must be delivered in a measurable way to ensure that both positive and negative aspects of care are identified. The information can then be used to modify or improve the service provided to patients.

Patient-centred care is reliant on health care professionals being able to distinguish between the 'disease', the ultimate labelling of the process embodying symptoms, diagnosis and treatment, and 'illness' which captures the patient 'experience' including their general wellbeing and lifestyle. When healthcare practitioners understand how both interact and affect the patient, they can implement measures to address the disease and the patient's experience of illness and patient-centred care (7).

It follows that, when healthcare staff acknowledge and accept the patient in terms of both the disease and illness, they can begin to encourage and support the patient to actively participate and engage in each stage of their healthcare, which is a key component of patient-centred care (8). By empowering the patient and increasing both their understanding and confidence in the care and treatment process, healthcare staff can effectively contribute to the enhancement of patient satisfaction, quality of care given and potentially, to improvements in treatment efficacy (9). Distinguishing between the disease and illness, and planning a patient-centred care strategy is not as straightforward as it might seem. There is mounting evidence to suggest that different patient groups respond to patient-centred interventions in different ways on their treatment pathway. For instance, it has been suggested that patients are less likely to engage in decision-making and communication with healthcare staff as their condition becomes more severe. Patient-centred care strategies therefore need to be flexible and tailored to individual patients and put in practice by staff trained in providing a level of care which supports the physical and emotional needs of each patient.

As summarised by Jayadevappa and Chhatre, "The patient-centred care model that integrates mutually beneficial partnerships among healthcare providers, patients and families has profound implications for the planning, delivery, and evaluation of care." (10). This is borne out by a review of evidence considering the link between patient experience and clinical effectiveness which identified consistent, positive associations between patient experience and safety and clinical effectiveness when patient-centred care is employed within the healthcare setting (11).

Whilst there is no doubt that there is a strong correlation between patient-centred care strategies, patient satisfaction and clinical effectiveness, the absence of a universally agreed definition has meant that care providers have employed such strategies in different ways. Nevertheless, regardless of how it is implemented, at its core, patient-centred care involves multi-layers of relationships including those between patient and physician; patient and nurse and patient and non-nursing support staff. It is a process that should be employed flexibly and designed to accommodate specific environments or patient groups. It is a process that should be devised jointly between patient and provider, ensuring it is receptive, realistic and effective.

Monitoring patient-centeredness

Patient feedback is essential to allow clinics to continuously strive to improve care and ensure it is patient-centred. Patient-reported experience measures (PREMs) are questionnaires that assess patients' experiences whilst receiving care and are indicators of quality of care (12). They can be used to monitor the quality of care from the patient's perspective. Relational PREMs assess patients' experiences of their encounters with staff during treatment while functional PREMs gauge their perceptions of more practical issues, such as the quality of the clinic's facilities. PREMs can be administered online and completed anonymously. They help clinics to monitor the standard of care and to take steps to improve care where needed.

1.2
Benefits of patient-centred care for patients, staff and clinic

When applied systematically, patient-centred care offers significant benefits to patients, staff and the clinic.

Benefits for patients

There is strong evidence that patient-centred care has direct benefits on patients' wellbeing and that continuity of care reduces treatment concerns and improves treatment tolerability (13). While a live birth is the goal of ART, the reality is that most cycles fail. Multiple attempts are often needed to improve the chance of success. However, ART is stressful and the psychological burden of treatment is one of the most commonly cited reasons for stopping treatment (14). Taken overall, evidence shows that a patient-centred approach in fertility care settings can:

- increase patient satisfaction and emotional wellbeing
- enhance patient self-care
- improve patient understanding of and compliance with treatment protocols; and
- increase the likelihood of patients continuing treatment until a viable pregnancy is achieved, which in turn leads to higher cumulative live birth rates.

Benefits for staff

Decreasing the stress of treatment not only has a positive impact on patients but is also likely to improve staff wellbeing, job satisfaction, engagement and retention. To achieve these benefits for patients and staff, clinics need to develop a patient-centeredness implementation plan with the following key elements.

- The increasing complexity of ART requires a highly specialised workforce. Patients expect fertility staff to be knowledgeable, trustworthy, empathetic and supportive. They value good relationships with fertility clinic staff who display the appropriate attitude(15). All fertility clinic staff require comprehensive training in all aspects of ART including the medical and psychological aspects as well as communication skills in order to meet patients' needs. Staff also require ongoing training, education and support to fine tune the skills and resources they need to deliver high quality person-centred care.
- Staff-patient ratios need to allow staff sufficient time to meet the information and support needs of individual patients.
- The physical environment should be comfortable and allow privacy for staff-patient interaction.
- The IT system must give staff immediate access to up-to-date information about the progress of individual patient's treatment so that they can respond to any treatment-related questions.
- Regular patient experience questionnaires, robust patient feedback and a clear complaints process allow staff to continuously review and improve their care.

Benefits for the clinic

In today's competitive environment, there are clear benefits for clinics that implement patient-centred care. Drop-out rates decrease if patients are well supported and assisted in managing the emotional challenges of ART. This, in turn, means that they undergo more treatment cycles, which improves their chances of having a baby and the clinic's bottom-line and cumulative success rate. Patients who have a positive care experience will recommend the clinic to others. Conversely, patients who have a negative care experience will advise others to avoid the clinic in question. The power of social media to endorse or criticise clinics should not be underestimated.

The value of a patient-friendly physical environment

A welcoming and comfortable physical environment enhances patients' overall experience of care. The clinic environment should be appropriate for everyone who attends. While fertility clinics are all about helping people to have babies, a significant number of outcomes are unsuccessful. Patients who have experienced many failed cycles may find it distressing to see pictures of babies on display in clinics. Non-heterosexual individuals and couples appreciate diverse patient groups being visually represented and included in images displayed in a clinic setting or on clinic websites.

Patients also highlight the importance of ensuring privacy. Patients report that it can be physically and emotionally uncomfortable to be asked to remove clothing only to then wait a long time for treatment to commence, particularly if there are inadequate measures in place to protect their privacy. Given the sensitivities involved in treatment, privacy should also be ensured in all conversations between patients and clinic staff, particularly when conveying bad news. Discussions about the outcome of egg collections should be handled sensitively and with regard to the privacy of patients, noting that it can be disturbing for patients to overhear details of the outcome of other women's egg collections.

The same applies to conversations regarding the number or quality of embryos available for transfer. Patients report that privacy can also be an issue when they are called without warning at work or in other public places where they are not able to comfortably talk about their treatment or process news relating to adverse outcomes.

Comfortable, private spaces should be available for face-to-face staff-patient interactions. If staff communicate with patients by telephone, they need to ensure that the timing is convenient for the patient and that they have privacy during the conversation.

1.3
Informing patients

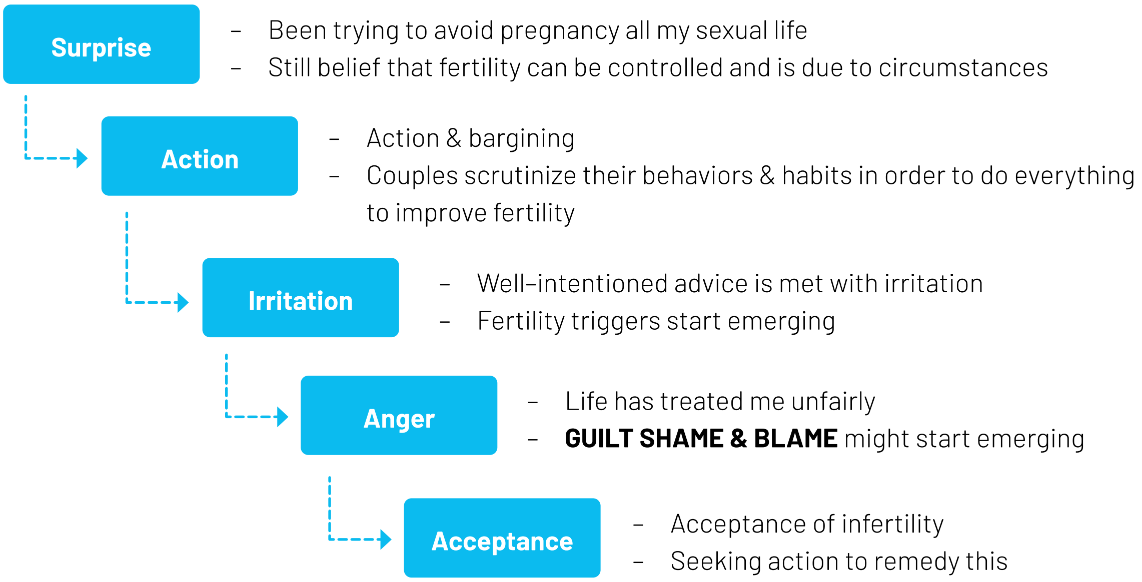
Sources of information accessed by patients before seeking fertility care

Even before visiting a fertility clinic, patients have often researched extensively about reproduction and their inability to conceive. Given the prevalence and ease of access to electronic media including search engines that can access all types of information, and in more recent years, social media such as Facebook, LinkedIn and Twitter, people are often overwhelmed with information. Patients report reading posts and bulletin boards as well as joining online support groups which are not moderated by a health professional. These sources of information are not always trustworthy and the information they provide may not be accurate or scientific. On the basis of information patients have gathered from potentially unreliable sources, physicians report feeling questioned and challenged by patients about the processes and medication regimes they suggest. To counter misinformation, it is important that clinic websites provide comprehensive, user-friendly and evidence-based information. Patients who visit the website should be able to access information about the credentials of the people who work at the clinic, the available treatment options and what they entail, evidence about the risks and benefits of the treatment options offered, age-specific success rates, cost of treatments, and what patients can do to improve their chance of success. We will explore this topic in greater detail in chapter 4.

The psychological impact of infertility

The infertility journey leaves patients feeling helpless and with no control. The figure shows the stages couples may have already been through by the time they present for the first visit.

Figure:
Couples scrutinise their behaviours



Surprise
- Been trying to avoid pregnancy all my sexual life
- Still belief that fertility can be controlled and is due to circumstances

Action
- Action & bargining
- Couples scrutinize their behaviors & habits in order to do everything to improve fertility

Irritation
- Well-intentioned advice is met with irritation
- Fertility triggers start emerging

Anger
- Life has treated me unfairly
- **GUILT SHAME & BLAME** might start emerging

Acceptance
- Acceptance of infertility
- Seeking action to remedy this

Studies have reported that 40% of patients visiting a fertility clinic for the first time have clinically significant symptoms of anxiety and/or depression (16). Once receiving treatment, even more women and men experience depression and anxiety. This speaks volumes about the psychological impact of unsuccessful attempts to conceive, and how distressed people may be even before they seek medical treatment (17).

In light of this, it is essential that the fertility specialist and the multidisciplinary team display empathy, kindness and support throughout the treatment process. If patients are to make informed decisions, they also need accessible, accurate information about treatment options, the risks and benefits of those options, and their personal chance of success based on their individual circumstances.

What patients want to know before starting treatment

Patients prefer a stepped approach to treatment with the least invasive options explored first. They want a clear roadmap of the scheduled treatment so that they are aware of the overall plan, and what options they have if the treatment is unsuccessful. Patients also want detailed information about the administration of medication, possible side-effects, and who to contact if they have questions. Financial stress can add to the emotional strain experienced by patients. It is therefore imperative to give them detailed and transparent information about anticipated treatment costs to help them manage the financial planning.

Patients report feeling overwhelmed with information when they first attend clinics and appreciate information being broken down and communicated in different ways. Allowing enough time in consultations and making educational materials readily available in a wide range of formats such as brochures, illustrated guides, diagrams, flowcharts, and audio and video tools will help patients to absorb the complexities of ART. Both written and verbal information is needed to help patients manage treatment and make the best possible decisions for themselves.

The information provided should at least include:

- the available treatment options
- the likely prospects of success, considering the patient’s individual circumstances
- the likelihood that multiple cycles may be needed to achieve a pregnancy
- comprehensive information about the full cost of treatment
- the evidence supporting any add-ons available
- possible risks associated with treatment procedures
- point of contact for any questions during treatment
- how to provide feedback or make a complaint; and
- how to access support.

It is also important to give patients the opportunity to clarify information following their consultation without incurring additional costs, for example, if a staff member makes a follow-up call to resolve any questions which may arise.

Information and support after a treatment cycle

Patients report that the most difficult part of ART treatment is the wait after embryo transfer to find out whether the treatment has worked. It is vital to ensure that patients know who to contact if they have any questions or concerns during this time. Clinics should also offer patients emotional support at key stages of the treatment cycle and proactively check-in after adverse outcomes or when ending treatment. If the treatment is unsuccessful, patients should be offered the opportunity to discuss the outcome and ask any questions they may have. They should also be informed about available counselling services and how to access these if required. If a pregnancy has been achieved, patients should be offered pregnancy-related health information and a referral for pregnancy care.

Using technology to enhance access to information and support

New technologies can be used to complement verbal and written information. This topic will be explored in greater detail in chapters 4 and 5. Here is a typical example to start the ball rolling. If clinics offer patients the opportunity to access and communicate with clinic staff online, this may help those who have questions about their treatment. In their analysis of the exchanges that occurred in one such forum, Aarts *et al*. reported that the most frequently asked questions related to medication, factors associated with treatment success, and practical matters. The most common reason for asking questions online was that the patient had forgotten to ask these questions during their face-to-face visit. Almost all patients reported that the health professional had understood their question and had provided complete and reassuring responses (18). Electronic communication can also facilitate patient-provider communication and information sharing. A survey among fertility patients in the US showed that almost all were comfortable communicating electronically with the clinic and very few had privacy concerns that prevented them from communicating electronically with their physician (19).

Technology can also be used to enhance emotional support. An evaluation of a cognitive behaviour coaching programme for women and men undergoing fertility treatment found that it significantly reduced levels of depression in clinically distressed and depressed patients (20). Another study of the impact of a brief online education and support programme for female infertility patients reported that women in the intervention group felt significantly more informed about the medical decisions they made and had fewer infertility-related social concerns than women in the control group (21).

The Covid-19 pandemic has accelerated the need for and use of technology to provide medical information and psychological support and to help patients navigate treatment. Information packs and virtual resources can be made available which allow patients to maintain anonymity yet receive support and relevant information from a variety of sources.

Catering for individual needs

Developments in ART mean that individuals or couples can contemplate or undergo ART procedures for a wide range of reasons. People from the following groups should be offered information tailored to their specific needs and circumstances:

- donors and surrogates
- people with diverse sexualities and genders
- single women
- same-sex couples
- people from a diversity of cultural, religious, ethnic and linguistic backgrounds
- women freezing their eggs for subsequent use
- people preserving fertility before cancer treatment
- partners and carers.

Conclusion

In the context of assisted reproductive technology , person-centred care is care which, regardless of treatment outcome, leaves everyone feeling that they were given the best chance. Person-centred care is essential to ensure that the emotional and physical needs of fertility patients are identified and satisfied. Person-centred care must be delivered in a measurable way to ensure that both positive and negative aspects of care are identified. The information acquired should be used to modify or improve the service provided to patients. Patient-reported experience measures (PREMs) can be used to monitor quality of care from the patient's perspective. They can be administered online and completed anonymously, and help clinics monitor the standard of care delivered and to take steps to improve care where needed.

There is strong evidence that patient-centred care has direct benefits on patients' wellbeing and that continuity of care reduces treatment concerns and improves treatment tolerability. Decreasing treatment-related stress not only has a positive impact on patients but is also likely to improve staff wellbeing, job satisfaction, engagement and retention. Drop-out rates decrease if patients are well supported which means that they have more cycles. This improves their chance of having a baby and the clinic's bottom-line and cumulative success rate.

Patients want a clear roadmap of the scheduled treatment, so that they are aware of the overall plan, and what options they have if the treatment is unsuccessful. Patients also want detailed, transparent information about anticipated costs, the likely prospects of success considering their circumstances, administration of medication, possible side-effects, point of contact if they have questions, and how to access psychological support. Information and support should be tailored to the specific needs of individuals or couples including infertile heterosexual couples, same-sex couples, donors and surrogates, people with diverse sexualities and genders, single women, people from different cultural, religious, ethnic, and linguistic backgrounds, women freezing their eggs for subsequent use, people preserving fertility before cancer treatment, and partners and carers.

Recommendations

- ART clinics should implement person-centred care and embed it in all their systems as evidence shows that it benefits patients, staff and the financial success of the clinic in question.
- Clinics should assess patients' experiences of care on a regular basis and use the information to monitor the standard of care and improve care where needed.
- Clinics should ensure that patients have access to transparent, evidence-based information on all aspects of treatment at every stage of the process and in a range of formats.
- Information should be tailored to the specific needs and circumstances of the wide range of people who access ART.

References

1. Mead, N. and Bower, P. *Patient-centredness: a conceptual framework and review of the empirical literature.* Soc Sci Med, 2000. 51(7): p. 1087-110.
2. World Health, O., *The World health report: 2000: Health systems: improving performance.* 2000, Geneva: World Health Organisation.
3. van Empel, I., et al., *Weaknesses, strengths and needs in fertility care according to patients.* Human Reproduction 2010. 25(1): p. 142-149.
4. Lynch, C.D., et al., *Are increased levels of self-reported psychosocial stress, anxiety and depression associated with fecundity?* Fertility and Sterility, 2012. 98(2): p. 453-458.
5. Rooney, K.L. and Domar, A.D., *The relationship between stress and infertility.* Dialogues in clinical neuroscience, 2018. 20(1): p. 41-47.
6. Cai, Q.F., et al., *Fertility clinicians and infertile patients in China have different preferences in fertility care.* Human Reproduction, 2014. 29(4): p. 712-719.
7. Morris, K., *Cole's Medical Practice in New Zealand.* 2017, Medical Council of New Zealand: https://www.mcnz.org.nz/assets/standards/da3a9995b9/Coles-Medical-Practice-in-New-Zealand.pdf
8. Tobiano, G., et al., *Patient participation in nursing care on medical wards: An integrative review.* Int J Nurs Stud, 2015. 52(6): p. 1107-20.
9. Vahdat, S., et al., *Patient involvement in health care decision-making: a review.* Iranian Red Crescent medical journal, 2014. 16(1): p. e12454-e12454.
10. Jayadevappa, R. and Chhatre S., *Patient Centered Care - A Conceptual Model and Review of the State of the Art.* The Open Health Services and Policy Journal, 2011. 4: p. 15-25.
11. Doyle, C., Lennox, L. and Bell, D., *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness.* BMJ Open, 2013. 3(1): p. e001570.
12. Kingsley, C. and Patel, S., *Patient-reported outcome measures and patient-reported experience measures.* BJA Education, 2017. 17(4): p. 137-144.
13. Gameiro, S., Canavarro, M.C. and Boivin, J., *Patient-centred care in infertility health care: direct and indirect associations with wellbeing during treatment.* Patient Educ Couns, 2013. 93(3): p. 646-54.
14. Domar, A., *Patient Retention, Nursing Retention: The Importance of Empathic Communication and Nursing Support*, in *Patient-Centred Assisted Reproduction* Domar, A., Sakkas, D. and Toth, T.L. Editors. 2020.
15. Dancet, E.A.F., et al., *The patients' perspective on fertility care: a systematic review.* Human Reproduction Update, 2010. 16(5): p. 467-487.

16. Chen, T.-H., et al., *Prevalence of depressive and anxiety disorders in an assisted reproductive technique clinic.* Human Reproduction, 2004. 19(10): p. 2313-2318.
17. Greil, A., Slauson-Blevins, K. and McQuillan, J. *The experience of infertility: a review of recent literature.* Sociology of Health & Illness, 2010. 32(1): p. 140-162.
18. Aarts, J.W., et al., *Communication at an online infertility expert forum: provider responses to patients' emotional and informational cues.* Journal of Psychosomatic Obstetrics and Gynaecology, 2015. 36(2): p. 66-74.
19. Broughton, D.E., et al., *Social media in the REI clinic: what do patients want?* Journal of Assisted Reproduction and Genetics, 2018. 15(10): p. 018-1189.
20. Haemmerli, K., Znoj, H. and Berger, T., *Internet-based support for infertile patients: a randomized controlled study.* Journal of Behavioral Medicine, 2010. 33(2): p. 135-146.
21. Cousineau, T.M., et al., *Online psychoeducational support for infertile women: a randomized controlled trial.* Human Reproduction, 2008. 23(3): p. 554-66.

Chapter 2

Informing and preventing

Ana Oliveira Pereira
Bola Grace
Sandra Greenbank

Introduction

In this chapter we focus on the importance of knowledge and prevention. We will explore different aspects such as how to inform patients correctly about the fertility treatment they are receiving, fertility awareness, nutrition, and the need to better engage men in fertility discussions.

Informing patients about our recommendations at every stage in their journey is crucial for patients and fertility staff alike. The manner in which we inform them will govern the support we give our patients. It will also show them just how much we care. Fertility awareness is also vital for patients as it encompasses individual and non-individual risk factors, as well as the awareness of sociocultural needs. This chapter will then focus on information trends, delayed childbearing, low fertility awareness among people of reproductive age and on concerted efforts to improve knowledge. Clinics will be given evidence-based recommendations on how to support patients on initial presentation. This chapter also summarises the importance of increased fertility awareness for patients with specific health conditions, such as cancer. We also explore the need to better engage men in fertility discussions. There is a disproportionately high focus on women since fertility is often perceived to be a 'female health issue'. In addition, we discuss the importance of training for clinic staff as evidence has highlighted poor fertility awareness among healthcare professionals per se.

Nutrition is an important factor in the fertility process. It should be stressed that a healthy, balanced diet is key to maintaining good overall health. In this section, we provide clear recommendations for fertility clinics, emphasising the importance of discussing dietary and lifestyle advice with patients.

2.1
How to deliver information on fertility treatment

Personal beliefs and cultural practices are central to our patients' lives. Fertility staff also have their own personal values that may affect their daily practice. Some of them may be prejudiced against different group populations or specific treatments such as same sex couples, singles or surrogacy. Fertility staff should recognise these situations and openly discuss at weekly meetings how these personal beliefs can influence their provision of care (1).

Staff involved in patient care (doctors, embryologists, nurses, psychologists and assistants) must recognise that each patient has a unique background such as country of origin, language, ethnicity, personal and religious beliefs as well as sexual orientation. This background will also shape their decisions about a certain treatment or medical procedure (2, 3, 4).

For example, some couples will not agree to gynaecological examination by a male doctor. In certain ethnic and Muslim patient groups in particular, masturbation is prohibited or viewed as a sexual activity to be followed by a bath. Men's disengagement from treatment may reflect their discomfort with sperm collection, misunderstanding of the procedures or fear of being diagnosed as infertile (5). In these situations, a male or female team member should ask the man and woman about any constraints relating to these issues in order to resolve the situation by adopting a flexible approach and adjusting protocols, as necessary.

Staff must also consider patients' prior knowledge and experience relating to infertility diagnosis, fertility treatments and medical language. It should be noted that some patients will be encountering fertility issues for the first time and may be overwhelmed by the medical and legal jargon used. Some biological concepts may well be unfamiliar to even well-educated individuals. For instance, not everyone will understand what is meant by gamete donation and genetic inheritance (6). Doctors and other healthcare professionals must carefully establish whether the treatments proposed have been fully understood. Explanations must be provided and Informed Consent should be discussed clearly and succinctly(7)(8).

Evidence demonstrates that effective staff-patient relationships and communication are commensurate with greater patient satisfaction, treatment compliance and outcome realisation. Dissatisfaction in terms of communication and the manner in which information is provided may lead to patient drop-outs or a change of clinic. Team training could be delivered through specialist services, role-playing, couple satisfaction surveys and discussions with couples who have undergone fertility treatment in the past, amongst other things (9).

Supportive doctor-patient communication involves establishing a good relationship even with "difficult patients" (who may be angry, demanding, depressed or anxious). This will include collecting relevant information, understanding the patient's perspective, assisting in the decision-making process and respecting the patients' feelings, wishes and expectations. A key challenge for clinicians is understanding that, in many cases, the patient is a couple who often have different feelings, opinions and desires to be reconciled (10) .

Some studies show important aspects of the 'information, communication and education' dimension identified by patients. The latter expect and want sufficient time to discuss their individual case with the fertility clinic staff. They are looking not only for clear guidance but also a shared decision. They appreciate written information about treatment options that could help them become parents. The emotional aspects of treatment should also be discussed along with how to cope with the burden of ART. Patients want to receive both general and specific information related to their diagnosis. "Too much information kills the information" – "information overkill!" (11). Patients in drop-out studies have mentioned lack of empathy and negative interactions with staff or insufficient care for the male in the partnership as key factors in their decision to discontinue treatment (12)(13).

Both similar and different issues are at stake when patients travel abroad for treatment. Indeed, cross-border similarities exist in terms of the patients' perspective of important care issues. The same human factors come to the fore in the different countries. In order of importance, these are 'relationships with staff', 'communication', 'patient involvement and privacy' and 'emotional support' (14).

However specific concerns may arise. It may be difficult to ensure appropriate consent when there is no common language. One option is to translate the written information into a well-known language and provide counselling and psychological support in a language understood by patients (15).

The legislation of the country of origin must be taken into account in order to avoid legal problems in the future. For certain treatments (gamete donation, same sex couples, surrogacy, singles) legal advice should be sought in the country of origin.
Patients undergoing infertility treatment or ART sometimes have to be given bad news, whether in the context of diagnosis, poor prognosis or treatment failure. Staff members involved in this process should develop skills on how to interact and communicate negative results in a more sensitive and caring manner, adopting specific protocols that meet patient approval (16).

Patients should be explicitly informed of success rates and of the likely need to repeat treatments. Several studies highlight the patients' determination and commitment to undergo the necessary treatments to achieve pregnancy. If treatment proves unsuccessful, they consider giving up, due to the emotional impact of what they deem to constitute failure. However, there is strong evidence that success depends on more than one complete cycle of treatment including the transfer of frozen embryos. Therefore, the treatment plan discussed with patients should be based on the possibility of multiple cycles, and doctor and patient should discuss expectations of success based on this assumption (17).

Practice shows the importance of discussing potential parenthood, namely the number of children desired, the risk of twin pregnancies and the woman's age, etc. Doctors and patients should consider these aspects when deciding on treatment.

The psychosocial risk of twin pregnancies should be taken into account for single women. The success vs. burden of less social support must be discussed with the patient and reviewed before the final treatment decision is made(IAD or IVF) (18).

Doctors and embryologists should provide information on the importance of creating embryos for subsequent use during ART treatments in order to maximise the chances of having a child. However, strategies should also be put forward to limit the number of embryos to be created. Patients must have the opportunity to discuss the creation and use of embryos in depth, taking their personal, moral or religious convictions into consideration. Practice shows that many patients accept the creation of surplus embryos without giving sufficient thought to the future use of unused embryos. People tend to change their minds after IVF treatment and once their family is complete.

Decisions regarding the fate of unused embryos are difficult and emotionally distressing. This explains why people tend to postpone the decision for as long as the law or clinics allow. The available options should be discussed once the legal storage period has elapsed. If donating the embryos to medical research is a viable option, information on the various types of research may facilitate the decision-making process (19). If patients decide to donate the embryos, counselling is strongly advised in order to explore all the issues regarding the future welfare of donors, recipients and children (20). Clinics should take into account, as far as possible, patients' wishes on what to do with surplus embryos. Provided that there is no legal prohibition, clinics should facilitate "farewell" rituals or compassionate transfers (21).

Fertility professionals would benefit from learning about the physical and emotional responses to treatments. Numerous studies have shown that one of the main reasons why patients discontinue fertility treatments prematurely is because of the difficulty in dealing with the resulting emotional distress caused by an unsuccessful treatment or poor prognosis. Psychological symptoms associated with infertility are similar to those linked to other serious medical conditions. Patients are expected to feel high levels of stress, anxiety and depression if treatment proves unsuccessful (22).

In addition to information on procedures and success rates, patients should be guided on how to deal with the critical stages of the process – namely the waiting time for results and the delivery of results. They should be prepared for the high levels of stress expected between embryo transfer and the pregnancy test, as well as the deep shock and sadness associated with a negative result. Clinical practice shows that patients benefit from planning ahead for this period (23).

Patients should not be given results unexpectedly. The fertility staff need to decide when and how to deliver the results. "Allowing them to initiate the call or return to the office to receive the results in person may increase the couple's control and decrease their sense of powerlessness". Patients who received negative results could express greater dissatisfaction with the communication process. Some practices can minimise the impact of a negative outcome. Use different ways to inform patients (e.g., written materials versus verbal delivery). Individualising the way in which these results are communicated can minimise the emotional response and prevent patients from leaving the clinic. Implementing follow-up protocols, for example a telephone call from the doctor or nurse within 24-48 hours of receiving a negative result, can decrease the feeling of abandonment. The next step should be a care consultation during which the doctor could offer factual explanations, treatment alternatives, if appropriate, and encourage patients not to give up if they have a good chance to succeed (23), (24).

Clinical practice shows that a grieving period is expected after a negative result. This can last for at least 1 month. A break in treatment is sometimes desirable to allow individuals to rebalance and take stock of the situation. If distress persists, the individuals in question should be referred for psychological care (25). Many couples decide not to start or continue ART treatments, even against doctors' advice. The decision to discontinue treatment is mainly made by the couple, regardless of the cause of infertility (26).

Staff must be aware of the high drop-out rates and the factors that determine it, namely patients, clinic-related reasons and treatment type (nature, intensity and medical intrusiveness). Patients may sometimes discontinue treatment due to their own aversion to the treatment, such as treatment-related fear, especially second-line therapy, religious values or balancing success vs. the cost of treatment (27). However, a great deal of research has shown that patients give up fertility treatment prematurely due to psychological and emotional factors, especially in the case of those presenting psychological vulnerability such as previous depression or anxiety disorders (28).

Most patients have psychological resources to cope with the demands of treatment, even if they relate high levels of distress to specific stages of treatment. However, according to research into the risk of developing emotional problems, 20% of patients experienced significant distress. These persons are more likely to give up treatments and engage in unhealthy behaviour such as smoking, poor diet and alcohol consumption, etc. These patients should be identified well in advance in order to provide appropriate support (29).

Fertility staff must be informed about the specific psychological needs that patients experience at different stages during treatment. Doctors and nurses should be aware of the patients' emotional state and refer them for psychological support or counselling if necessary. Written information must be provided on the psychological support available throughout treatment. For patients of a different mother tongue, written material must be offered in their specific language (32).

Patients should be encouraged not to discontinue treatment whilst the prognosis remains favourable. However, statistical data show that after approximately the fifth unsuccessful treatment cycle, the chances of achieving pregnancy are very low. Patients in this situation should be supported in the decision-making process as the decision to stop treatment is very difficult. Patients expect their doctor to guide them throughout the entire treatment process, and rely on his or her expertise to advise them on their chances of success. Most patients will continue treatment unless their doctor clearly advises them to stop. Patients tend to foster unrealistic hopes, sometimes based on unlikely successes. Doctors should gently quell these hopes and refrain from showing excessive optimism that could lead couples to continue (31).

Clinicians should inform patients from the outset that not everyone will achieve the much desired outcome, i.e. pregnancy. As this is a difficult issue for staff, it would be beneficial if patients could anticipate this possibility in advance. Doctors are available to discuss treatment options with patients but when all treatment options fail or patients drop out, it would be beneficial to have a final appointment to discuss other options (adoption or acceptance of childlessness) or to help identify those patients most likely to experience long-term emotional difficulties (32).

Where appropriate, patients should be informed of other treatment options that guarantee greater chances of success. A move to gamete donation usually occurs after many years of unsuccessful treatments. However, clinic staff addressing the use of donor gametes can expect resistance from patients in this regard. Several studies show that both heterosexual men and women prefer genetic over non-genetic parenthood, especially among individuals with a lower level of education (33),

It would be useful to outline this hypothesis at the start of the process, particularly when financial resources are limited or if age or other factors impact. (34)

Evidence suggests that both donor-conceived children and their parents are psychologically well adjusted and do not differ from own-gamete conceived children. Practice shows that couples mainly fear that the lack of biological ties will affect their bond with the children. As a general rule, they also have some concerns about the health, motivation and profile of donors. Explanations about the donor screening and selection process coupled with information relating to studies focusing on this type of family may encourage them to accept this form of parenthood, when the desired outcome is to take a baby home (35), (36), (37).

In the case of gamete donation in heterosexual couples with a strong desire to maintain secrecy and conceal treatment despite awareness of the significance of disclosure, patients' desire for privacy must be respected, and special attention should be paid to donor matching in the case of different races or ethnicities where fewer donors are available.

The gamete donation protocols and practices at the fertility centres tend to operate on the basis of heterosexual couples with infertile partners. Nowadays, the lesbian population forms a significant portion of patients presenting for ART. It is important to have a better understanding of the reproductive considerations that lesbian couples face, their expectations and fertility treatment goals (38).

The practice of donor matching according to the characteristics of the infertile parent no longer makes sense especially for single woman or same sex couples, who demonstrate considerable openness when it comes to disclosing treatment. Whenever possible, the wishes of these patients must be taken into account or patients should be allowed to participate in the donor selection process (39).

Practice shows that when entering the gamete process, patients have important questions to address. How involved will they be in the donor selection process? It this based entirely on centre criteria, which do not necessarily include the partner's wishes? Will patients be able to make their own choices? In the case of foreign gamete banks, will they be able to select the donor? In the case of non-anonymous donation, how will the child be able to obtain the name of the donor, since they will need to prove they were born from a specific donor?

Clinics benefit from establishing protocols in order to answer all of these questions. Patients should be informed about the legal status of the treatment, i.e. anonymous, open identity, identity release for offspring and the possibility of known donors. The same applies to the amount of information provided such as general physical characteristics, photographs, personal and family health history and personally non-identifiable information (40).

Nowadays, clinics must be aware of the greater importance of providing personal donor-related information as disclosure is strongly advised, particularly in the case of single women and same sex couples, where secrecy does not exist and the donor is often mentioned in day-to-day family life (41). Even in the case of anonymous donors, an extended profile with personal information should be offered in order to facilitate the family narrative and satisfy normal childhood curiosity (42).

In gamete donation treatments, the size of the desired family and the relevance of sharing the same genetics must be considered in advance. In such cases, patients should be advised to reserve more straws for future treatments, since the same donor may not be available in future due to quota reservations.

For same sex female couples, shared motherhood using the ROPA (Reception of Oocytes from the Partner) method is a patient-friendly process. The couple must decide which option is best based on the desired family size (43)(44).

In the case of gamete or embryo donation, counselling is strongly advised for all patients to allow them to explore all of the issues related to this particular method of creating a family (45)(46).

References

1. General Medical Council. Personal beliefs and medical practice. https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice
2. Gameiro, S., Refaie E.E., de Guevara, B.B., Payson, A., Women from diverse minority ethnic or religious backgrounds desire more infertility education and more culturally and personally sensitive fertility care. Human Reproduction 2019; 34:1735–1745.
3. Kirubarajan, A., Patel, P., Leung, S., Park, B., Prethipan, T., Sierra, S., Barriers to fertility care for racial/ethnic minority groups: a qualitative systematic review. F&S Reviews 2021;2: 150-159.
4. Kirubarajan, A., Patel, P., Leung, S., Park, B., Cultural competence in fertility care for lesbian, gay, bisexual, transgender, and queer people: a systematic review of patient and provider perspectives. Fertility&Sterility 2021;115: 1294-101.
5. Blell, M., British Pakistani Muslim Masculinity, (In)fertility, and the Clinical Encounter. Medical Anthropology 2018;37:117-130
6. Bunting, L., Tsibulsky, I., Boivin, J., Fertility knowledge and beliefs about fertility treatment: findings from the International Fertility Decision-making Study. Human Reproduction 2013;28: 385–397.
7. Madeira, J.L., Andraka-Christou, B., Paper trails, trailing behind: improving informed consent to IVF through multimedia applications. Journal of Law and the Biosciences 2016:2–38
8. Madeira, J.L., Rehbein, J., Christianson, M.S., Lee, M., Parry, J.P., Pennings, G., Lindheim, S.R., Using the engaged MD multimedia platform to improve informed consent for ovulation induction, intrauterine insemination, and in-vitro fertilization. Fertility and Sterility 2018; 110 :1338-1346.
9. Matusitz, J., Spear, J., Effective doctor-patient communication: an updated examination. Soc Work Public Health 2014; 29:252-66.
10. Leone, D., Borghi, L., Del Negro, S., Becattini, C., Chelo, E., Costa. M., De Lauretis, L., Ferraretti, A.P., Giuffrida, G., Livi, C., Luehwink, A., Palermo, R., Revelli, A., Tomasi, G., Tomei, F., Filippini, C., Vegni, E., Doctor-couple communication during assisted reproductive technology visits. Human Reproduction 2018; 33: 877–886.
11. Dancet, E.A.F., Nelen, W.L.D.M., Sermeus, W., De Leeuw, L., Kremer, J.A.M., D'Hooghe, T.M., The patients' perspective on fertility care: a systematic review. Human Reproduction Update 2010; 16: 467–487.

12. Dancet, E.A.F., Spiessens, C., Blocquiaux, L., Sermeus. W., Vanderschueren, D., D'Hooghe, T.D., Testicular biopsy before ART: the patients' perspective on the quality of care. Human Reproduction 2010; 25: 3072–3082.
13. Boivin, J., Domar, A.D., Shapiro, D.B., Wischmann, T.W., Fauser, B.C.J.M., Verhaak, C., Tackling burden in ART: an integrated approach for medical staff. Human Reproduction 2012; 27: 941–950.
14. Dancet, E.A.F., D'Hooghe, T.M., Sermeus, W., Van Empe, I., Strohmer, H., Wyns, C., Santa-Cruz, D., Nardo, L.G., Kovatchki, D., Vanlangenakker, L., Garcia-Velasco, J., Mulugeta, B., Nelen, W.L.D.M., Kremer, J.A.M., Patients from across Europe have similar views on patient-centered care: an international multilingual qualitative study in infertility care. Human Reproduction 2012; 27: 1702–1711.
15. Shenfield, F., Pennings. G., De Mouzon, J., Ferraretti, A.P., Goossens, V., ESHRE's good practice guide for cross-border reproductive care for centers and practitioners. Human Reproduction 2011; 0:1–3.
16. Leone, D., Menichetti, J., Barusi, L, Chelo, E., Costa, M., De Lauretis, L., Ferraretti, A.P., Livi, C., Luehwink, A., Tomasi, G., Vegni, E., Breaking bad news in assisted reproductive technology: a proposal for guidelines. Reproductive Health 2017;14:87
17. Harrison, C., Gameiro, S., Boivin, J., Patient willingness, preferences and decision-making about planning for three complete cycles of IVF/ICSI treatment. Human Reproduction 2021; 36: 1339–1352.
18. Jadva, V., Sbadger, S., Morrissett, M., Golombok, S., Mom by choice, single by life's circumstance...' Findings from a large-scale survey of the experiences of single mothers by choice. Human Fertility 2009; 12: 175–184
19. Fuscaldo, G., Russell, S., Gillam, L., How to facilitate decisions about surplus embryos: patients' views. Human Reproduction, 2007; 22:3129–3138.
20. Goedeke, S., Daniels, K., Thorpe, M., Embryo donation and counseling for the welfare of donors, recipients, their families and children. Human Reproduction, 2016; 31: 412–418.
21. Riggan, K.A., Allyse, M., Compassionate transfer: an alternative option for surplus embryo disposition . Human Reproduction 2019; 34:791–794
22. Domar, A.D., Zuttermeister, P.C., Friedman, R., Psychological impact of infertility. J Psychosom Obstet Gynaecol 1993; 14: 45-52
23. Pasch, L.A., Holley, S.R., Bleil, M.E., Shehab, D., Katz, P.P., Adler, NE., Addressing the needs of fertility treatment patients and their partners: are they informed of and do they receive mental health services? Fertility and Sterility 2016; 106: 209-215.
24. Groh, C.J., Wagner, C., The art of communicating ART results: an analysis of infertile couples' experience. Journal of Reproductive and Infant Psychology 2005; 23:333-346.
25. Patel, A., Sharma, P.S.V.N., Kumar, P., Role of Mental Health Practitioner in Infertility Clinics: A Review on Past, Present and Future Directions. J Hum Reprod Sci 2108; 11: 219-228
26. Walschaerts, M., Bujan, L., Parinaud, J., Mieusset R., Thonneau, P., Treatment discontinuation in couples consulting for male infertility after failing to conceive. Fertility&Sterility 2013; 99: 1319-1323.
27. Boivin, J., Domar, A.D., Shapiro, D.B., Wischmann, T.W., Fauser, B.C.J.M., Verhaak, C., Tackling burden in ART: an integrated approach for medical staff. Human Reproduction 2012; 27: 941–950.
28. Holley, S.R., Pasch, L.A., Bleil, M.E., Gregorich, S., Katz, K.K., Prevalence and Predictors of Major Depressive Disorder. Fertility & Sterility 2015; 103:1332-1339.
29. Gameiro, S., Boivin, J., Domar, A., Optimal in-vitro fertilization in 2020 should reduce treatment burden and enhance care delivery for patients and staff . Fertility & Sterility 2013; 100: 303-309.
30. ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction - a guide for fertility staff. https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Psychosocial-care-guideline
31. Copp, T., Kvesic, D., Lieberman, D., Bateson, D., McCaffery, K.J., Your hopes can run away with your realistic expectations: a qualitative study of women's and men's decision-making when undergoing multiple cycles of IVF. Human Reproduction Open 2020; 00: 1–8.
32. Gameiro, S., van den Belt-Dusebout, A., Bleiker, E., Braat, D., van Leeuwen, F.E., Verhaak, C.M., Do children make you happier? Sustained child-wish and mental health in women 11–17 years after fertility treatment. Human Reproduction 2014; 29: 2238–2246.
33. Hendriks, S., Peeraer, K., Bos, H., Repping, S., Dancet, E.A.F., The importance of genetic parenthood for infertile men and women. Human Reproduction 2017; 9: 2076–2087.
34. Kirkman-Brown, J.C., Martins, M.V., 'Genes versus children': if the goal is parenthood, are we using the optimal approach? Human Reproduction 2020; 35: 5–11.
35. Golombok, S., Ilioi, E., Blake, L., Roman, G., Jadva, V., A longitudinal study of families formed through reproductive donation: parent-adolescent relationships and adolescent adjustment at age 14. Dev Psychol 2017; 53:1966.
36. Jadva, V., Children conceived by gamete donation: psychological adjustment and mother-child relationships at age 7. J Fam Psychol 2011; 25: 230–239.
37. Imrie, S., Jadva, V., Golombok, S., Making the Child Mine": Mothers' Thoughts and Feelings About the Mother–Infant Relationship in Egg Donation Families. Journal of Family Psychology 2020; 34:469-479.

38. Carpinello, O.J., Jacob, M. N., Nulsen, J., Benadiva, C., Utilization of fertility treatment and reproductive choices by lesbian couples. Fertility&Sterility 2016; 106: 1709-1713.
39. Pennings, G., The right to choose your donor: a step towards commercialization or a step towards empowering the patient. Human Reproduction 2000; 15: 508–514.
40. Indekeu, A., Janneke, A.B.M., McCormick, E., Benward, J., Scheib, J.E., Factors associated with searching for people related through donor conception among donor-conceived people, parents, and donors. F&S reviews 2021; 2: 93-119.
41. Svanberg, A.S., Sydsjo, G., Claudia Lampic, C., Psychosocial aspects of identity-release gamete donation – perspectives of donors, recipients and offspring, Upsala Journal of Medical Sciences 2019; https://doi.org/10.1080/03009734.2019.1696431.
42. Stuart-Smith, S.J., Smith, J.A., Scott, E.J., To know or not to know? Dilemmas for women receiving unknown oocyte donation. Human Reproduction 2012; 27: 2067–2075.
43. Rori, L.E., Steele, L.S., Epsteins, R., Lesbian and bisexual women's recommendations for improving the provision of assisted reproductive technology services. Fertility&Sterility 2006; 86: 735-738.
44. Wyverkens, E., Provoost, V., Ravelingien, A., De Sutter, P., Pennings, G., Buysse, A. Beyond sperm cells: a qualitative study on constructed meanings of the sperm donor in lesbian families. Human Reproduction 2014; 29: 1248–1254.
45. Visser, M., Gerrits, T., Kop, F., van der Veen, F., Mochtar, M., Exploring parents' feelings about counseling in donor sperm treatment. Journal of Psychosomatic Obstetrics & Gynecology. 2016; 37: 156-163
46. Schrijvers, A.M., van Rooij, F.B., Overbeek, G., de Reus, E., Schoonenberg, M., van der Veen, F., Visser, M., Bos, H.M.W., Motchar, M.H., Psychosocial counselling for intended parents who opt for donor sperm treatment: which topics do they find relevant? Journal of Reproductive and Infant Psychology 2019; 38: 474-484.

2.2
Fertility awareness

In a general context, fertility awareness incorporates information on fertility and human reproduction, such as the menstrual cycle, timing and occurrence of pregnancy, likelihood of getting pregnant from having unprotected sexual intercourse at various times during the menstrual cycle, and the role of male fertility and sperm survival (1). It can also include how specific methods of family planning work, how to use them and how they affect fertility (2). Fertility awareness also includes the ability to effectively apply reproductive health information to one's life to achieve personal, desired outcomes (3). This requires individual knowledge and skills, personal experience, and a family and wider community environment that empowers people to take action and make their own fertility-related decisions (4). Good fertility awareness can empower and enable men and women to make strategic life choices relating to their fertility and reproductive health. The international glossary on infertility and fertility care (5) defines fertility awareness as:

> *"the understanding of reproduction, fecundity, fecundability, and related individual risk factors (e.g. advanced age, sexual health factors such as sexually transmitted infections, and life style factors such as smoking, obesity) and non-individual risk factors (e.g. environmental and work place factors); including the awareness of societal and cultural factors affecting options to meet reproductive family planning, as well as family building needs".*

In clinical settings, fertility awareness covers more in-depth knowledge of fertility awareness-based methods (FABMs) for family planning, used in achieving birth control (6). Examples of such methods include the Billings Ovulation Method, Cycle Beads Method, Two Day method, Standard Day Method, Temperature Methods and the Symptothermal Method (STM) (6–10). These methods typically involve an assessment of signs associated with ovulation and being fertile, such as the observation and characterisation of cervical secretions, basal body temperature, monitoring of cycle days (6,8–12) and use of this information for family planning.

A marked increase in childbearing at advanced maternal and paternal age has recently been observed in many high-income countries (13). Since earning potential generally tends to increase with age, delaying parenthood is a rational economic strategy and one of the reasons frequently cited for delaying childbearing. Economic reasons such as studying, employment and career progression are not the only motivators for a delay in family building but are collectively cited as the most important reasons (14, 15). Changing social norms on the ideal age for parenthood (16), education, availability of contraception and ARTs (17) are also contributing factors. It has been suggested that social advantage could reduce some impact of advanced maternal age (18). Moreover, a higher happiness score is reported in children of mature parents (19). Some studies also reveal greater satisfaction and less stress in older parents (20) (19). Indeed, patients should not be judged when they initially attend clinics.

Overall, the demographic shift towards delayed childbearing and family building is of increasing public health and clinical concern due to elevated risks of poor outcomes for mother and baby (21, 22). Although many remain childless by choice (23–25) and most women will be able to conceive naturally if they do so by the age of 35 (26), for those who have difficulty conceiving, poor outcomes increase rapidly (27). Improvement of fertility knowledge and awareness continues to be a crucial component of public health initiatives for preventing involuntary childlessness and achieving desired family building intentions (28–31).

Clinics should not assume that patients have adequate fertility knowledge. Studies reveal a common misconception that most women will conceive immediately after they begin to try. Years of education focus on how to prevent pregnancy rather than how to attain it, thus promoting the perception that pregnancy is inevitable if contraception is not used. This idea is reinforced by pill usage, where "just missing one pill can result in pregnancy" making women believe that they are more fertile than they really are (32). In reality, the incidence of conception, especially with increasing maternal age, is quite low compared to common estimates. As such, there has been a growing debate and concern amongst health and education professionals about the general lack of knowledge on fertility and reproductive health globally. Additionally, there have been several campaigns across Europe aimed at improving fertility awareness (33), especially on topics such as age-related fertility decline, knowledge of menstrual cycle and overestimation of assisted reproductive technology (ART) success rates. Significant advances in ART are also evident. However, this also focuses on potential solutions such as IVF and social egg freezing rather than on the possible root causes, which may include a lack of fertility awareness of potentially modifiable factors.

Clinics must recognise the importance of fertility awareness for general health. Improvements in cancer treatments such as chemotherapy and radiotherapy have significantly increased survival rates. Unfortunately these cancer treatments can adversely affect other aspects of a patient's health, including reproductive health (34–40). Studies have shown that approximately one in ten cancer cases are diagnosed in men and women of reproductive age (41) and the loss of fertility is one of the long-term effects of prolonged cancer treatments (36,40). Evidence shows that cancer patients have significant concerns regarding the effect of cancer treatment on their fertility. Cryopreservation (freezing) of men's sperm or women's oocytes or embryos may give people with cancer or other medical treatments causing premature infertility the option to try and have children in the future.

Although many obese men and women experience normal fertility, obesity and being overweight, both of which are preventable, can have negative consequences, not only on general health, but also on reproductive health (42). Research highlights poor knowledge of the implications of obesity on reproductive health outcomes (43) such as menstrual irregularities, PCOS (polycystic ovary syndrome) (44), infertility (45), reduction in conception rates (46), lowered response to fertility treatments (47–51) and sexual dysfunction in women. It can also contribute to miscarriages and various other maternal and perinatal complications (42, 52–56).

Finally, various chronic health conditions can affect fertility. Diabetes in pregnant women is associated with an increased risk of stillbirth, miscarriage, complications, metabolic, developmental and growth abnormalities of the foetus and pre- and post-natal complications for the mother (54, 57–60). Women who develop gestational diabetes are also more likely to develop type 2 diabetes later in life (61). These issues are discussed in further detail in chapter 2.4 on diet and nutrition. Clinic staff should be aware of the range of health conditions that will affect individual fertility needs.

2.3
Engaging men in fertility discussions

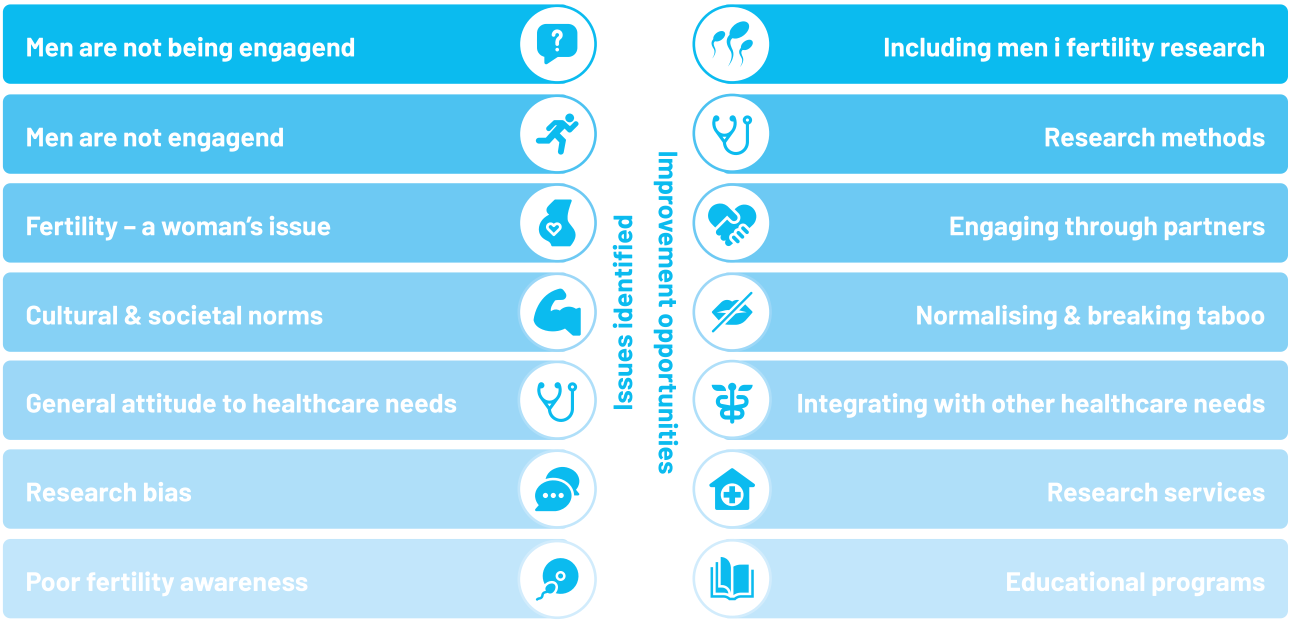
Although the biological contribution of both men and women is necessary, fertility discussions disproportionately focus on women and infertility is often perceived as a female issue. However, research shows that men and women are equally affected by infertility (62, 63). Studies (64–66) have shown that approximately 40–50% of all cases are due to "male factor" infertility. Furthermore, the reproductive impact of paternal ageing, albeit significantly less pronounced than that of female ageing, is at least partly responsible for the link with reduced fertility and the increase in pregnancy-related complications and adverse outcomes for offspring (67–69).

The low involvement of men in fertility discussions impedes the implementation and promotion of effective, male-friendly fertility practices and policies (70). Advanced paternal age plays a significant role on male fertility and on the health of the offspring (13), contributing to reduced fertility of a couple especially when the woman is also of advanced age. Male fertility starts to decline around the age of 45 (26, 71). Advanced paternal age can be associated with decreased serum androgen concentration, diminished sexual activity, changes in testicular morphology and deterioration of semen quality (volume, motility and morphology), reduced DNA integrity of sperm and, possibly, epigenetic effects (68, 72–74). A review of fertility awareness studies showed that men had little knowledge of factors influencing fertility (75).

We advise couples experiencing difficulties conceiving to attend healthcare consultations together as both partners are affected by the decisions and outcomes of the investigation and treatment. We advocate the active participation of men, recognition of their responsibility in the informed decision-making process regarding sexual and reproductive health issues, and the use of male contraceptive methods (76). Policies highlight the importance of fertility awareness and preconception health for all men and women whether or not they choose to have children (77). This is because a component of preconception health focuses on people staying healthy throughout life.

We recommend increasing support for men to engage with fertility awareness, family building, preconception care and reproductive health services. Some of the key issues and improvement opportunities related to increasing fertility awareness for men are highlighted in Figure below.

Figure:
Issues and improvement opportunities for improving fertility awareness for men. Grace *et al*. 2019 (70).



Given the increasing recognition of the importance of paternal influences in child health (78, 79), men should be encouraged to take a more active role and support should be provided for those who may feel sensitive or embarrassed by the topic. Men and women should also be encouraged to take part in discussions and to encourage the involvement of their partners.

Male-friendly websites and mobile applications based on robust scientific evidence are effective resources for fertility clinics to reach out and educate men in this area. Healthcare providers, researchers and educators may well have succumbed to the traditionally held beliefs regarding male involvement and interest in this subject. We recommend that clinics routinely provide men with reproductive health information. However, it is important to note that when encouraging partner involvement, the necessary safeguards should be implemented to prevent discrimination or the marginalisation of women who do not have a male partner or who choose not to involve their male partner in their care.

Healthcare professionals (HCPs) are typically ranked as the most trusted source for providing fertility information (80) – hence their engagement is critical. Studies have shown that educating healthcare providers in fertility awareness can help to improve the quality of information provided (81, 82). Moreover, people who had consulted their healthcare professionals were more knowledgeable about their fertility status (83). However, the quality of advice provided depends on the HCP's knowledge as well as their attitude towards fertility information and whether they feel it is their duty to provide such information.

Although school education remains a consistent source of information, it does not adequately cover fertility education. Healthcare professionals play a key role in improving fertility awareness and are often cited as the most trusted fertility information source. However, they are not necessarily better informed than the general population. Studies have highlighted gaps in the HCPs' fertility knowledge. HCP clinical management recommendations regarding infertility also revealed significant shortcomings in their knowledge of related risks, especially in the case of ethnic minorities who are at higher risk. The need to educate both the general public and healthcare professionals is apparent from the lack of knowledge about fertility and preconception. However, it is not uncommon to find that healthcare professionals are unclear of their role in fertility education.

Evidence suggests a lack of clarity among healthcare professionals as to whether preconception care and education is their responsibility (84). The lack of established guidelines regarding fertility education is a contributing factor.

Additional HCP training on fertility and reproductive health is required to boost fertility awareness. In terms of wider implications, improvements through a more holistic life-long approach to reproductive health, including family building, should be a key component of public health programmes. This requires collaborative initiatives supported by policy makers, healthcare professionals, educators and other special interest groups in order to help individuals achieve their desired goals in terms of family building.

References

1. womenshealth.gov. Trying to conceive | womenshealth.gov [Internet]. 2015 [cited 2015 Aug 25]. Available from: http://www.womenshealth.gov/pregnancy/before-you-get-pregnant/trying-to-conceive.html
2. NHS. Natural family planning: fertility awareness - Contraception guide - NHS Choices. 2015 [cited 2015 Aug 25]; Available from: http://www.nhs.uk/Conditions/contraception-guide/Pages/natural-family-planning.aspx
3. Sedgh, G., Singh, S., Hussain, R., Intended and Unintended Pregnancies Worldwide in 2012 and Recent Trends. 2014;
4. Institute for Reproductive Health. Fertility Awareness as Power: Why accurate information is important | Institute for Reproductive Health [Internet]. 2015 [cited 2015 Jun 29]. Available from: http://irh.org/blog/fertility-awareness-as-power-why-accurate-information-is-important/
5. Zegers-Hochschild, F., Adamson, G.D., Dyer, S., Racowsky, C., De Mouzon, J., Sokol R, et al., The international glossary on infertility and fertility care, 2017. Hum Reprod [Internet]. 2017; 32(9):1786–801. Available from: http://dx.doi.org/10.1016/j.fertnstert.2017.06.005
6. Frank-Herrmann, P., Gnoth, C., Toledo, E., Baur, S., Pyper, C., Jenetzky, E., et al., The effectiveness of a fertility awareness-based method to avoid pregnancy in relation to a couple's sexual behaviour during the fertile time: A prospective longitudinal study. Hum Reprod. 2007; 22 (5): 1310–9.
7. Germano, E., Jennings, V., New Approaches to Fertility Awareness-Based Methods: Incorporating the Standard Days and Two-Day Methods into Practice. J Midwifery Women's Health. 2006; 51: 471–7.
8. Pallone, S.R., Bergus, G.R., Fertility awareness-based methods: another option for family planning. J Am Board Fam Med. 2009; 22: 147–57.
9. Thijssen, A., Meier, A, Panis, K., Ombelet, W., "Fertility Awareness-Based Methods" and subfertility: a systematic review. Facts, views Vis ObGyn [Internet]. 2014; 6(3): 113–23. Available from: http://www.pubmedcentral.nih.gov
10. Halpern, V., Nanda, K., KF, S., LM, L., Fertility awareness-based methods for contraception. Cochrane Database Syst Rev [Internet]. 2004; (4): N.PAG-N.PAG 1p. Available from: http://doi.wiley.com
11. Da, G., Mf, G., Halpern. V., Nanda, K., Kf, S., Lm, L. Fertility awareness-based methods for contraception (Review). 2012; (4).
12. Pyper, C.M., Fertility awareness and natural family planning. Eur J Contracept Reprod Health Care. 1997; 2: 131–46.

13. Heffner, L.J., Advanced maternal age - how old is too old? N Engl J Med [Internet]. 2004; 351(19): 1927–9. Available from: http://www.nejm.org/doi/full/10.1056/NEJMp048087

14. Mills, M., Rindfuss, R.R., McDonald, P., te Velde, E., Why do people postpone parenthood? Reasons and social policy incentives. Hum Reprod Update. 2011; 17 (6): 848–60.

15. Brand, J.E., Davis, D., The Impact of College Education on Fertility: Evidence for Heterogeneous Effects. Demography. 2011; 48: 863–87.

16. McQuillan, J., Greil, A.L., Shreffler, K.M., Pregnancy intentions among women who do not try: Focusing on women who are okay either way. Matern Child Health J. 2011; 15 (2) : 178–87.

17. Leridon, H., Can assisted reproduction technology compensate for the natural decline in fertility with age? A model assessment. Hum Reprod. 2004; 19(7): 1548–53.

18. Carolan, M,, Frankowska, D., Advanced maternal age and adverse perinatal outcome: A review of the evidence. Midwifery [Internet]. 2011; 27 (6): 793–801. Available from: http://dx.doi.org/10.1016/j.midw.2010.07.006

19. Myrskylä, M., Margolis, R., Happiness: Before and After the Kids. Demography. 2014; 51(5): 1843–66.

20. Barclay, K., Myrskylä, M., Advanced Maternal Age and Offspring Outcomes: Reproductive Aging and Counterbalancing Period Trends. Popul Dev Rev. 2016; 42 (1): 69–94.

21. Maheshwari, A., Porter, M., Shetty, A., Bhattacharya, S., Women's awareness and perceptions of delay in childbearing. Fertil Steril [Internet]. 2008 Oct [cited 2015 Jun 10]; 90 (4): 1036–42. Available from: http://www.sciencedirect.com/science/article/pii/S0015028207029901

22. Cooke, A., Mills, T.A., Lavender, T., Advanced maternal age: delayed childbearing is rarely a conscious choice - a qualitative study of women's views and experiences. Int J Nurs Stud [Internet]. 2012 Jan [cited 2015 Jun 10]; 49 (1): 30–9. Available from: http://www.sciencedirect.com/science/article/pii/S0020748911002999

23. Tanturri, M.L., Mencarini, L. Childless or childfree? Paths to voluntary childlessness in Italy. Popul Dev Rev. 2008; 34 (1): 51–77.

24. Kreyenfeld, M., Konietzka, D., Analyzing Childlessness. In: Childlessness in Europe: Contexts, Causes, and Consequences [Internet]. 2017. p. 3–15. Available from: http://link.springer.com/chapter/10.1007/978-3-319-44667-7_1/fulltext.html

25. Hara, T., Increasing Childlessness in Germany and Japan: Toward a Childless Society? Int J Japanese Sociol [Internet]. 2008; 17 (1): 42–62. Available from: http://doi.wiley.com/10.1111/j.1475-6781.2008.00110.x

26. RCOG. Reproductive Ageing. Sci Impact Pap [Internet]. 2011; (24): 15–30. Available from: https://books.google.com/books?id=-SlaAQAAQBAJ&pgis=1

27. Djahanbakhch, O., Ezzati, M., Zosmer, A., Reproductive ageing in women. Vol. 211, Journal of Pathology. 2007. p. 219–31.

28. Harper, J., Boivin, J., O'Neill, H.C., Brian, K., Dhingra, J., Dugdale, G. et al., The need to improve fertility awareness. Reprod Biomed Soc Online [Internet]. 2017; 4: 18–20. Available from: http://linkinghub.elsevier.com/retrieve/pii/S2405661817300096

29. Virtala, A., Vilska, S., Huttunen, T., Kunttu, K., Childbearing, the desire to have children, and awareness about the impact of age on female fertility among Finnish university students. Eur J Contracept Reprod Health Care. 2011; 16(April): 108–15.

30. García, D., Vassena, R., Prat, A., Vernaeve, V., Increasing fertility knowledge and awareness by tailored education: A randomized controlled trial. Reprod Biomed Online. 2016; 32 (1).

31. Yu, L., Peterson, B., Inhorn, M.C., Boehm, J.K., Patrizio, P., Knowledge, attitudes, and intentions toward fertility awareness and oocyte cryopreservation among obstetrics and gynecology resident physicians. Hum Reprod. 2015; 31 (2).

32. Wilcox, A.J., Dunson, D.B., Weinberg, C.R., Trussell, J., Baird, D.D., Likelihood of conception with a single act of intercourse: Providing benchmark rates for assessment of post-coital contraceptives. Contraception. 2001; 63 (4): 211–5.

33. Harper, J., Hammarberg, K., Simopoulou, M., Koert, E., Pedro, J., Massin, N. et al., The International Fertility Education Initiative: research and action to improve fertility awareness. Hum Reprod Open [Internet]. 2021 Aug 25 [cited 2021 Sep 8]; Available from: https://academic.oup.com/hropen/advance-article/doi/10.1093/hropen/hoab031/6357711

34. Committee, T.E., Society, A., Medicine, R., Fertility preservation and reproduction in cancer patients. Fertil Steril. 2005; 83 (6): 1622–8.

35. Maltaris, T., Weigel, M., Mueller, A., Schmidt, M., Seufert, R., Fischl, F. et al. Cancer and fertility preservation: fertility preservation in breast cancer patients. Breast Cancer Res. 2008; 10 (2): 206.

36. Diedrich, K., Fauser, B.C.J.M., Devroey, P., Cancer and fertility: Strategies to preserve fertility. Reprod Biomed Online [Internet]. 2011; 22 (3): 232–48. Available from: http://dx.doi.org/10.1016/j.rbmo.2010.11.001

37. Rodriguez-Wallberg, K.A., Oktay, K. Fertility preservation during cancer treatment: Clinical guidelines. Cancer Manag Res. 2014; 6 (1): 105–17.

38. Letourneau. J.M., Ebbel, E.E., Katz, P.P., Katz, A., Ai, W.Z., Chien, A. J. et al. Pretreatment fertility counseling and fertility preservation improve quality of life in reproductive age women with cancer. Cancer. 2012; 118 (6): 1710–7.

39. Tournaye, H., Dohle, G.R., Barratt, C.L.R., Fertility preservation in men with cancer. Lancet [Internet]. 2014; 384 (9950): 1295–301. Available from: http://www.sciencedirect.com/science/article/pii/S0140673614604955
40. Kasum, M., Beketić-Orešković, L., Peddi, P.F., Orešković, S., Johnson, R.H., Fertility after breast cancer treatment. Eur J Obstet Gynecol Reprod Biol [Internet]. 2014; 173: 13–8. Available from: http://www.sciencedirect.com/science/article/pii/S0301211513005654
41. Quinn, G.P., Knapp, C.A., Malo, T.L., McIntyre, J., Jacobsen, P.B., Vadaparampil ST. Physicians' Undecided Attitudes Toward Posthumous Reproduction: Fertility Preservation in Cancer Patients with a Poor Prognosis. J Support Oncol [Internet]. 2012; 10 (4): 160–5. Available from: http://dx.doi.org/10.1016/j.suponc.2011.09.006
42. Nelson, S.M., Fleming, R., Obesity and reproduction: impact and interventions. Curr Opin Obstet Gynecol. 2007; 19 (4): 384–9.
43. Cardozo, E.R., Brocks, M., Ekpo, G., Neff, L.M., Barnes, R.B., Marsh, E.E., Weight matters: knowledge of the relationship between obesity and reproductive health outcomes amongst infertility patients. Vol. 96, Fertility and Sterility. 2011. p. S123.
44. Pasquali, R., Gambineri, A., Pagotto, U. The impact of obesity on reproduction in women with polycystic ovary syndrome. Vol. 113, BJOG: An International Journal of Obstetrics and Gynaecology. 2006. p. 1148–59.
45. Brannian, J.D., Obesity and fertility. S D Med. 2011; 64 (7): 251–4.
46. Metwally, M., Li. T.C., Ledger, W.L., The impact of obesity on female reproductive function. Obes Rev. 2007; 8 (6): 515–23.
47. Pandey, S., Pandey, S., Maheshwari, A,, Bhattacharya, S., The impact of female obesity on the outcome of fertility treatment. J Hum Reprod Sci. 2010; 3 (2): 62–7.
48. Brewer, C.J., Balen, A.H., The adverse effects of obesity on conception and implantation. Vol. 140, Reproduction. 2010. p. 347–64.
49. Luke, B., Brown, M.B., Stern, J.E., Missmer, S.A., Fujimoto, V.Y., Leach, R., Female obesity adversely affects assisted reproductive technology (ART) pregnancy and live birth rates. Hum Reprod. 2011; 26 (1): 245–52.
50. Moran, L.J., Dodd, J., Nisenblat, V., Norman, R.J., Obesity and reproductive dysfunction in women. Endocrinol Metab Clin North Am. 2011; 40: 895–906.
51. Brown, K., Apuzzio, J., Weiss, G., Maternal obesity and associated reproductive consequences. Women's Health (Lond Engl) [Internet]. 2010; 6 (2): 197–203. Available from: http://www.ncbi.nlm.nih.gov/pubmed/20187726
52. Pesant, M.H., Wunder, D., Pralong, F., Giusti, V., The impact of obesity on fertility. Rev Med Suisse. 2010; 6 (242): 662–5.
53. Brooks, R., Maklakov, A., Sex differences in obesity associated with total fertility rate. PLoS One. 2010; 5(5).
54. Simmons, D., Diabetes and obesity in pregnancy. Best Pract Res Clin Obstet Gynaecol. 2011; 25 (1): 25–36.
55. Tough, S.C., Siever, J.E., Jack, M., Reproductive assistance, emotional health, obesity, and time to pregnancy among women under 35 years of age. J Obstet Gynaecol Can [Internet]. 2010; 32 (12): 1153–62. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21176327
56. Siega-Riz, A.M., Laraia, B., The implications of maternal overweight and obesity on the course of pregnancy and birth outcomes. Matern Child Health J [Internet]. 2006; 10 (5 Suppl): S153-6. Available from: http://www.pubmedcentral.nih.gov
57. McCance, D.R., Pregnancy and diabetes. Best Pract Res Clin Endocrinol Metab. 2011; 25 (6): 945–58.
58. Ballas, J., Moore, T.R., Ramos, G.A., Management of diabetes in pregnancy. Vol. 12, Current Diabetes Reports. 2012. p. 33–42.
59. Evidence NHS, Practice C. Diabetes and pregnancy. Can J diabetes [Internet]. 2013;37 Suppl 3 (April 2007): S343-6. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24838051
60. Negrato, C.A., Mattar, R., Gomes, M.B., Adverse pregnancy outcomes in women with diabetes. Diabetol Metab Syndr [Internet]. 2012; 4 (1): 41. Available from: http://www.pubmedcentral.nih.gov
61. NHS. Gestational diabetes - NHS Choices. 2015 [cited 2015 Aug 29]; Available from: http://www.nhs.uk/conditions/gestational-diabetes/Pages/Introduction.aspx
62. ASRM. ASRM: Quick Facts About Infertility [Internet]. 2015 [cited 2015 Oct 19]. Available from: https://www.asrm.org/detail.aspx?id=2322
63. Fisher, J.R.W., Baker, G.H.W., Hammarberg, K., Long-term health, well-being, life satisfaction, and attitudes toward parenthood in men diagnosed as infertile: challenges to gender stereotypes and implications for practice. Fertil Steril [Internet]. 2010; 94(2): 574–80. Available from: http://dx.doi.org/10.1016/j.fertnstert.2009.01.165
64. Kumar, N., Singh, A., Trends of male factor infertility, an important cause of infertility: A review of the literature. J Hum Reprod Sci [Internet]. 2015; 8 (4): 191. Available from: http://www.jhrsonline.org/text.asp?2015/8/4/191/170370
65. Sharlip, I.D., Jarow, J.P., Belker, A.M., Lipshultz, L.I., Sigman, M., Thomas, A.J. et al., Best practice policies for male infertility. Vol. 77, Fertility and Sterility. 2002. p. 873–82.

66. Krausz, C., Male infertility: pathogenesis and clinical diagnosis. Best Pract Res Clin Endocrinol Metab. 2011; 25 (2): 271–85.

67. Smith, K.R., Paternal age bioethics. J Med Ethics [Internet]. 2015; 41 (9): 775–9. Available from: http://jme.bmj.com/content/early/2015/06/02/medethics-2014-102405

68. Ramasamy, R., Chiba, K., Butler, P., Lamb, D.J., Male biological clock: A critical analysis of advanced paternal age. Fertil Steril [Internet]. 2015; 103 (6): 1402–6. Available from: http://dx.doi.org/10.1016/j.fertnstert.2015.03.011

69. Palmer, N.O., Bakos, H.W., Fullston, T., Lane, M., Impact of obesity on male fertility, sperm function and molecular composition. Spermatogenesis [Internet]. 2012; 2 (4): 253–63. Available from: http://www.pubmedcentral.nih.gov

70. Grace, B., Shawe, J., Johnson, S., Stephenson, J. You did not turn up… I did not realise I was invited…: understanding male attitudes towards engagement in fertility and reproductive health discussions. Hum Reprod Open. 2019 Mar 1; 2019 (3).

71. Harris, I., Fronczak, C., Roth, L., Meacham, R., Fertility and the Aging Male. Rev Urol. 2011; 13 (4): e184–90.

72. Nybo Andersen, A.M., Hansen, K.D., Andersen, P.K., Davey Smith, G., Advanced Paternal Age and Risk of Fetal Death: A Cohort Study. Am J Epidemiol [Internet]. 2004; 160 (12): 1214–22. Available from: http://aje.oxfordjournals.org/cgi/doi/10.1093/aje/kwh332

73. Balasch, J., Gratacós, E., Delayed childbearing: effects on fertility and the outcome of pregnancy. Eur J Obstet Gynecol Reprod Biol. 2012; 24 (3): 187–93.

74. Liu, K., Case, A., Advanced reproductive age and fertility. J Obs Gynaecol Can. 2011; 33 (11): 1165–75.

75. Hammarberg, K., Collins, V., Holden, C., Young, K., McLachlan, R., Men's knowledge, attitudes and behaviours relating to fertility. Hum Reprod Update. 2017; 23 (4): 458–80.

76. World Health Organisation. WHO regional strategy on sexual and reproductive health. 2015 [cited 2015 Aug 27]; Available from: http://www.euro.who.int/en/health-topics/Life-stages/sexual-and-reproductive-health/publications/pre-2007/who-regional-strategy-on-sexual-and-reproductive-health

77. Centers for Disease Control and Prevention. Women | Preconception Care | CDC [Internet]. 2015 [cited 2015 Jul 1]. Available from: http://www.cdc.gov/preconception/women.html

78. Stephenson, J., Heslehurst, N., Hall, J., Schoenaker, D.A.J.M., Hutchinson, J., Cade, J.E. et al., Before the beginning: nutrition and lifestyle in the preconception period and its importance for future health. Lancet [Internet]. 2018; 391 (10132): 1830–41. Available from: http://dx.doi.org/10.1016/S0140-6736(18)30311-8

79. Fleming, T.P., Watkins, A.J., Velazquez, M.A., Mathers, J.C., Prentice, A.M., Stephenson, J. et al., Origins of Lifetime Health Around the Time of Conception: Causes and Consequences. Lancet [Internet]. 2018; 391(10): 555–7. Available from: http://dx.doi.org/10.1016/S0140-6736(18)30312-X

80. Lundsberg, L.S., Pal, L., Gariepy, A.M., Xu, X. Chu, M.C., Illuzzi, J.L., Knowledge, attitudes, and practices regarding conception and fertility: A population-based survey among reproductive-age United States women. Fertil Steril [Internet]. 2014; 101. Available from: http://dx.doi.org/10.1016/j.fertnstert.2013.12.006

81. Hampton, K.D., Mazza, D., Newton, J.M., Fertility-awareness knowledge, attitudes, and practices of women seeking fertility assistance. J Adv Nurs. 2013; 69: 1076–84.

82. Rodriguez, D., Female Fertility: A Conceptual and Dimensional Analysis. J Midwifery Women's Health 2013; 58: 182–8.

83. Bunting, L., Tsibulsky, I., Boivin, J., Fertility knowledge and beliefs about fertility treatment: Findings from the International Fertility Decision-making Study. Hum Reprod. 2013; 28 (2): 385–97.

84. Barrett, G., Shawe, J., Howden, B., Patel, D., Ojukwu, O., Pandya, P. et al., Why do women invest in pre-pregnancy health and care? A qualitative investigation with women attending maternity services. BMC Pregnancy Childbirth [Internet]. 2015; 15 (1): 236. Available from: http://www.biomedcentral.com/1471-2393/15/236

2.4
Diet and lifestyle factors for fertility

Various lifestyle-related factors such as obesity, smoking, substance abuse and heavy alcohol consumption are known to have a negative impact on both male and female fertility and the success of ART (1, 2). Other lifestyle habits may also adversely affect reproductive health, and advice on modifiable lifestyle factors should be given to couples to help them make positive changes to potentially improve their chances of a healthy pregnancy. This will enhance overall wellbeing and make the couple feel that they can do something together, which is within their control.

With timelines in mind, 3-6 months is an ideal timeframe to focus on nutrition and lifestyle changes to enhance fertile health, but of course any length of time is beneficial.

Smoking

Smoking is associated with an increased risk of infertility and lower ART success rates in women (1, 2) and with impaired semen quality (3) in men.

Weight

Weight is often related to eating and activity habits. It is a well-known fact that obesity can have a significant impact on male and female fertility, and these patients should be supported to lose weight safely and effectively without compromising their nutritional intake or over-exercising, in order to help protect their fertility.

The good news is that the negative effects of obesity on fertility are reversible. With an average weight loss of 10.2 kg, 90% of previously anovulatory, obese women began ovulating (16).

Women who are underweight and have extremely low amounts of body fat are at higher risk of ovarian dysfunction and infertility (17). Underweight women are also at increased risk of premature births (18). Underweight women should be encouraged to increase their intake of nutrient-dense foods to promote weight gain, without resorting to unhealthy foods.

Dietary advice

A healthy, varied and balanced diet is key to maintaining good overall health. A diet rich in carbohydrates, fibre, folate and lycopene (11) as well as fruit and vegetables will improve semen quality (12).

Semen parameters may be negatively affected by the consumption of alcohol and red meat, but positively influenced by fruit and cereal consumption. Red meat may also negatively impact fertilisation and implantation rates (5).

Antioxidant intake has been associated with a shorter time to pregnancy (4) while high antioxidant levels have been seen to increase semen quality, compared to low or moderate amounts (13). A Cochrane review recorded a significant increase in live birth rate for men with an oral antioxidant intake(14).

Trans fats (mostly found in packaged food) may increase the risk of infertility in women (15).

Alcohol

In men, alcohol consumption has been linked with negative side effects such as testicular atrophy, diminished libido and reduced sperm count (19, 20, 21). Links between alcohol and sperm morphology have been observed alongside an impact on morphology and motility (22).

In women, alcohol consumption has been shown to increase the length of time taken to conceive (23), decrease the conception probability rate by over 50% (24), decrease the implantation rate, increase the risk of spontaneous abortion and foetal death (25, 26), and increase the risk of ovulatory disorders and abnormal blastocyst development (27).

The amount of alcohol considered safe when trying to conceive is not known. Couples should be advised to minimise their intake or avoid alcohol altogether when trying to conceive.

Caffeine

Caffeine has been associated with an increased time to pregnancy over 9.5 months, particularly following consumption of over 500 mg per day (28). Women who consume more than 100 mg of caffeine/day may be more likely to experience a miscarriage or spontaneous abortion (29, 30, 31). Caffeine consumption during the first trimester is linked to both miscarriage and stillbirth (32). The risk of stillbirth increased by almost 80% and 300% following the consumption of 4-7 cups and 8 cups of coffee, respectively (33).

Exercise

Physical activity may help improve ART outcome, with women exercising in the year prior to receiving infertility treatment, being more likely to have a positive outcome (6). Higher implantation and live birth rates have been documented in women who remain active during infertility treatments (7, 8)

Sleep

Adequate sleep is an important factor for human health and wellbeing (9). However, the link between sleep quality and reproductive health is largely unknown. Sleep disturbances are related to high levels of stress and anxiety, and may therefore indirectly affect reproductive health in both partners, as well as testosterone production and semen parameters in the male partner (10).

Toxic exposure

While the human body has defences to protect against the environmental toxins to which it is exposed through eating, drinking, breathing and skin contact, these chemicals may also have a negative impact on fertility. Patients should therefore be advised to minimise their exposure as much as possible.

Air pollution has been found to affect morphology and motility, and to increase DNA fragmentation (34, 35, 36). For women, exposure to air pollution can lead to preterm delivery, miscarriage, stillbirth, spontaneous abortion and foetal loss (37, 38).

Recommendations for clinics

Diet and lifestyle should be discussed sensitively and without apportioning blame. Aim to start from the couple's current position and move them forward step by step. Everyone has a different 'baseline' and too much too soon can be overwhelming. Both couples should ideally be involved in the process. The best results are achieved when the patient agrees to the steps to be taken. For example, when discussing reduced alcohol consumption, discuss with the patient whether total abstinence is the best option for them or whether they would prefer to consume a set number of units on set days of the week or each month. It is important for the patient to feel involved in these discussions in order for targets to be achievable.

With the above in mind, help clients to:

- stop smoking
- if overweight, aim for slow, steady weight loss (no fad diets);
- Do not advise patients to follow a low-fat diet, but encourage them to limit their carbohydrate intake to no more than a small portion (potatoes, pasta, rice, beans) at each meal. Healthy fats, protein and fibre should also be included in each meal to keep hunger pangs at bay (consider eggs, poultry, fish, nuts and seeds as well as all vegetables).

- (see exercise, below) If underweight, do not advise patients to eat 'junk foods'. Instead, explore whether their digestive system requires attention and screen for coeliac disease as this may affect nutrient absorption without exhibiting any gastrointestinal symptoms. Advise patients to snack on high-calorie, nutritious foods such as nuts, seeds and avocado on crackers.
- The Mediterranean diet is mostly akin to the types of foods that promote fertility. Print out the Mediterranean diet pyramid or recommend a good Mediterranean cook book.
- Foods to include: legumes, wholegrains, fruits, vegetables, olive oil, poultry, eggs, fish (including oily fish twice a week), herbs and spices.
- Foods to limit: red meat, sweets, products made from refined flour such as white bread and pasta.
- Advise patients to cook from scratch wherever possible and to avoid heavily processed foods.
- Inquire whether patients are getting 7-9 hours of good quality sleep each night, and whether they feel refreshed on waking. Recommend some of the following for those with sleeping problems: meditation apps, gentle yoga exercises, turning phones off in the evening, installing blackout blinds and establishing a healthy bedtime routine.
- Both partners should ideally partake in gentle exercise for 30-60 minutes daily, such as walking, swimming, yoga or Pilates. Some muscle building is preferable since this helps to increase the metabolic rate. However, over-exercising may be detrimental for both partners.
- Strategies to reduce toxic exposure may include avoiding cycling in traffic, taking the scenic route in order to avoid polluted roads, using more natural hygiene products and cleaning products, purchasing an air purifier if living or working in a polluted environment, and reducing the use of plastics such as cling film, plastic food containers or water bottles.

References

1. Anderson, K., Nisenblat, V., Norman, R., Lifestyle factors in people seeking infertility treatment - A review. Aust N Z J Obstet Gynaecol. 2010; 50 (1): 8-20.
2. Homan, G.F., Davies, M., Norman, R., The impact of lifestyle factors on reproductive performance in the general population and those undergoing infertility treatment: a review. Hum Reprod Update. 2007; 13 (3): 209-223.
3. Mitra, A., Chakraborty, B., Mukhopadhay, D., Pal, M., Mukherjee, S., Banerjee, S. et al., Effect of smoking on semen quality, FSH, testosterone level, and CAG repeat length in androgen receptor gene of infertile men in an Indian city. Syst Biol Reprod Med. 2012; 58 (5): 255-262.
4. Ruder, E.H., Hartman, T.J., Reindollar, R.H., Goldman, M.B., Female dietary antioxidant intake and time to pregnancy among couples treated for unexplained infertility. Fertil Steril. 2014; 101 (3): 759-766.
5. Braga, D.P., Halpern, G., Figueira, R.de C., Setti, A.S., Iaconelli, A. Jr., Borges, E. Jr., Food intake and social habits in male patients and its relationship to intracytoplasmic sperm injection outcomes. Fertil Steril. 2012; 97 (1): 53-59.
6. Evenson, K.R., Calhoun, K.C., Herring, A.H., Pritchard, D., Wen, F., Steiner, A.Z., Association of physical activity in the past year and immediately after in vitro fertilization on pregnancy. Fertil Steril. 2014; 101 (4): 1047-1054.
7. Ferreira, R.C., Halpern, G., Figueira, R.de C., Braga, D.P., Iaconelli, A. Jr, Borges, E. Jr., Physical activity, obesity and eating habits can influence assisted reproduction outcomes. Womens Health (Lond). 2010; 6 (4): 517-524.
8. Palomba, S., Falbo, A., Valli, B., Morini, D., Villani, M.T., Nicoli, A. et al. Physical activity before IVF and ICSI cycles in infertile obese women: an observational cohort study. Reprod Biomed Online. 2014; 29 (1): 72-79.
9. Luyster, F.S., Strollo, P.J. Jr., Zee, P.C., Walsh, J.K., Boards of Directors of the American Academy of Sleep Medicine and the Sleep Research Society. Sleep: a health imperative. Sleep. 2012; 35 (6): 727-734.
10. Kloss, J.D., Perlis, M.L., Zamzow, J.A., Culnan, E.J., Gracia, C.R., Sleep, sleep disturbance, and fertility in women. Sleep Med Rev. 2015; 22: 78-87.
11. Mendiola, J., Torres-Cantero, A.M., Vioque, J., Moreno-Grau, J.M., Ten, J., Roca, M., Moreno-Grau, S., Bernabeu, R., A low intake of antioxidant nutrients is associated with poor semen quality in patients attending fertility clinics. Fertil Steril 2010, 93: 1128–1133.

12. Wong, W.Y., Zielhuis, G.A., Thomas, C.M., Merkus, H.M., Steegers-Theunissen, R.P., New evidence of the influence of exogenous and endogenous factors on sperm count in man. Eur J Obstet Gynecol Reprod Biol 2003, 110: 49–54.
13. Silver, E.E.W, Effect of antioxidant intake on sperm chromatin stability in healthy non-smoking men. J Androl 2005, 26: 550–1336.
14. Showell, M.G., Brown, J., Yazdani, A., Stankiewicz, M.T., Hart, R.J., Antioxidants for male subfertility. Cochrane Database of Systematic Reviews (Online) 2011. 1:CD007411, doi:10:1002/14651858.
15. Chavarro, J.E., Rich-Edwards, J.W., Rosner, B.A., Willett, W.C., Protein intake and ovulatory infertility. Am J Obstet Gynecol 2008, 198: 210. e1,210.e7.
16. Clark, A.M., Thornley, B., Tomlinson, L., Galletley, C., Norman, R.J., Weight loss in obese infertile women results in improvement in reproductive outcome for all forms of fertility treatment. Hum Reprod 1998, 13: 1502–1505.
17. Kirchengast, S., Gruber, D., Sator, M., Hartmann, B., Knogler, W., Huber, J., Menopause-associated differences in female fat patterning estimated by dual-energy X-ray absorptiometry. Ann Hum Biol 1997, 24: 45–54.
18. Grodstein, F., Goldman, M.B., Cramer, D.W., Body mass index and ovulatory infertility. Epidemiology 1994, 5:247–250.
19. Muthusami, K.R., Chinnaswamy, P., Effect of chronic alcoholism on male fertility hormones and semen quality. Fertil Steril 2005, 84: 919–924.
20. Donnelly, G.P., McClure, N., Kennedy, M.S., Lewis, S.E., Direct effect of alcohol on the motility and morphology of human spermatozoa. Andrologia 1999, 31:43–47.
21. Olsen, J., Bolumar, F., Boldsen, J., Bisanti, L., Does moderate alcohol intake reduce fecundability? A European multicenter study on infertility and subfecundity. European Study Group on Infertility and Subfecundity. Alcohol Clin Exp Res 1997, 21: 206–212.
22. Gaur, D.S., Talekar, M.S., Pathak, V.P., Alcohol intake and cigarette smoking: Impact of two major lifestyle factors on male fertility. Indian J Pathol Microbiol 2010, 53: 35–40.
23. Mutsaerts, M.A., Groen, H., Huiting, H.G., Kuchenbecker, W.K., Sauer, P.J., L. and J.A., Stolk, R.P., Hoek, A., The influence of maternal and paternal factors on time to pregnancy–a Dutch population-based birth-cohort study: the GECKO drenthe study. Hum Reprod 2012, 27: 583–593.
24. Hakim, R.B., Gray, R.H., Zacur, H., Alcohol and caffeine consumption and decreased fertility. Fertil Steril 1998, 70: 632–637.
25. Rasch, V.: Cigarette, alcohol, and caffeine consumption: Risk factors for spontaneous abortion. Acta Obstet Gynecol Scand 2003, 82: 182–188.
26. Windham, G.C., Fenster, L., Swan, S.H.: Moderate maternal and paternal alcohol consumption and the risk of spontaneous abortion. Epidemiology 1992, 3: 364–370.
27. Gill J.: The effects of moderate alcohol consumption on female hormone levels and reproductive function. Alcohol 2000, 35: 417–423.
28. Bolúmar, F., Olsen, J., Rebagliato, M., Bisanti, L., European Study Group on Infertility and Subfecundity. Caffeine intake and delayed conception: A European multicenter study on infertility and subfecundity. Am J Epidemiol 1997, 145: 324–334.
29. Stefanidou, E.M., Caramellino, L., Patriarca, A., Menato, G., Maternal caffeine consumption and sine causa recurrent miscarriage. Eur J Obstet Gynecol Reprod Biol 2011, 158: 220–224.
30. Cnattingius, S., Signorello, L.B., Anneren, G., Clausson, B., Ekbom, A., Ljunger, E., Blot, W.J., McLaughlin, J.K., Petersson, G., Rane, A. et al, Caffeine intake and the risk of first-trimester spontaneous abortion. N Engl J Med 2000, 343: 1839–1845.
31. Tolstrup, J.S., Kjaer, S.K., Munk, C., Madsen, L.B., Ottesen, B., Bergholt, T., Gronbaek, M., Does caffeine and alcohol intake before pregnancy predict the occurrence of spontaneous abortion? Hum Reprod 2003, 18: 2704–2710.
32. Greenwood, D.C., Alwan, N., Boylan, S., Cade, J.E., Charvill, J., Chipps, K.C., Cooke, M.S., Dolby, V.A., Hay, A.W., Kassam. S. et al, Caffeine intake during pregnancy, late miscarriage and stillbirth. Eur J Epidemiol 2010, 25:275–280.
33. Wisborg, K., Kesmodel, U., Bech, B.H., Hedegaard, M., Henriksen, T.B., Maternal consumption of coffee during pregnancy and stillbirth and infant death in first year of life: Prospective study. BMJ 2003, 326: 420.
34. Chalupka, S., Chalupka, A.N., The impact of environmental and occupational exposures on reproductive health. JOGNN 2010, 39: 84–102.
35. Jurewicz, J., Hanke, W., Radwan, M., Bonde, J.P., Environmental factors and semen quality. Int J Occup Med Environ Health 2009, 22: 305–329.
36. Sokol, R.Z., Kraft, P., Fowler, I.M., Mamet, R., Kim, E., Berhane, K.T., Exposure to environmental ozone alters semen quality. Environ Health Perspect 2006, 114: 360–365.
37. Chalupka, S., Chalupka, A.N., The impact of environmental and occupational exposures on reproductive health. JOGNN 2010, 39: 84–102.
38. Ritz, B. Wilhelm, M., Hoggatt, K.J., Ghosh, J.K., Ambient air pollution and preterm birth in the environment and pregnancy outcomes study at the University of California, Los Angeles. Am J Epidemiol 2007, 166: 1045–1052.

Chapter 3

Support from the outset

Sarah Banks
Mandy Rodrigues
Stephanie Toulemond
Olivia Montuschi

Abstract

Emotional support for patients has become increasingly important in recent years, and with many reporting feelings of depression, anxiety, isolation and loss of control, patients are looking to their clinic to provide more than just medical care.

Studies have shown that patients undergoing ART are at high risk of experiencing psychiatric disorders. They therefore need to receive support in coping with their diagnosis and treatment.

Support should not be one size fits all, and clinics need to offer a range of support services so that patients can access the most appropriate for them. Additional consideration should be given to those looking at other routes to parenthood, using donated gametes, travelling overseas for treatment or making a decision to end treatment, in order to ensure they get the additional support they need.

Patients should be encouraged to access appropriate support and should feel supported by all clinic staff at every point of contact.

This chapter provides information to help you understand how patients feel and practical tools you can use to support your patients' emotional wellbeing throughout treatment.

The emotional impact on fertility care staff working in an emotionally charged environment will also be discussed. Studies show that poor doctor wellbeing is associated with a higher likelihood of doctors delivering suboptimal care and a lower likelihood of delivering better quality care. In contrast, good doctor wellbeing is associated with greater patient satisfaction and better compliance.

This shows that factors such as stress and burnout impact healthcare provision and patient outcomes. Medical staff with less stress, more support and coping mechanisms have more energy and mental resources to direct their full attention to patients.

Staff support, training and provision of resources are important to prevent potential staff burnout, poor job satisfaction and a high staff turnover.

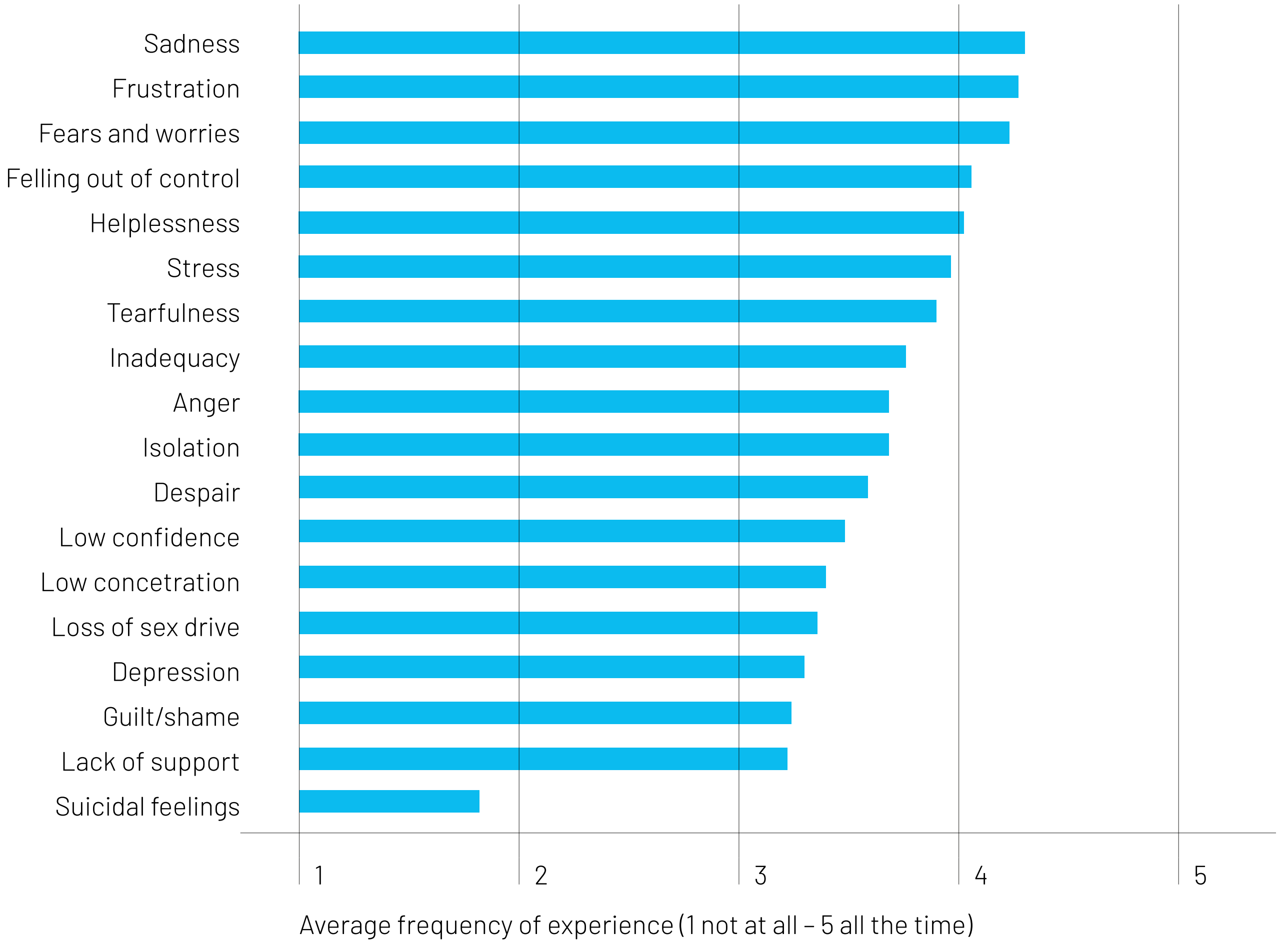
3.1
Emotional support for patients

Introduction

Research has shown that women struggling with infertility experience the same level of depression as women with Cancer, HIV and heart disease (1), and 42% of respondents in a recent Fertility Network survey reported having felt suicidal at some point (2).

If you apply that percentage to the number of women undergoing IVF in any one year, over a million women worldwide potentially feel suicidal every year due to infertility. And that figure does not include those who are not currently receiving treatment and who cannot afford to have treatment - hence the percentage number including this group would be much higher than 42%, especially in the case of couples who have very little support and struggle with cultural taboos. Patients who are struggling to conceive report feelings of depression, anxiety, isolation and loss of control. The inability to conceive naturally can cause feelings of shame, guilt and low self-esteem. These feelings may lead to varying degrees of depression, anxiety, distress and a poor quality of life.

Figure:
The psychological impacts of fertility problems and treatment



Fertility Network Study (2)

This shows the huge emotional trauma caused by infertility and explains why these women may struggle with the intensity of treatment. It also demonstrates why providing a high level of emotional support is critical for helping patients cope whilst going through fertility treatment.

Studies have shown that *'patients who undergo assisted reproductive treatment (ART) are at significant risk of experiencing psychiatric disorders and it is important to recognise, acknowledge and assist these patients as they cope with their infertility diagnosis and treatment.'* (3)

The studies concluded that 25% to 60% of infertile individuals report psychiatric symptoms and that their levels of anxiety and depression are significantly higher than in fertile controls (3).

Patients spend a significant amount of time at their fertility clinic, and it is important that they receive emotional support throughout treatment. Research has shown that *'1 in 10 patients chooses not to start treatment due to a number of reasons, including rejection of treatment, personal reasons, relational problems, financial issues, and psychological burden of treatment.'* (4) (5)

It is not enough to just provide access to a psychological counsellor. Patients should be encouraged to access appropriate support and should feel supported by all clinic staff at every point of contact.

Emotional support is subjective - all patients cope in different ways and are affected by infertility in different ways. Studies show that the longer patients have been trying to conceive and undergoing ART, the more their depression increases, the more suicidal thoughts they express, and they will need different levels of support.

'Those most in danger of experiencing high levels of distress and suicidal feelings were those who had unsuccessful treatment, who spent longer trying to conceive, who experienced some relationship strains and who had less support from friends and family.' (2)

The ESHRE guidelines study concluded 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 wellbeing and compliance with treatment.'* (5).

A survey by the HFEA (6) of over 1000 patients and their partners on the service they received at their clinic, found that:

- Improving patient satisfaction is likely to have the greatest impact on overall satisfaction with the fertility process as a whole.
- Many spoke highly of the healthcare professionals, yet some felt that the healthcare professionals lacked empathy and that the process felt rushed.

Whilst emotional care in clinics is good, there is still work to do in terms of increasing the emotional support they offer patients, and their understanding of the emotional impact on patients and how they can better support them.

Clinics should recognise that if they are supporting patients in every communication they have with them, those patients will feel more valued and trusting of the clinic. Patients will be able to cope more effectively with treatment and will return to their clinic for further treatment.

Discussion and Recommendations

Emotional support is the responsibility of all members of staff

- It is important to create a culture within the clinic where all staff understand their responsibility to support patients at all stages of their treatment and at every appointment. There should be a whole team approach to support that includes all members of staff, from receptionists through to consultants. Patient support should not just be the responsibility of the counsellors. Everyone should understand their responsibilities in supporting patients – what it includes and why it is important.
- ESHRE guidelines on patients' preferences state that *'fertility staff should be aware that patients value how staff relate to them, staff showing that they understand the emotional impact of infertility, that both partners are involved in the treatment process and the decision-making, receiving psychosocial care from sensitive and trustworthy members of staff and receiving care for their direct needs based on their medical history.'*(5).

Provide staff training on the emotional impact of infertility and how to offer more emotional support

- Staff need to have a good understanding of how patients feel when going through treatment so that they can empathise with their patients and support them effectively.
- *'Fertility patients have clear preferences about the care they receive – fertility staff should know these preferences and incorporate them into their service delivery.'*(5)
- Clinics should provide staff training on the emotional impact of infertility, empathy and patient support to ALL members of staff. Refresher training and new staff induction on emotional support should also be provided. The ESHRE GDG concluded that *'Fertility staff must inform themselves of the specific needs patients experience at different treatment stages and tailor psychosocial care accordingly.'*(5)

Emotional support for patients is important at all stages of treatment, from the very first to the very last point of contact they have with the clinic.

- Every point of contact, for every patient, with every staff member should be supportive.
  It is important for patients to feel safe and supported from their first point of contact with a clinic to ensure that they feel comfortable starting treatment. Research shows that patients will choose their clinic based on their first impressions. They will choose not to start treatment if they do not feel that they can cope with it and they will stop treatment if they do not feel supported.
- The 2018 HFEA Pilot study found that 36% of patients chose a particular clinic for treatment based on a good initial impression of the clinic and staff. (6)

All staff to provide empathic patient-centred care and understanding throughout the patient's time with the clinic.

- ESHRE guidelines state that *'receiving patient-centred care is associated with better patient well-being, positive staff characteristics (communication, respect, competence, involvement and information) are associated with better patient well-being and positive clinic characteristics (information, competence of clinic and staff and continuity) are associated with better patient well-being.'*(5)
- Deliver clear, supportive and timely communication in patient-friendly language.
- Provide patients with one consistent point of contact at the clinic to provide consistency, avoid patients repeating their details to different members of staff and to make patients feel important.

Provide information on the support services available and clearly explain the benefits of support.

- Offer a range of support services to allow patients to choose the most appropriate for them, with different levels of support to suit different patient needs, and provide 24-hour support. Clinics should actively encourage patients to access additional emotional support, especially counselling, and signpost the services regularly. It is also helpful to provide information to take away, in the patient's own language, so that patients can re-read it in their own time.
- Provide individualised support information, relevant to the patients' circumstances - same sex couple, solo parenting, donor recipients.
- ESHRE guidelines state that *'patients value the offer of specialized psychosocial care (infertility counselling or psychotherapy) when they have expressed a need for emotional support and the provision of information about psychosocial care options (contact details of support groups, online support options, access to counselling).* (5)
- Support services could include infertility counselling, support groups, buddy systems, patient information sessions, leaflets on coping mechanisms and signposting local/national resources (HFEA, FNUK, Resolve). Clinics could look at forming links with trusted support services to expand the support available if there are no in-house teams. A 2016 Fertility Network study found that 17% of respondents had attended a support group but 52% would have liked to attend had there been one. (2)

Create links with local GPs to start the support earlier

- Work is needed to educate and inform GPs so that they are more able to support patients. Care plans should be drawn up around continuous tailored care and improved communication. *'A good start to the treatment process is crucial; the qualitative phase suggests that negative experiences at this stage can have a negative impact on patients and can make them question whether the rest of the fertility experience will be difficult / challenging.'* (6)

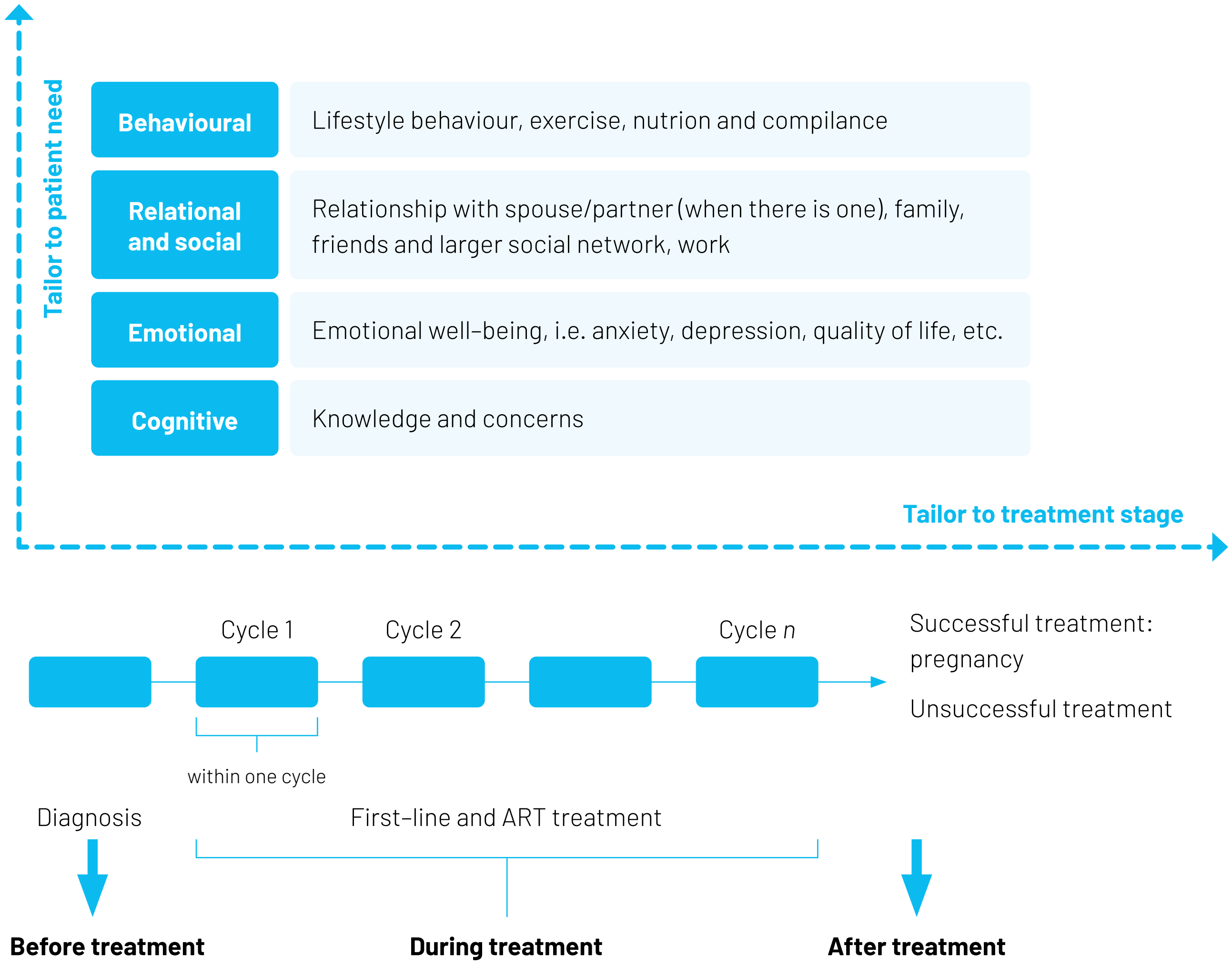
Show an interest in patients as persons and treat them as individuals.

- *"The key driver model shows that the main drivers of satisfaction are the "interest shown in you as a person", the quality of counselling and the coordination and administration of treatment. Improving patient satisfaction for this measure is likely to have the greatest impact on overall satisfaction with the fertility treatment process as a whole.'* (6).

Create a robust feedback process on patient experience, including emotional support, with a clear process for acting on feedback.

- Clinics should create a process that ensures that patient feedback on emotional support is monitored, with feedback acted upon and discussed in full team meetings.

Figure:
Schematic representation of the guideline approach for the provision of psychosocial care tailored to specyfic infertility and assisted reproductive technology (ART) treatment stages and patient needs.



Behavioural	Lifestyle behaviour, exercise, nutrition and compilance
Relational and social	Relationship with spouse/partner (when there is one), family, friends and larger social network, work
Emotional	Emotional well-being, i.e. anxiety, depression, quality of life, etc.
Cognitive	Knowledge and concerns

ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction (4)

Before Treatment

Provide patients with a clear understanding of the IVF process to allow them to make informed decisions on treatment. Give them the opportunity to ask questions and discuss their concerns, without passing judgement.

ESHRE GDG recommends that *'fertility staff should provide preparatory information about medical procedures because it decreases infertility-specific anxiety and stress and that staff offer patients the opportunity to discuss uptake or not of recommended treatment and receive decisional support to deliberate their choice.'*(5)

- Provide patients with written/online information on the process to take home to re-read after the appointment. This information should be clear, concise and written in a patient-friendly manner. It should be provided in the patient's own language.
- *'Sometimes the amount of information received in the consultation can be overwhelming, and it would be helpful to have hard-to-access information recorded to take away, either in note form or as a voice recording.'*(6)
- Provide individualised information on treatment for the patients' specific circumstances - donor recipient, surrogacy, same sex couples, solo parents.
- Provide patients with clear information on success rates, in a clear and easy-to-understand format. The HFEA survey found that *'not being informed of success rates left patients feeling confused, with some saying it made the process harder to comprehend.'*(6)
- Providing patients with one point of contact throughout treatment will build trust and reduce stress and repetition for the patient.

Provide information to support patients in making lifestyle changes that will aid their fertility, health and emotional wellbeing.

- ESHRE GDG recommends *'providing patients with information about lifestyle behaviours that may negatively affect their general and reproductive health, and support patients in changing lifestyle behaviours that negatively affect their general and reproductive health, as well as their chances of treatment success.'*(5)

Provide patients with one point of contact throughout treatment

Use SCREENIVF to identify patients at risk of developing emotional problems and help them to access emotional support.

- THE ESHRE GDG recommends that fertility staff use the SCREENIVF before the start of each treatment cycle to assess the patient's risk factors for emotional problems after the cycle. *'Some patients are more vulnerable to the demands of treatment and need additional psychosocial care or specialised services.'*(5)
- By identifying the patients who may develop emotional problems, staff can be watchful for signs and encourage them to access emotional support. However, it is important that all patients are offered emotional support to ensure that everyone who needs it knows how to access it.

During treatment

Be aware of the points of treatment where patients are most anxious and incorporate more support into that part of the treatment process.

- ESHRE GDG found that *'emotional stress fluctuates throughout the cycle, with the peaks when patients are awaiting results - egg retrieval, embryo transfer and the waiting time before the pregnancy test.'*(5)
- Put processes in place to have more contact with patients at key points of treatment as outlined above (calls, text message to check in with patients).
- Remind patients of the support services available and how they can access them.
- Allow more time in appointments at key points of treatment for patients to ask questions and get reassurance.

Encourage patients to find ways of coping during treatment and provide information on active coping tools to deal with the stress of being overwhelmed and the grief of infertility

- ESHRE Guidelines state that *'The use of meaning-based coping (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, and the use of active coping (goal-oriented problem solving, thinking rationally about the problem) seems to be associated with lower infertility distress* (5).

Talk through any changes to their treatment plan and provide patients with the opportunity to talk about treatment with key members of staff.

- Patients need reassurance on changes (why treatment is changing, and what it could mean for the outcome) and want to feel informed about the treatment process.

After treatment

After a failed cycle

Emotional support is most important at this stage of treatment, regardless when the failure occurred.

Verhaak *et al*, 2007, found that *'patients experience high emotional distress when they are informed that the treatment was unsuccessful, and that 1 to 2 in 10 women experience clinically significant levels of depressive symptoms.'* (5)

'The further into treatment a patient goes, the more often they display symptoms of depression and anxiety. Patients with one treatment failure had significantly higher levels of anxiety, and patients with two failures experienced more depression when compared with those without a history of treatment.' (3)

Support for patients after a failed treatment cycle

- Remind patients of the availability of an infertility counsellor, the benefits of their help and encourage them to access this support. The ESHRE GDG recommends that *'fertility staff refer patients who, after unsuccessful treatment, experience or are at risk of experiencing clinically significant psychosocial problems to specialised psychosocial care (infertility counselling or psychotherapy).'* (5)
- Maintain contact with patients whilst waiting for their follow-up appointment – build points of contact with patients into the process after a failed cycle - for example, a wellbeing call, text message as a reminder of the support available. This will create a better experience for your patients and they will be more likely to continue treatment with you.
- Keep the waiting time between a failed cycle and the follow-up appointment as short as possible to reduce patient anxiety.
- Make time in the follow-up appointment for patients to ask questions and provide the opportunity for them to speak to the embryologists for more information on their specific case.

The care and support you provide will dictate whether they want to start another cycle of treatment with you. Patients may move clinics or stop treatment if the care they receive is inappropriate. *'Patients also cite negative experiences of care as a reason for discontinuing fertility treatment'* (4).

A study on the link between stress and infertility found that *'the more depressed the infertile woman, the less likely she is to start infertility treatment and the more likely she is to drop out after only one cycle. Researchers have also shown that despite a good prognosis and having the finances available to pay for treatment, discontinuation is most often due to psychological reasons.'* (3)

After a positive test result

Continue to offer support to patients when they get a positive pregnancy test. Many women still feel anxious that something will go wrong with the pregnancy. *'Women who have conceived with IVF/ICSI may experience more pregnancy-specific anxiety than women who conceived spontaneously.'* (5)

- Refer them to more psychological support if staff feel they are at risk of experiencing clinically significant psychosocial problems after successful treatment.
- Continue to offer emotional support to patients after a positive result in line with the continued medical care before referring them to the maternity services.
- ESHRE GDG recommends offering patients the opportunity to discuss their pregnancy concerns.

3.2

Exit strategies

'For women at the end of their fertility journey, deciding when to stop treatment is incredibly difficult. It is important to always remain sensitive to the fact that their wished-for future as parents (or in completing their family in cases of secondary infertility) not being achieved, can lead to isolation, loss of identity and purpose for a time.' (9)

Provide support to patients in making the decision to stop treatment.

Provide access to counsellors, allow time during consultations for patients to talk about their medical situation and chances of success, and encourage access to support groups with others who are in the same situation.

- *'Referral to counselling can help people to process their treatment experiences, grieve their losses, reflect on and make decisions about alternative parenting options or plans for a childless future.'* (9).

Provide tools to patients to give them support in making decisions about stopping treatment, coping with the feelings of grief, thinking about alternative parenting options or deciding how to move forward with their lives without children.

'An increasing number of people are reaching the end of their reproductive window without having the children they wished for. Substantial research shows that adjusting to this can be challenging, as people often undergo a grief process.' (10)

- Provide patients with access to support tools such as 'My Journey', which is a self-help interactive programme that provides step-by-step support to help develop skills to address several aspects and ease acceptance of an unfulfilled wish for children. *'Research by My Journey indicates that guided psychosocial support can facilitate people's adjustment to their unfulfilled wish for children. It may also encourage people to seek further support if they feel they need it.'* (10)

- Create an in-house support hub, app or website to ensure patients can be supported as they consider alternative parenting options or moving forward with their life. This promotes continuity of patient care and ensures patients feel fully supported throughout their treatment experience.
- Provide information on support organisations and charities that support patients in making the decision to stop treatment and how to live a fulfilled life without children (for example: Fertility Network, Resolve, Gateway Women, Walk in our shoes).

Provide information to patients on other routes to parenthood, but in a sensitive manner, with the opportunity to talk through them if the patient would like to.

- *Information about alternative parenting options is often available in clinics, but it is important that nurses can sensitively signpost women and their partners to other resources about living life without children. This needs to be managed according to the needs of that woman (and partner), particularly as feeling alone and isolated are common following unsuccessful treatment, and they may not yet be ready to hear about alternatives.'* (9).
- Link with charities that provide this information so it can be backed up by support. For example, the Fertility Network UK have provided Options Packs to patients in the UK which include information on donor conception, adoption, and fostering, together with support for people who are involuntarily childless or who have a family smaller than they had hoped for as a result of secondary infertility.

Conclusion

A survey by the HFEA of over 1000 patients and their partners found that improving patient satisfaction is likely to have the greatest impact on overall satisfaction with the fertility process as a whole. (6)

As many research studies have shown, infertility patients experience distress, depression, anxiety and a reduction in their quality of life. *'It is important for infertility providers and counsellors to offer assistance to these patients by way of psychological interventions and emotional support.'* (3)

A review by Cardiff University and the Domar Center for Mind/Body Health (7) states that ART should look at enhancing the delivery of treatment for patients and staff by minimising the sources of burden felt by patients, clinics and staff.

It states that two specific burdens can be addressed:

- Patient vulnerability – this can be tackled by screening for psychological distress, referring to appropriate support, reducing barriers to support and identifying the points of treatment where more support should be offered.
- Negative patient – staff interactions – this can be tackled through staff training in communication and interaction skills, encouraging shared decision-making, prioritising support that addresses aspects of treatment that are problematic for patients and staff, and monitoring the outcome of these changes on patients, staff and clinics.

Implementing the recommendations from this section into your processes will ensure that your patients have a better treatment experience, which will help them cope better with treatment and the outcome (positive or negative). They will feel happier, more in control and less overwhelmed and they will have more trust in you as a clinic and their treatment plan.

References

1. The psychological impact of infertility: a comparison with patients with other medical conditions – Domar, A.D., Zuttermeister, P.C., Friedman, R.
2. Fertility Network UK Survey on the Impact of Fertility Problems, 2016, Payne, N., Van den Akker, O.
3. The Relationship between stress and infertility. Rooney, K.L., Domar, A.D.
4. Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. 2012. Gameiro, S., Boivin, J. Peronace, L., Verhaak, C.M.
5. ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction – a guide for fertility staff, 2015. Gameiro, S., Boivin, J., Dancet, E., de Clerk, E., Emery, M., Lewis-Jones, C., Thorn, P., Van den Broeck, U., Venetis, C., Verhaak, C.M., Wischmann, T., Vermeulen, N.
6. HFEA Pilot national fertility patient study, 2018, HFEA.
7. Optimal in-vitro fertilization in 2020 should reduce treatment burden and enhance care delivery for patients and staff, Gameiro, S., Boivin, J., Domar, A.D.
8. A cross-sectional cohort study of infertile women awaiting oocyte donation: the emotional, sexual and quality of life impact. Carter, J., Applegarth, L., Josephs, L., Grill, E., Baser, R.E., Rosenwaks, Z.
9. Royal College of Nursing Fertility Care and Emotional Wellbeing RCN Guidance, 2020
10. My Journey, website developed by Cardiff University Fertility Studies, in collaboration with APFertilidade - Portuguese Fertility Association and Fertility Network UK

3.3
Benefits of a patient mentor programme

Section 3.1 showed the huge emotional trauma caused by infertility and why providing a high level of emotional support at all levels and throughout the process is critical for helping patients cope whilst going through fertility treatment. In addition to the psychological support from clinic staff and professionals, it is important to note that patients value *"the provision of opportunities to contact previous patients, and the organisation of live support groups with other patients."* (1)

Figure 11 in the previous section 3.1 shows that infertility problems trigger emotions such as isolation, guilt/shame and lack of support (2). Infertility often comes with a certain social stigma: fertility patients isolate themselves from their close circle, keeping silent about what they are going through out of guilt, shame or lack of understanding from their family and friends.

The Internet offers an unlimited number of online peer support groups. These groups have a clear beneficial effect allowing fertility patients to:

- reduce the feeling of isolation (3), experience that they are not alone in this situation and receive emotional support from others who understand the challenges of infertility and its treatment,
- increase knowledge and empowerment in treatment decision-making (3)
- normalise their situation,
- get advice on coping strategies from others who have been on the same journey.

A study confirmed that most men (80.1%) and women (89.8%) expressed interest in online peer support (4). The Internet therefore provides the option to receive information and support in an anonymous, accessible and cost-effective manner. However, it also has the potential to reinforce isolation (5). From this perspective, one-to-one inter-patient support that is organised and promoted by the clinic can provide all the benefits of peer support (reduce isolation, increase knowledge and normalise the situation) without the drawbacks of exclusive online support.

One potential problem associated with a patient mentor programme is the risk of patients giving inappropriate advice (medical or psychological) - especially in cases where former patients mentor current patients. This should be taken into account by the clinic when creating a mentor programme.

Recommendations

- Propose one-to-one support between patients in similar personal and medical situations (social status, age, type of treatment)
- Each patient will be an individual point of contact for another patient who is undergoing the same kind of treatment (i.e. IVF, egg donation, etc.) and who has the same personal situation (e.g. heterosexual couple, homosexual couple, single women). Patients will give their written permission before being put in contact with anyone.
- Explicit rules and conditions regarding participation will be established. The aim is to share experiences and emotional support, NOT to share medical information and/or advice, and to keep all discussions confidential.
- The clinic must refute any responsibility regarding the content of the conversation and exchange of information.

Propose support groups within the clinic

- With the same explicit rules and conditions as for programme participation.
- With different groups depending on the type of treatment (OFV, egg donation, etc.) and personal situation (heterosexual couples, single women, lesbian couples).
- The meetings will be supervised by clinic staff (psychologist or counsellor).
- Meetings should take place at least once or twice a month to provide an effective support service to patients.
- Consider running online and face-to-face support groups to provide different levels of support and anonymity for patients.
- Invite staff members and trusted support services to speak at the group sessions to give advice on key topics and to answer questions.
- Promote the support groups in all forms of patient communication to heighten awareness of the peer support available.
- Consider setting up a separate support group (online or face-to-face) for men only, to give them a safe space to talk and receive support from other men.

References

1. A systematic review published in 2010 included 51 studies from 14 countries, evaluating patients' experiences with fertility care (Dancet, et al., 2010).
2. Fertility Network UK Survey on the Impact of Fertility Problems, 2016, Payne, N., Van den Akker, O.
3. Malik and Coulson, 2008b: Computer-mediated infertility support groups: an exploratory study of online experiences
4. Infertility patients' needs and preferences for online peer support - Paul H. Grunberg, Cindy Lee Dennis, Deborah Da Costa, Phyllis Zelkowitz Hinton et al., 2010: Infertility; isolation and the Internet: a qualitative interview study.

3.4
Supporting staff

Introduction

Within the multidisciplinary fertility clinic team, there is a need to train all staff in communication skills in order to facilitate patient satisfaction, treatment compliance and patient retention. The fertility clinic setting is characterised by a lack of control, helplessness and emotional challenges for the patients, which may impact on the staff member's ability to deliver compassionate care. This may be due to feeling overwhelmed or to a lack of training. Staff support and Continuing Professional Development (CPD) are important to mitigate against potential staff burnout and work dissatisfaction along with a high staff turnover, possibly compromising care and pregnancy rates along the way. This section addresses the type of care to be offered to patients and how this assists clinic staff both professionally and personally.

Clinics work within a multidisciplinary practice. Patients encounter a number of specialists including reception staff, accounting staff, nurses, treatment coordinators, theatre staff, fertility specialists and embryologists. Many clinics are fortunate in that they have trained psychologists or counsellors to provide patient support. However, this is not always the case, notwithstanding the fact that patients may be reluctant to attend counselling or may need immediate feedback from staff members available in that precise moment in time. Burnout has been addressed in health-care professionals dealing with patients in terms of their own ability to deliver potentially bad news and to control their own emotions. They might also have their own ethical or moral codes of behaviour, which make the task more challenging. It is important to provide the team with psychological support and relevant training in communication skills in order to manage patients holistically.

Rationale

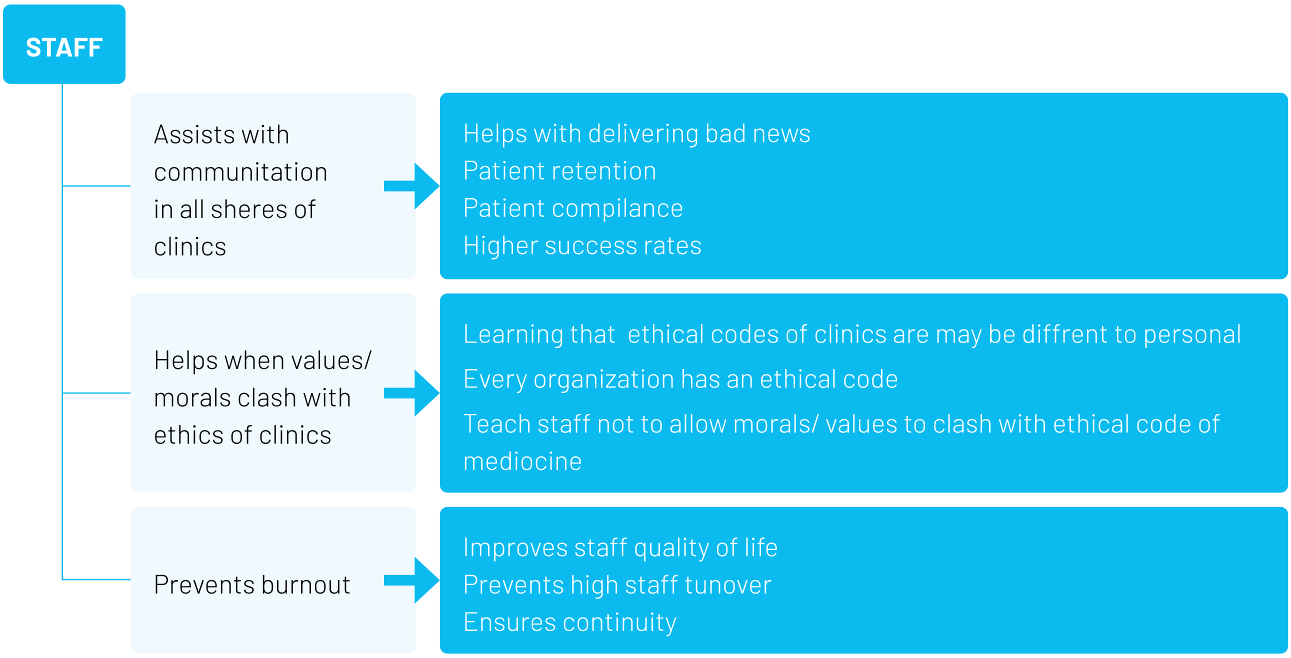
Studies state that patients are reluctant to seek psychological support. This highlights the importance of all staff being trained in communication skills (1). Furthermore, over time, patients are more likely to challenge doctors and speak out - hence communication skills are imperative from the ground up. Person-centred therapy is primarily based on the work of Carl Rogers, a humanist, whose theory included warmth, congruence and empathy. This provides the basis for the manner in which patients can be managed effectively and with kindness, without giving solutions or directives. The fertility clinic setting does not always allow communication on all aspects of care, but the compassion and warmth shown by staff members in all patient interactions goes a long way. Person-centred therapy is based on simple, easy-to-follow principles which are transferable to all members of staff. In the fertility clinic context, many individuals deal with patients and it is not easy to deliver bad news or manage the ensuing repercussions. Every patient wants to feel like a person, and not just a number, and this transcends the contact not only with counsellors but with the entire multidisciplinary team.

Guidelines in communication of entire team

Whole team

- Fertility specialist
- Labolatory staff
- Coordinators
- Nursing staff
- Psychologists/ counsellors
- Reception
- Accounts team

Caregivers have an ethical responsibility to treat the couple as well as future generations. Caregivers often bear the brunt of this emotionally charged journey and require skills to understand and manage it effectively. The goal of all involved is time to pregnancy. Complaints frequently emerge that staff are not suitably adept at managing the emotional needs of patients. Patients value continuity of care and relationships with familiar staff. They value staff who are sensitive and attentive. This transcends the entire process, from the very first point of contact to the fertility specialist. Patients also appreciate consistency and a reasonable timeframe to discuss their fertility concerns in a holistic manner without fear of judgement. The roles and responsibilities of various staff members need to be clear. In fact, some studies revealed that patients were willing to trade off ongoing pregnancy rates in favour of care, and a large number of patients changed clinics due to a lack of compassion or patient centredness (2). Furthermore, the attitudes of staff impacted on treatment success and satisfaction with care and compliance (3).



STAFF

Assists with communitation in all sheres of clinics

Helps with delivering bad news
Patient retention
Patient compilance
Higher success rates

Helps when values/ morals clash with ethics of clinics

Learning that ethical codes of clinics are may be diffrent to personal
Every organization has an ethical code
Teach staff not to allow morals/ values to clash with ethical code of mediocine

Prevents burnout

Improves staff quality of life
Prevents high staff tunover
Ensures continuity

Learning that ethical codes of clinics may be different.
Why is person-centred therapy the method of choice? There have been many debates over the years as to whether therapy is an art or a science. Science translates to knowledge of theory and learning whereas art requires softer skills which can be taught to others. This model teaches people to remain supportive, positive and non-judgemental whilst a patient is expressing negative emotions or simply looking for someone to listen to them.

It is acknowledged that fertility clinics sometimes have to deliver bad news to a patient. The patient's negative emotion might be directed towards the bearer of the bad news and some members of staff might take this personally. Fertility staff must also be sufficiently knowledgeable about the psychosocial care available to effectively address the patients' needs and refer them to the correct support networks or resources. Given the relative simplicity of person-centred care, this care can be delivered by all staff members within their specific roles, whilst still acknowledging the need for trained mental health professionals such as psychologists, counsellors and/or psychiatrists (4). Person- centred therapy emphasises the attitudes and personal characteristics of the individual, i.e., the particular staff member, and the quality of the relationship between two people, i.e., the patient and the staff member. Person-centred therapy not only benefits patient-staff interactions but also relationships between colleagues as the premises of person-centred therapy are universal. The model is simple, comprising three premises:

Warmth

Congruence

Empathy

1. Warmth or unconditional positive regard.

   This is the individual's attitude of acceptance, respect and care. This does not imply that the caregiver agrees with everything the patient says. However, the caregiver has a fundamental belief that all people are born good, and have the potential to self-actualize, given the right environment. This unconditional positive regard allows a patient to express what he or she feels or thinks without fear of being judged.
2. Congruence is honesty and transparency.
3. Empathy is a skill used by trained person-centred caregivers to show understanding of the patients' emotions. It involves techniques such as reflecting on the patients' emotion.

The person-centred approach utilises non-directiveness as a technique. This refers to empowering the patient to make his or her own decision within a non-judgemental environment. This is why person-centred therapy is useful across the entire fertility clinic as even those staff members who do not have answers or whose role excludes giving advice can make use of this model to engage with patients in any setting. The role and responsibility as healers and participant observers in the patient relationship can be challenging. Being a participant observer means you have to remain objective, yet is in a relationship with the patient, you are probably emotionally invested as well.

Much research has focused on potential staff burnout in medical settings (5). The healthcare industry and especially the field of infertility, which is often shrouded with uncertainty, challenges staff-patient relationships. Burnout challenges staff retention and is detrimental to patient care. Warmth and compassion are integral to person-centred care. The more you tend towards burnout, the less likely you are to express compassion (6). This is why it is imperative to include professional training in patient-centred therapy as well as support for staff. Job satisfaction nurtures the ability to express compassion. A lack of job satisfaction can lead to compassion fatigue, which is another way of describing burnout. CPD and regular staff support and debriefing, can mitigate against burnout. CPD and regular evaluation of staff practices can help staff discuss their interaction with patients, including the challenges they face and ways to improve. It has been suggested that new staff members be trained in person-centred care from the onset in order to gain competency. The following recommendations are provided for clinics (8):

Suggestion for clinic

Hiring of staff

Teaching staff basics of person-centered approach (PCA)

Ongoing training

CPD talks and assessments on PCA

Debrefing

Drebrefing sessions

Culture

Creating PCA amongst staff culture

Process

Implement a blended learning approach

Outcome

Patient freedback

Staff turnover

Blending learning:
Resources-written
Group interaction
Lectures
Visual material

Debriefing:
Awareness of diferences in values and ethics
Take into account religious, spiritual, own moral code

Teaching Person-Centered Approach

Includes skills such as:
Listening skills via
Role playing
Simulation
Non-verbal behaviours

Assessments

We would probably describe ourselves as persons of integrity, believing in justice, mutual respect and hard work. These are all values and moral qualities in which we believe. On the other hand, there are ethics which consist of a set of rules that determine how to behave within a specific moral framework, i.e. ethics determine what is acceptable in society while values determine what is important. A code of ethics and morals can be summarised below:

The ethical standards and guidelines implemented in medicine are there to protect the interests of patients, employers and the government that regulates ART. These ethical codes consist of uniform guidelines. Whilst values and morals differ from person to person, ethics are a set of rules according to which people should behave within the workplace. What is moral is not always ethical and vice-versa. The concept of Omerta in the Mafia, where Mafia members have an ethical code of silence, historically used to protect criminals from the police, provides one example. This is deemed ethically correct behaviour for the organisation but can also be viewed as wrong from a moral standpoint. In law, a lawyer who tells the court that his/her client is guilty may be acting out of a moral desire to see justice done, but this is deeply unethical because it violates the attorney-client privilege. In an ideal world, we want compatibility. In reality, we have to find a way to bridge the gap between personal values and ethical standards within an organisation.

Both ethics and values set guidelines for behaviour. We tend to think ethics, morals and values are the same thing. However, the distinct difference is that ethics are codes of conduct which vary across sectors. ART has had a dynamic history. Up to the birth of Louise Brown in 1978 through IVF, this particular sector had limited means to help patients. Since then, ART has become more readily available and this explosion of knowledge has brought with it a myriad of new challenges ethically, morally, socially and legally. Fertility clinics ethically take into account decisions regarding the futility of ART, the LGBTQ+ population, single parenthood, unmarried couples, donor eggs, sperm and gametes, surrogacy, the number of embryos to be transferred, selective reduction and termination, to mention the most pressing. Ethically, we cannot discriminate. However, individuals within the clinic setting have different viewpoints, different religions, morals and values. It is suggested that these be addressed by a mentor or team leader within the clinic to have peace of mind that one is working within an organisation that has its own ethical code that might not necessarily be compatible with personal morals or values. However, staff need to be trained to prevent personal values from leading to judgmental behaviour towards patients.

Conclusions and recommendations

Patient retention, treatment compliance and patient satisfaction are not only driven by time to pregnancy and success rates. These factors are also determined by the care and compassion offered to patients from all staff members. Training staff in person-centred therapy promotes effective communication, warmth and empathy on a journey fraught with helplessness, disappointment and anxiety. Staff also need to understand their roles and responsibilities in communicating with patients, and person-centred therapy provides a framework in which to empower the patient in a non-directive manner. Furthermore, training in effective communication mitigates against burnout, and staff retention is improved, thus benefitting patients attending a fertility clinic.

References

1. Boivin, J. (1999), Why are infertile patients not using psychosocial counselling? Human Reproduction, 14 (5), 1384–1391.
2. Domar, A.D. (2020), Patient Retention, Nursing Retention: The Importance of Empathic Communication and Nursing Support. Domar, A.D., Sakkas, D., Toth, T.L. (Eds.). Patient-Centred Assisted Reproduction. Cambridge University Press: United Kingdom.
3. Gameiro, S., Canavarro, M.C., Boivin, J. (2013), Patient-centred care in infertility health care: direct and indirect associations with wellbeing during treatment. Patient Education and Counselling, 93, 646-654.
4. Pedro, J., Canavarro, M.C., Boivin, J., Gameiro, S. (2013), Positive experiences of patient-centred care are associated with intentions to comply with fertility treatment: findings from the validation of the Portuguese version of the PCQ-Infertility tool. Human Reproduction, 28, 2462-2472.
5. Gameiro, S., Boivin, J., Domar, A. (2013), Optimal in-vitro fertilization in 2020 should reduce treatment burden and enhance care delivery for patients and staff. Fertil Steril, 100, 302-309.
6. Wilkinson, H., Whittington, R., Perry, L., Eames, C. (2017), Examining the relationship between burnout and empathy in healthcare workers: A systematic review. Burnout Research, (6), 18-29.
   Santana, M.J., Manalani, K., Lu, M. (2018), How to practice person-centred care: A conceptual framework. Health Expert, 21(2), 429-440.

3.5
The needs of national and international patients

Introduction

A growing number of patients travel abroad to undergo fertility treatments – a worldwide phenomenon called Cross-Border Reproductive Care (CBRC).

A systematic review (1) shows that the main reasons for choosing CBRC are related to regulatory, ethical or legal restrictions in the country of origin, and that some additional factors include a lack of expertise in the home country, the cost of treatment, the lack of publicly funded treatments and excessive waiting times.

CBRC can therefore be broadly explained as follows:

MAIN REASONS WHY INTERNATIONAL PATIENTS TRAVEL FOR ART	
Regulatory, ethical or legal restrictions in the country of origin	1. Eligibility criteria, mainly related to: – Social status (for example: single women, homosexual couples) – Patient's age (patients having reached the maximum age in their home country) 2. Illegality of some treatments or medical procedures in the home country. Some examples in France: – DGP – Fertility preservation for non-medical causes, – ART with non-anonymous donors (for example, Portugal and Denmark in Europe)
Expertise	Lack of expertise in the home country causing patients to travel to countries with better quality care and success rates
Timing	Excessive waiting times in the home country to: – Start ART – Benefit from a donor's eggs due to a shortage of donors
Costs	Benefit from more accessible treatments in countries where costs are lower (for example, Czech Republic in Europe)
Other sociocultural considerations	Additional sociocultural considerations are sometimes involved, such as social acceptability of ART in the home country (for religious or cultural reasons, or for age reasons).

Specificities of international patients

Clinical evidence

In the absence of specific studies or evidence regarding the psychological and emotional impact of undergoing ART abroad, the Patient Care Guidance Development Group based their recommendations on different studies not specific to CBRC, but whose conclusions are particularly relevant for international patients. Those conclusions relate to:

1. **The impact of organisational and logistic problems on fertility patients:**

   A review of the reasons for discontinuing fertility treatments (2) shows that organisational problems (14%) are the 5th reason why patients discontinue treatment following an initial failed ART cycle after financial issues (50%), the psychological (22%) and physical (17%) burden of treatment, and clinic-related reasons (17%).

   A review evaluating patients' fertility care experiences (3) identified that some of the main features of clinics deemed important by patients are related to practical and organisational aspects: the waiting time during treatment, the frequency of appointments, the distance to the clinic, the duration of the consultation and the waiting time for the first appointment.

   Another study (4) showed that the majority (62%) of fertility patients with paid work reported IVF-related absence from work averaging 23 h compared to 9.5 h for non-IVF-related absence.

   - **Relevance for international patients:** the logistic practical and organisational aspects are particularly critical for international patients who face more complex organisation and logistics procedures, extra costs and considerable absence from work due to the need to travel for treatment.

2. **The emotional and social needs of fertility patients, especially during the oocyte retrieval to transfer stage:**

   Studies show that emotional and cognitive needs are related to the uncertainty surrounding treatment outcome, and tend to peak just before oocyte retrieval, embryo transfer and the pregnancy test (5). Women perceived less social support during the retrieval to transfer stage, but more support during the waiting stage of the IVF cycle than during equivalent stages in the normal menstrual cycle (6).

   - Relevance for international patients: during 2 of these 3 critical stages (oocyte retrieval and embryo transfer), international patients are not in their home country and can therefore face additional stress and emotional distress coupled with less social support (distance from home and close circle).

3. **The importance of clear, fluid communication and of providing transparent and understandable written information about the treatment.**

   Various studies (3)(5)(6) have assessed and confirmed the importance of clear, customised information, communication, and education for fertility patients to help dispel anxiety and stress specifically related to patient infertility. The Van Empel study (5), in particular, stated that patients were willing (hypothetically) to sacrifice 9.6% in pregnancy rate for receiving clear, customised information.

   - **Relevance for international patients:** the physical distance and language difference can make it more difficult to guarantee access to and clear understanding of information, communication and education.

Additional stress and anxiety factors for international patients

In addition to the emotional distress and psychological burden related to ART treatments in general, undergoing ART treatments in a clinic in a foreign country inevitably comes with additional stress and anxiety factors related to:

STRESS or ANXIETY FACTORS	FACTS
The logistic and organisational complexity of the process	– International patients travel several times to the country in which the clinic is located (first visit, egg and sperm retrieval, embryo transfer). – They have to leave their home country for 1 to 7 days per cycle, and need to organise their work and social obligations accordingly. – For the egg collection and embryo transfer, international patients have little visibility regarding the exact date of the procedure - and therefore tend to organise their trip (hotel and travel) at the last minute.
The complexity of the process per se	ART in general and the various steps involved can be complex and difficult for patients to understand and remember. – This complexity is increased for international patients because of the physical distance involved, the cultural and linguistic differences and the need to travel at some point in the process (beginning in the home country and finishing in the destination country).
The social impact of ART abroad	– International patients need to justify repeated absences and travels abroad - at work, and to their friends and family. – International patients usually travel alone or with their partner and face less support from their close circle during emotionally challenging moments such as oocyte retrieval or embryo transfer.
The lack of knowledge of the country of destination	International patients do not always know the country or city to which they are travelling. Language or cultural differences, fear of the unknown as well as the lack of information about local therapists and local support can make it more emotionally challenging for patients and more difficult to organise.
The financial cost of the treatment	– When the reason for CBRC is legal, social or medical (see chart "Main reasons for international patients to travel for ART"), the cost of ART per se is often greater than in the home country and is not covered by their social security system. – The logistic costs of travel and hotel accommodation bring additional financial pressure. This, in turn, triggers strong psychological pressure regarding the final result and the option to repeat treatment if unsuccessful.

Recommendations for improving the care of international patients

Specific needs of international patients

Fertility clinic staff should take into account that:

- International patients are **likely to face additional stress before and at the beginning of ART (stimulation phase)** because of the distance, additional costs, lack of knowledge of the country of destination and the complexity of organising ART abroad,
- International patients may experience more **emotional distress and anxiety, especially during the critical phases of oocyte retrieval and embryo transfer, as they are in an unknown environment at key points in the cycle** when with they have less emotional and social support from their close circle,
- Consequently, international patients often place **greater demands** on their fertility clinic in terms of communication and emotional support from staff.
- International patients therefore have **specific needs** that fertility clinic staff can address by guaranteeing:
    - Easy access to regular, clear and understandable information, in their own language, before, during and after the treatment,
    - A rapid response to patients' questions and demands,
    - Transparency regarding the different options available and the budget,
    - Additional attention to patient care: staff showing empathy and understanding, being sensitive and trustworthy, and focusing on the emotional impact of ART for international patients,
    - Emotional support in the patient's language from current and former patients, and from clinic staff or collaborators (psychologist, counsellor, coach)

Recommendations

BEFORE TREATMENT	
Provide written information in the patient's language comprising:	– Complete, clear, personalised and understandable preparatory information (or guide) for the patient to take home – Individualised information on treatment to suit the patient's specific circumstances – Details of all the different steps involved in the process, in both the home country and the country of destination, and the organisational implications, – A clear explanation of the medical procedures and potential outcomes. – Clear information on success rates – This guide will increase the patients' knowledge and reduce the stress related to uncertainty, fear of the unknown and the sensation of losing control of the process. – Total transparency from a financial perspective (no hidden conditions). It is important to run through the budget in person (or during an online consultation). Do not just send it out by email. – Clear information about the legal & medical differences between countries (information about donors, laws governing ethics, etc.). This information should, also be provided in written format.
Provide emotional support in their language	– Propose emotional and psychological support systematically from the first consultation – and not only to patients identified as "at risk" of experiencing psychological problems or distress during treatment. – Include in the process and budget one diagnostic session with a psychologist, counsellor or coach in the patient's mother tongue (either one-to-one or online). – Suggest that patients be accompanied by a "mentor": a former patient from their home country, who has also undergone fertility treatment in the same foreign country and faced the same logistic and organisational issues.

DURING TREATMENT	
Reduce the number of persons in contact with the patient	– Just one communication contact (coordinator) from beginning to end, ideally from the same country of origin (or at least, totally bilingual). – Just one doctor for all the procedures throughout the process (first visit, insemination, egg retrieval, egg transfer, follow-up)
Continued information throughout the process	Communicate with the patient at least once a week throughout the process, even when there are no advances and no new information to share (for example: in the weeks/months of searching for a donor, in the lead-up to the pregnancy test, and between 2 treatments).
Guaranteed response	Document and strictly respond to emails and phone calls within2 h in the case of urgent messages during the protocol (from onset of stimulation to the pregnancy test); respond within 24 h in all other cases.
Provide emotional support in their language	– Propose emotional and psychological support to all patients, – Suggest a "mentor".

AFTER TREATMENT	
Provide emotional support in their language	Propose at least one session with a mother-tongue psychologist, counsellor or coach regardless of whether the result is positive or negative.
Provide information and explanations	Online appointment with the doctor during results' week to explain the outcome and assess options.

References

1. A systematic review published in 2011, called "Cross-border reproductive care: a review of the literature" (Hudson, N., Culley, L., Blyth, E., Norton, W., Rapport, F., Pacey. A.) included 18 empirical research studies and 36 debate papers.
2. "Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment" (Gameiro, S., Boivin, J., Peronace, L., Verhaak, C.M., Hum Reprod Update 2012; 18: 652-669).
3. A systematic review published in 2010 and including 51 studies from 14 countries, evaluating patients' experiences with fertility care (Dancet, et al., 2010).
4. A prospective cohort study which followed up 380 women with a paid job while they underwent a standard IVF cycle (Bouwmans, et al., 2008).
5. Van Empel et al. collected data from 925 individuals undergoing any stage of fertility treatment at eight ART clinics (van Empel, et al., 2011).
6. A prospective cohort study comparing the daily reactions of 20 women during an IVF cycle with their reactions during a regular menstrual cycle (Boivin and Takefman, 1996).
7. Pook and Krause conducted an RCT to assess an intervention based on an information leaflet for infertile men starting infertility diagnosis (Pook and Krause, 2005).

3.6
Donor conception is different

Introduction

This section puts the case that donor conception is significantly different from fertility procedures undertaken with a couple or the individual's own gametes. In many ways it is not 'fertility' treatment at all but a different route to parenthood and needs to be acknowledged as such.

People considering donor conception will need to engage with issues that others undergoing treatment with their own eggs or sperm do not have to consider. First and foremost is the perspective and long-term well-being of the child they hope to create. The upshot of this is the responsibility to share with the child the fact that he/she was donor-conceived and, if possible, to have some information available about the donor(s). Sharing information about donor conception with significant others in the child's life is also an important consideration.

Background

In the past, secrecy about donor conception, from the child and others, was considered to be in the best interests of all parties. It was believed to protect the infertile parent from societal censure, the doctors concerned from professional disapproval, and the child from bewilderment and mockery. There was also a lack of clarity around the legal status of the parent and donor.

But times and opinions have now changed. Parents are more willing to share information about their use of donated gametes. Many now see it as ethically wrong to conceal the truth from their children. Clinics advertise rather than hide their donor conception services.

Donor-conceived adults – those who have been told about or who have discovered their beginnings – are asserting their rights not only to be told but also to find out about their genetic heritage. States and private organisations now keep registers of donor- conceived individuals and donors. Direct-to-consumer DNA testing now provides previously unforeseen opportunities. Adult individuals may discover that a parent or parents is/are not as they expected. They may also be able to connect with genetic relatives. The USA is leading the way in connecting groups of half-siblings and sometimes their donor as well, but this is also happening in Europe. Clinics need to recognise that anonymous donation cannot be guaranteed and that secrecy is not a wise strategy for parents.

These are all reasons why donor conception is different to creating life with the parents' own gametes and why potential parents need to think about their children's future before rather than after treatment.

The role of clinics and support organisations is important in helping potential parents to understand from the outset that donor conception is a different way of forming a family and, not just a modified IVF treatment cycle. Donor conception is not right for everyone.

The move from secrecy to openness

The DC Network refers to 'openness' rather than 'disclosure' about donor conception because openness indicates a state of mind over time and disclosure implies a one-off sharing of the information. A willingness to be open with other family members and with the child may be a good indicator that would-be parents have moved on from feelings of their own loss and sadness and are focusing on the child-to-be.

Good support from their clinic staff and counsellor is important in helping to bring about this change in mind-set. But for many would-be parents, contact with other families through a support organisation such as the DC Network can be a major confidence booster. Parents who are at ease with the decisions they have made and are comfortable talking about donor conception are most likely to raise children who are confident in their own identity.

Loss

When an individual or couple need help to conceive a child, loss is an inevitable part of the process: loss of hopes and dreams of producing a child with a partner through an act of love, loss of control as cycles and medical processes seem to dominate every facet of life and the loss of spontaneous connection. Donor conception adds another layer of loss for all types of family.

Everyone experiences the loss of a full genetic link and the need to acknowledge the fact that another man or woman, known or unknown, is helping to produce the child they will raise. Many single women and men may regret not having a partner to have a child with; lesbian and gay couples would have liked to create a new life with their partner; and heterosexual couples, assuming that they would be able to conceive without help, grieve their inability to do so and the loss of their beloved partner's contribution to creating the child they so hoped to have together.

Donor conception offers the hope of a child but, unless losses are acknowledged and grieved for initially, it is hard, particularly for heterosexual couples, to move to a place where hope is the dominant emotion. Clinic staff who understand this can support couples and individuals in the grieving process by not pressing them to make decisions about donor conception too quickly. The passage of time is not only hugely valuable for healing wounds created by loss, but it is also likely to result in better decision-making when the time is right.

Loss is not just felt by those seeking treatment. Staff who have invested professional and emotional energy to help those who have not achieved a pregnancy despite numerous attempts may feel loss or even a sense of failure. Because of the emphasis on own-gamete conception, it can sometimes be quite difficult for staff to close the door on this option and suggest donor conception instead. To overcome feelings of inadequacy, guilt or loss per se, the implications of this move may be minimised. It can be helpful for staff to be able to recognise their own feelings and get support if necessary. This will help them to better focus on supporting the person or persons concerned in grieving their loss and considering gamete donation. Counselling can be valuable for everyone involved.

Who is the donor?

Attitudes to donors have changed over time. In the past, sperm donors were considered simply as providers of a means to an end. Their contribution was gratefully received by clinics and recipients alike, but no-one wanted to know more about them as people.

More recently, parental attitudes to children have begun to change. A minority of parents started to reject the advice they had received. Secrecy, they thought, was not a sound basis for strong family relationships. It was ethically wrong to conceal the truth from children about important facts that concerned them.

In the UK, a social movement to encourage parents to tell their children about their conception grew. At the same time, the voices of donor-conceived adults who had discovered their origins were starting to be heard. They asserted a right to know who their biological fathers were. Simply telling children they were donor-conceived was not enough. Some countries, including the UK, provided additional non-identifying information and made this available to potential parents. The donor as a recognisable individual began to emerge, thus challenging the idea of anonymity.

Starting with Sweden in 1985, some countries, including the UK in 2004, passed laws to allow identifying information about donors (and sometimes half siblings) to be accessible to donor-conceived people at the age of 18. Donors were also given rights to limited information about the outcome of their donations. Known donation from a family member or friend became more widely considered and donor conceived adults gave their seal of approval.

Direct-to-consumer DNA testing

More recently, the landscape has completely changed once again with direct-to-consumer DNA testing becoming widely available, inexpensive and popular. As a result, connections are being made, both intentionally and unintentionally, between donor-conceived people and their donors, and between donor-conceived half-siblings. Because of the potential for future connection, the donor needs to be acknowledged from the outset as a real person who could enter the life of a donor-conceived person at some point.

It is a modern reality that must be understood by donors, parents and potential parents as well as by donor conception and clinical professionals.

Specific implications for each family type

Heterosexual couples: Moving from own-gamete treatment to considering using a donor or donors is a major transition for most couples. As with all transitions feelings can be up and down, changing daily and hourly. A complication can be if each partner feels differently about donor conception. If well supported and un-pressured about decision-making, couples may move from feeling devastated to accepting the use of gametes from another person to help create the situation they desire – parenthood. Others may come to the decision that it is not right for them, and possibly their culture or community, to bring a child created in this way into their world. Both decisions should be considered appropriately good outcomes. Counselling, ideally more than one session, can be very beneficial in helping would-be parents to understand the responsibilities of becoming a parent by donor conception and to decide whether or not they feel they can take these on.

Single women and men: Becoming a parent without a current partner is a life-changing decision for most women and men contemplating donor conception (plus surrogacy for men). As well as the emotional impact, there are the practical considerations of parenting alone to take into account. Single women with fertility issues find that the move from using their own eggs to accepting double or embryo donation can be a transition similar to that faced by heterosexual couples and often felt as an additional loss. Reassessment of her situation with the support of a counsellor can be helpful as a woman not only needs to adjust to her own loss but also to the potential losses felt by her child who will be raised without a second parent or a genetic link to their mother.

Solo parenthood for men is a newer phenomenon but shares some features with single women. With the support of a clinic team and counselling services, men wishing to become single parents can be helped to understand their responsibilities and the challenges they may face in making the best decisions for their child.

Same-sex couples:
For many same-sex couples, the dominant emotion on contemplating donor conception is delight that there is now a way for them to have a genetically connected family.

Female couples may face difficult questions about which partner should carry a child or attempt a pregnancy first. One woman may donate an egg to her partner so that she might experience pregnancy and birth whilst the genetic connection would be with the donating partner. Fertility difficulties may also be encountered, leading to the need for double embryo donation and the associated feelings of loss of genetic connection.

For male couples, which partner should provide the sperm to create an embryo with an egg from the surrogate mother or egg donor, is often a tricky question. Some male couples seek to create embryos with sperm from each partner and then have one from each man transferred to the uterus of a surrogate. The hoped-for result is twins where no-one should know the genetic link to each man.

In the UK, the right of a child to know their genetic parentage has been law since 2005 and British men who have twins created in this latter way cannot gain full legal parentage until their children have undertaken DNA tests to establish genetic links to each partner. The genetic relationship may feel irrelevant to the parents but is important information for the children.

Same-sex couples must inevitably start to share information about donor conception with their children and others before their offspring encounter children from heterosexual families in nursery onwards. Gay men are probably more likely to talk about their surrogate (and hopefully have an on-going relationship with her) but, if a separate egg donor was used, she may not be mentioned and the child and others may come to believe that the surrogate is the genetic as well as the birth mother.

Counselling and good preparation for donor-conception parenthood by the clinic or a support organisation like DC Network, can be helpful to all potential parents in addressing the issues that are specific to them, as well as those they share with other family types.

Using donor conception following unassisted conception or IVF with own gametes

Some families may find themselves seeking donor conception whilst already being a parent to a child conceived without donor assistance. Exactly the same principles regarding loss, adjustment over time and openness with all children and significant others apply. It is important for these parents to explore how they feel about having children with different origins and how this may impact each child and the whole family. DCN has a booklet that can help potential parents address the many questions they may have.

Using a different donor for second or subsequent children

Where there are no frozen embryos from a previous cycle of donor IVF or IVF was not used for a previous donor pregnancy, it is sometimes not possible for the same donor to be used for a second or subsequent child. Parents seeking full biological siblings often find this situation distressing. Counselling is likely to be helpful for parents, supporting them in thinking through what is most important to them and what might or might not be important for the siblings. All the same principles outlined in this section apply.

Cross-border differences

As previously mentioned in this chapter, many people seek donor conception procedures in countries other than where they are citizens. This is due to a number of reasons but primarily speed of treatment, availability of donors, money and the ability to have a procedure that is not allowed in their own country.

For example, egg donation is prohibited in a number of European countries. This means that those people for whom egg donation is the only way they might be able to conceive, must either forgo their dreams or travel abroad. If they conceive and return to their own country for the pregnancy and birth of the child, they are confronted with both legislative and cultural differences and have to decide whether or not to reveal their method of conception. If they do not reveal it, then inappropriate testing may be proposed during pregnancy and openness with the child will be compromised.

Women from the UK sometimes go elsewhere in Europe for egg donation because treatments are cheaper there. In most of these countries, the donors remain anonymous and little information is given. On returning to the UK, parents discover the prevailing culture of openness and may feel bad about having little information to share with their children and no way, other than a DNA test, for children to find genetic relatives.

Parents with anonymous donors sometimes console themselves about the lack of information by assuming that DNA testing will solve this issue in the future. This is, however, not guaranteed and even if the donor is identified they may reject contact because they did not agree to their identity being known. In addition, there may be language and cultural difficulties.

It is vital that these issues are raised with potential parents, ideally by counsellors, but they should also be embedded in the culture of the clinic where patients begin and end their treatment.

Donor conception tomorrow?

We have witnessed the wind of change in social attitudes, legal rights and scientific progress over the last generation. What felt unthinkable 30 years ago is happening today, and what feels unthinkable today will likely be happening 10 or 20 years from now. Donor-conceived children born today will see changes during their lifetime that we cannot accurately predict.

While the desire to create families and have children - regarded as a "human universal" - is unlikely to change, the ways of meeting the needs of those for whom the route to parenthood is not straightforward will inevitably alter. It is impossible to predict the future norm. Will intending parents and gamete donors expect to meet each other ahead of any medical procedures, in much the same way that intending parents and surrogates do now? Will the role of clinics continue to involve matching donors and recipients or will they only carry out the medical treatment? Will central registers of donors and treatment cycles still be maintained? Will the business of counsellors expand or contract? What will be the implications for birth certification and legal responsibility? Or will all of these questions be bizarrely outdated 20 years from now?

Recommendations

- Recognise that donor conception is different
- The first responsibility of those who manage fertility clinics is to make sure that their clinic culture acknowledges that donor conception is different. Appropriate recruitment, staff training and support should all reflect this.
- All those contemplating donor conception should be prepared for a different kind of parenthood. Support organisations and counsellors have a major role to play here.
- All clinic staff need to be willing to engage with the particular issues that would-be donor-conception parents face.
- Clinics must acknowledge that time to grieve, consider and move to the right decision for individual/couple and child, is vital,
- Donors and prospective parents need to be aware of the implications of DNA testing with respect to openness and anonymity. It should also be noted that DNA testing is not a panacea for anonymity.
- The mind-set and feelings of parents and donor-conceived children and adults can change over time. Parents need support to understand that the choices they make before treatment could have implications in the future.

Chapter 4

Virtual communication with patients

Veronica Montgomery
Julie Morgan
Andreia Trigo

Abstract

In this chapter we explore the many forms of virtual communications that fertility clinics may adopt to communicate with infertility patients. The purpose of this chapter is to provide guidance for clinics on best practice to ensure transparency for patients enabling them to make good, safe choices when choosing their treatment provider. We examine the information patients are seeking and how that information should be displayed. By employing best practice for online communications, fertility clinics can demonstrate accountability and credibility, which is beneficial to patients.

4.1
Online communication for fertility clinics

Introduction

There are a number of ways in which fertility clinics can communicate with their patients online. It is worth checking with all the professional bodies of which you are a member for specific guidance and advisories. You should also check with your local medical council about advertising. The medical councils in some countries prohibit doctors from advertising their services. The nature of online communication means that clinics can advertise their services to audiences outside of their physical location. In light of the Covid-19 pandemic, fertility clinics have had to adapt and adopt a more online approach to communicating with patients.

Clinic websites

Your fertility clinic website is your shop window to the world. As such, you have a duty of care to ensure that the information provided is accurate and up to date. The first consideration for your website is security. It is important that your website has a secure sockets layer (SSL). This protocol for web browsers and servers allows for authentication, encryption and decryption of data sent over the Internet. This is displayed via the URL with https://. This is crucial if your site has a payment portal and if you collect patient data.

In October 2020, a joint cybersecurity advisory was co-authored by the Cybersecurity and Infrastructure Security Agency (CISA), the Federal Bureau of Investigation (FBI) and the Department of Health and Human Services (HHS) in the USA. This advisory describes the tactics, techniques and procedures used by cyber criminals to target the healthcare sector for financial gain (1).

It is worth investing in a web expert either in-house or engaging the services of a specialist provider to ensure your site is visible on the web and that the site is secure.

Since fertility patients will be looking at a number of clinics, your website needs to be transparent with easily accessible information. More specifically, patients are most interested in your success rates, treatment price list and accreditation. The hardest element for patients is to compare success rates between clinics. Try to make yours as clear and concise as possible to enhance the patient experience.

Depending on where you are based and where you expect your visitors to be located you will also need to ensure that your privacy policy and your terms and conditions are clearly displayed. If you expect your website visitors to be in Europe then you will need to be GDPR-compliant. As a medical facility you will already have systems in place to protect patient confidentiality and this also applies to all data that you collect via your website. Your website may connect to a customer relationship management (CRM) system. If so, you need to ensure that these data are stored securely and are not accessible via your website.

For information and tips for best practice on your website, please read this blog (2).

Data collection and storage

You can collect patient data in a number of ways. You may have an online contact form via your website. This would usually document the patient's name, date of birth, home address, contact phone number, email address and medical history. When a patient enters this information, you need a disclaimer to advise them on how this data will be stored and have an opt in if you intend to keep this data for future marketing purposes.

All data that you collect must be stored securely with only a limited number of staff having authorised access to this information.

Social media

Social media refers to all public networking platforms where patients can interact with you as a service provider and other patients. These platforms provide an excellent opportunity for fertility clinics to share educational content. They are a good marketing tool to inform patients about specific infertility problems and demonstrate the expertise of your clinicians.

These platforms also provide an opportunity to broadcast in real time directly to patients and take live questions. It is important that your social media channels are monitored daily and that you have a dedicated team to generate content and monitor public comments.

According to the American Society for Reproductive Medicine (ASRM) guidelines on the use of social media in reproductive medicine:

- Patients use social media to get help and support
- Women are also more likely to use social networking and health-related websites than men
- Infertile women and couples often use web-based information when selecting a medical practice
- Social media presents unique opportunities; however, challenges also exist, specifically concerning online etiquette, outreach, ethics and patient privacy (3).

Social media has the ability to reach large audiences to recruit both patients and donors. Medical providers have an ethical obligation to provide accurate, transparent information. Clinics must avoid misrepresentation or the overestimation of important metrics such as success rates.

In the USA, all assisted reproduction providers are required by law to report success rates to the Center for Disease Control (CDC). In the UK, all assisted reproduction providers report their success rates to the Human Fertilisation and Embryology Authority (HFEA). This area of misrepresentation of success rates is heavily regulated in the USA.

The Society for Assisted Reproductive Technology (SART) in the USA has a condition of membership that fertility clinics must adhere to its advertising guidelines (4). Additionally, it is understood that the provision of information and education is the central purpose of many social media posts by healthcare providers. However, this must be balanced against the ethical risks posed by giving medical advice to individuals who are not yet established patients.

Furthermore, when patients ask for direct medical advice, it is important to take the conversation out of the public domain. You can publicly reply that you will send the patient a direct message. In a private conversation you can then arrange for the patient to speak directly with the medical team, thereby creating the secure electronic patient record.

Video communication

In light of the Covid-19 pandemic, fertility clinics have had to make operational changes to replace in-person consultations with virtual consultations. For some clinics, the transition was easy if they were already providing video consultations to overseas patients. But for other clinics, the transition to telemedicine can be more of a challenge. In light of this change ASRM put together a taskforce to highlight the pitfalls for clinics when using video communication platforms to communicate with patients (5).

Regardless of your location, you are advised to follow best practice where regulation does exist. Clinics in the USA must adhere to the Health Insurance Portability and Accountability Act (HIPAA). Therefore, when choosing a suitable video communication platform, it is important to realise that free video platforms are not designed for secure patient interactions and may put your clinic and your physicians at risk. To meet HIPAA compliance, you should subscribe to a video conferencing platform that offers high-level encryption. Most subscriptions exceed federal requirements. It is also important that, as a healthcare provider, you enter a contract with your video conferencing provider. This ensures that you share liability in the event of a data breach regarding patient information. The video conferencing software must also demonstrate an audit trail of users who access the patient information with a date and time stamp. You can get more information on HIPAA-compliant video conferencing software here (6).

You may also find these FAQs useful (7).

Express permission must be given if for any reason you wish to record the patient consultation. It is also the responsibility of the healthcare provider to record the consultation on their own server and not on that of a third party. If you communicate with a patient in a non-secure fashion then you leave yourself open to litigation.

Email

Electronic communication with patients definitely enhances their patient experience with your clinic. However, as the healthcare provider, there are many pitfalls to consider and some serious investment in your information technology systems is required to ensure patient confidentiality. As previously mentioned, electronic communication for US clinics is also covered by the HIPAA Act and remains good practice for other healthcare providers to follow regardless of physical location (6).

It is important to remember that IVF patients may move to another healthcare provider and will therefore require a copy of their medical record. The easiest way to send this information is electronically and preferably through a secure patient portal.

The benefits of electronic communication are:

- patients can send their medical record and previous tests results prior to a video consultation with a physician
- healthcare providers can relay information like test results, treatment plan and specific questions in a timely manner
- patients are able to ask questions that occur to them after their consultation
- physicians can send more detailed information on specific procedures or conditions requiring management
- improves the patients' perception of your clinic and the availability of your team in terms of offering a personal, individualised treatment plan
- offers care and treatment in real time
- reduces the amount of time spent on phone calls and in-person visits.

The disadvantages of electronic communication are:

- managing patient expectations – be clear in your communication as to when patients can expect a reply. Sometimes, your reply may be instant during office hours, but patients may expect the same swift response during out of clinic hours
- assumption that a named member of staff is always available to them – highlight that urgent enquiries should be directed to reception so that an available team member can advise in an emergency
- misunderstandings – a healthcare professional will pick up on patient gaps in knowledge with regard to medication instructions in a conversation that may not be picked up in electronic communication
- stand-alone communication via email may not be linked to the patient record, therefore it is important to either integrate emails to patient records or to copy in all members of the team who may communicate with the patient
- security and privacy of emails – you need to consider who can view internal emails and if patient information can be accessed by admin staff who do not have the patients' permission to view their records
- all staff communicating with patients should bear in mind that everything they put in writing could end up in the public domain if used as evidence in a lawsuit.

Mobile messaging

Many clinics have responded to the patient demand to communicate via mobile messaging services such as Facebook messenger, SMS messaging and What's App. This also has advantages and pitfalls that healthcare providers must manage to ensure they are compliant in terms of patient information. This form of communication is excellent for responding to patients in real time and gives a personal touch to communications. However, like email communications, healthcare providers are liable for all information put in writing in this format. And like social media platforms, this form of communication should only be used for engagement and lead generation. If you publish a dedicated number on your website and social media channels then ensure that a dedicated member of staff checks these messages daily. Also ensure there is an out of office reply to manage patient expectations.

If you wish to communicate with patients via mobile messaging, you should ensure messages are encrypted. Medical history and treatment protocols should not be discussed via this method of communication. Instead, this method can be used to establish the patient's status and eligibility to open a patient record. The aim here is to move the patient from an initial enquiry to a medical consultation. No medical advice should be offered via this platform. The non-medical aspects of a patient's treatment such as travel arrangements can be discussed but should be followed up in writing via email.

Newsletters

Newsletters are a powerful tool in your marketing toolbox and should be used to your best advantage. Have a good reason to send your newsletter. Keep it short and simple. Have three key messages that you want to convey. The purpose of a newsletter is to educate your patients, who may be past, present or future. Remember, an IVF patient takes on average of two years to decide on their course of treatment and their treatment provider, so your communication relationship with the patient is likely to be longer than your actual relationship with them as a patient!

Your newsletter needs to convey news from your clinic that is beneficial to the patient. Examples of this are new techniques that have met with success, new equipment that will improve patient outcomes, and new members of staff who bring experience and commitment to patient care. You may wish to announce live social media sessions with physicians or educational seminars that you are running. Make your content engaging, share research and your insight into the world of assisted reproduction. Keep items to a couple of paragraphs and then link to the full article on your website.

For more information on newsletter best practice, please read this blog (8).

Donor selection databases

It is becoming more common practice among IVF Units to allow intended parents to access a database of both egg donors and sperm donors to make their selection. These databases hold the key characteristics of donors such as height, weight, eye colour, hair colour, level of education and a photograph to compare their likeness to the recipient. Obviously, this level of information is reassuring to patients but holds a number of challenges for the healthcare provider. These databases should be stored on the clinic's own server as opposed to a third-party server. Access to these databases requires a protected layer of security.

Firstly, the main concern is security to ensure that this sensitive information is only accessed by intended parents. There is also the issue of anonymity. Anonymous donation is not allowed in certain countries including the UK; therefore, patients may look to overseas clinics to seek an anonymous donor. However, in light of DNA testing and social media, it is best practice to advise patients that anonymity may not last forever. The European Society of Human Reproduction and Embryology (ESHRE) is currently in the process of drawing up new guidelines on Good Practice recommendations to provide information to those using and participating in reproductive donation (9).

Standard practice is for both donors and recipients to undergo psychological evaluation and counselling to fully understand the implications of using donor eggs or sperm. This would be separate from the medical advice given on the procedure per se.

Virtual educational events

Prior to Covid-19, it was common practice for clinics to hold open evenings and invite potential patients into the clinic for a tour. This was also a good opportunity for the physicians to make a short presentation and for patients to meet the nursing and case coordinators in person. The old adage applies here - 'people buy people'. Since the pandemic, clinics have had to convey this personal touch via online seminars. Although the impact is not the same, if done correctly the warmth and empathy of the healthcare providers can still be conveyed.

Patients feel disconnected from their healthcare providers, so it is important to select a subject matter that patients will find engaging. Be mindful of awareness days each month and tailor your content around the general conversation, for example PCOS Awareness Month. This is a great example of how you can show transparency. Very few PCOS patients will actually need IVF. Indeed, current data suggest that only about 5% of PCOS patients go on to have IVF. However, PCOS is one of the leading causes of infertility. These patients are desperate for information and need to have the condition managed. Therefore, running an educational seminar will see good engagement and attendance and puts your clinic in a good position. Remember IVF patients are active on social media and a lot of your referrals will come through word of mouth.

It is best practice to keep your seminars short and informative; this should not be used as a sales pitch! Ideally, you should allow between 30-45 minutes for the entire seminar from start to finish. Include question time at the end and provide a contact email address for patients to follow up in a private conversation. Remember some patients are not confident enough to ask what they feel might be perceived by others as a pointless question .

Consent forms

There are a number of consent forms that patients must fully understand and sign before treatment commences. Counselling should also be offered prior to signing any consent forms. These consent forms should include:

- how long eggs, sperm or embryos can be stored
- the type of treatment the patient will undergo, including donation
- who will be the legal parent of a child born if donated eggs, sperm or embryos are used
- the child's legal parent if the intended parents are not married or in a civil partnership
- what happens to eggs, sperm or embryos if either patient dies
- how a patient's personal information can be used.

For more detailed information on informed consent, please see the next sections 4.2.2 and 4.2.3.
The HFEA in the UK has an in-depth section on consent forms for patients, which you should familiarise yourself with to ensure best practice (10).

Conclusions

As clinics adapt to the challenges of the Covid-19 pandemic, it is apparent that online communication now plays an integral role in the operation of IVF units. It is vitally important that clinics invest in information technology to ensure security and safety of patient data. It is also important to appreciate that all forms of online communication leave an audit trail and that, as healthcare providers, the duty of care extends beyond the physical location of the clinic. To meet patient expectations and remain competitive, it is also crucial for clinics to adapt to new technologies and engage with patients in a format that patients are most comfortable with. For more information on the Marketing of IVF Units and Agencies please see here11.

References

1. https://us-cert.cisa.gov/ncas/alerts/aa20-302a
2. https://thefertilityhub.com/best-practice-on-your-website/
3. https://www.asrm.org/globalassets/asrm/asrm-content/news-and-publications/practice-guidelines/for-non-members/social_media.pdf
4. https://www.sart.org/globalassets/__sart/members-only-documents/sart-policies/sart-advertising-policy.pdf
5. https://www.asrm.org/globalassets/asrm/asrm-content/news-and-publications/practice-guidelines/for-non-members/text_email_video_communication.pdf
6. https://www.healthit.gov/topic/health-it-initiatives/telemedicine-andtelehealth
7. https://www.hhs.gov/sites/default/files/ telehealth-faqs-508.pdf
8. https://thefertilityhub.com/the-power-of-newsletters-during-the-covid19-crisis/
9. https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Guidelines-in-development/Information-provision-in-donation
10. https://www.hfea.gov.uk/choose-a-clinic/consent-to-treatment/
11. Montgomery, V. (2016), Organization and Management of IVF Units – a practical guide for clinicians. Springer 329-341.

4.2
Helping patients make good, safe choices

Introduction

Prior to 2020, the fertility industry had been slow to embrace telehealth and other technologies. Unlike our more agile colleagues, assisted reproductive technology (ART) practitioners had favoured a more traditional approach, largely due to regulation and user and provider opposition (1). However, the COVID-19 pandemic changed this, requiring fertility clinics to rapidly implement virtual consultation and communication services, with delivery of patient care transformed forever. This will continue to evolve with the development of artificial intelligence (AI) and Web 3.0. This section of the guide will address potential barriers to care, in our new virtual world, and make recommendations to fertility clinics on how to ensure that they continue to help patients make good, safe choices.

Potential barriers to care

Health Literacy

Health literacy is the capacity in which a patient is able to search for, understand and use various information sources and services in order to make appropriate treatment decisions for themselves. Health literacy varies from person to person. It depends on the level of education, age, language, culture and background (2). Lower levels of health literacy are associated with increased misunderstanding of information and decreased patient involvement in shared decision-making. Clinic staff should be aware that barriers to virtual communication, such as reduced implicit feedback, levels of digital literacy (in both patients and staff) and exclusion (not all patients are comfortable with a digital set up or have the correct equipment available to them) may reduce health literacy.

Virtual communication

As previously mentioned, communication is at the core of healthcare. Misunderstanding health information leads to errors, miscommunication and poor decision-making. Accurate information gathering enables correct diagnosis, treatment, counselling and relationship building with patients. Good communication improves the patient's emotional and physical wellbeing, increases health literacy and improves their overall experience. This then reduces treatment drop-out and the potential for complaints and litigation. However, there are a number of barriers to communication that may disrupt this process, particularly when relying solely on virtual communication. Studies have shown that 65% of communication is non-verbal. Physical appearance, eye contact, body language, tone of voice, air pressure, smell, ambient sound and feelings of empathy, all affect clarity and interpretation (3). These non-verbal clues are reduced or eliminated in virtual communication, which may cause disconnection and misunderstanding (4).

Impaired informed consent and shared decision-making

We previously mentioned the importance of consent forms and what they should include, but we would like to stress the point that informed consent can only be given by someone who is competent (has the capacity to understand the proposed action), has been given adequate information (understands the risks, benefits, consequences and possible alternatives) and who willingly volunteers their consent (without duress) (5). There are multiple factors that may affect a fertility patient's medical decision-making ability:

1. Not all clinics give adequate information to patients prior to treatment, which causes them to turn to social media and/or the Internet to fill in the gaps. This form of information is often contradictory, unreliable, incomplete and non-patient specific. This then reduces the patient's ability to provide informed consent.

2. Patients are increasingly sharing their infertility journey on social media. In 2019, there were 3,393,636 Instagram posts sharing fertility-related information, the majority of which were authored by patients (6). Research indicates that patient's choices are influenced by anecdotal stories of success and media misinformation, which may ultimately have a negative impact upon a patient's ability to make an informed treatment choice (7).
3. Fertility patients may be embarrassed to report that they do not fully understand their treatment plan or have made an error with the administration of medication, for example. This leads clinic staff to overestimate how much information has been understood (8).
4. Decision-making about medical treatment can be a stressful and difficult process, particularly when undergoing fertility treatment (9).

Recommendations to assist patients in making good, safe choices

Personalised care and shared decision-making

Good clinical practice involves high-quality, patient-centred, personalised, evidence-based care, in which patients are able to make autonomous, informed decisions (10). Shared decision-making and informed consent should be an integral part of the ART protocol, but what is the best way to achieve this? It is a well-known fact that patients forget 40-80% of verbal information immediately and only half of what they do remember is correct (11). Therefore, medical personnel should provide transparent, honest information, presented in a format that can be easily understood and remembered. This ensures realistic expectations in the patient's specific situation, thereby reducing the burden of being a fertility patient, treatment drop-outs and any fear of regret in the future (12).

Informed consent

The consent to undergo ART treatment is unique in that it is intended to create children. To ensure that patients are able to provide informed consent, clinics should supply information regarding:

- benefits and risks of treatment options and alternatives;
- individualised treatment success rates;
- the procurement, use, storage and future use of eggs, sperm and embryos;
- independent psychological and implication counselling;
- the welfare of the child/children;
- cost schedule;
- clinic complaints procedure;
- withdrawal or change to consent;
- legal parenthood.

Specific patient groups, such as patients requesting cross-border reproductive care for gamete/embryo donation (both donors and recipients) should be provided with the following additional information:

- Regulations governing the recruitment, payment and number of families or offspring created from egg, sperm and embryo donation varies from country to country;
- With the increasing use of direct-to-consumer genetic testing and prenatal testing, patients who choose donor conception and the donors per se, should be informed that donor anonymity may no longer be guaranteed (13).

Information format

Fertility treatment is complex. It involves multiple processes that rely on highly motivated patients who are able to understand and adhere to instructions such as medication management. Studies have shown that despite attending a briefing session:

- 35.7% of patients were anxious about self-injecting;
- 38% were confused about the prescribed units of gonadotropin;
- almost half either made or speculated that they had made an error in taking their medication;
- 29% admitted not reporting this error to their clinic (14)(15).

Information provided prior to consent should pertain to both the physical and psychological aspects of treatment. It should be delivered in a culturally appropriate manner (16), which is sensitive to cross-cultural care, taking into account the health literacy of the individual patient (Table 1). Patients must be given the opportunity to fully absorb the information provided, before treatment commences, and then be encouraged to ask questions or clarify further points. This should be in a separate face-to-face video call, which allows for collaborative communication.

Table 1.

Recommended format of providing information prior to treatment
When creating patient information literature: Use the Six Sigma '5 Whys' basic root cause analysis method; – Who needs to be communicated to? – What needs to be communicated? – When should it be communicated? – Where/how should it be communicated? – Why should it be communicated?
Write clearly, in plain English, using short words and sentences, providing a full extended version (with references) for those patients who request it, particularly for more complex treatments.
Produce information in the patient's own language. If translation is required, clinics should use a trained medical translator to avoid inaccuracies in the translation.
Give information in a timely fashion, ideally in bite-sized pieces, so as not to overwhelm.
Materials should be available as a PDF, to be downloaded and printed off at home.
Respect and be aware of patient preferences for information and offer various types, specific to the individual patient, not presented in a generic way.
Consider various visual forms of communication such as pictures, drawings, charts, graphs, videos, pictograms, eLearning, written information, recorded educational webinars and practical tips, relevant for each part of the patient's journey.
Ensure all information is readily available either on the clinic website or via a patient portal.
Provide patients with a written individualised expected treatment timeline.
Understand the various methods of communication and supply-driven vs. demand-driven patient information.
Use a checklist to ensure that all the relevant information has been provided about treatment protocols, medication, supplements, wellness advice, potential side effects and out of hours contact details.
Consider an online, cloud-based platform or patient decision aid to supplement (not replace) clinician-patient conversation options.
Perform a 6-monthly audit of all information sources, including all of the clinic's social media platforms, to ensure consistency and continuity.

Telehealth and webside manner

Patients have embraced the benefits of telehealth, such as reduced travel time and cost, increased flexibility and availability. However, there are some practical issues which should be taken into account which improve both the patient's experience, and protect both the patient and the clinic (Table 2.)

Table 2.

Recommendations regarding telehealth and webside manner	
Telehealth	1. Be aware of data and cybersecurity. Use secure video software providing end-to-end encryption [compliant with General Data Protection Regulations (GDPR) and the Health Insurance portability and Accountability Act (HIPAA)]. 2. Advise the patient to be in a private, not public place, ask them to provide informed consent to telehealth and confirm their future contact preferences and email address. 3. Use an electronic medical record (EMR) that has a set of fully integrated telehealth features, which has the capacity to be upgraded as new telehealth features come onto the market, e.g., secure consent signing in block chain. 4. Create an online portal to allow for remote access, uploading to the patient's EMR and electronic consent signing, together with medical illustration software for use in patient education information. 5. Have an In-house IT department or outsource to an external technical support company. Consider network services and wireless signal. Run software updates and general housekeeping overnight to reduce daytime interruptions to bandwidth and video streaming. Provide staff training in technology proficiency.
Webside Manner	1. Consider using two screens, one to see the patient and the other to view the EMR/notes/investigation results. 2. Use the best possible equipment (camera and speakers) to aid clarity and consider wired Ethernet connections in case Wi-Fi proves troublesome. 3. Improve communication and compensate for the lack of implicit feedback and the mirror neuron system by concentrating on other paralinguistic aspects. Look directly into and lean towards the camera, have a friendly expression, use hand gestures and slow the speed of speech. Increase the loudness, tone and inflection of speech. 4. Consider digital literacy and exclusion; not all patients are comfortable with a digital set-up or have the correct equipment available to them. 5. For patients receiving treatment as a couple, ensure that each one is seen separately at some point during the consultation. Ask open-ended questions and give each partner the opportunity to confidentially disclose any information, relevant to their treatment, that they might be unwilling to share with their intimate partner. 6. Before the consultation, send the patient an email outlining what to expect and ask for a telephone number in case of connectivity or interruption issues. 7. After the consultation, send the patient a transcript of the conversation/consultation, together with recommendations, a proposed treatment timeline and expectation management of clinic response times to future queries.

Implementing patient-centred infertility care

Patient-centred care is one of the six dimensions of quality of care comprising 1) safety, 2) effectiveness, 3) patient-centeredness, 4) timeliness, 5) equity and 6) efficiency. Many patients choose to stop ART treatment despite having a good predicted success rate and being able to afford the costs incurred. This is called patient drop-out. Most cite the impact of the psychological burden of infertility, but others refer to a lack of patient-centred care behind their decision. By implementing a patient-centred approach, clinics can improve their overall performance and reduce patient drop-out (17) (Table 3).

Table 3.

Implementing patient-centred quality care in a fertility clinic	
Have a quality management system	It is advisable, even if not mandatory, to have a formal quality management system (QMS). This ensures that there is a structure in place which accounts for local regulations and consistently promotes and aims for best practice. It provides a basis for clinical audits, the monitoring of day-to-day performance and provides a platform for patient feedback and continual improvement.
Listen to the voice of the infertility patient (18)	1. Provide personalised information for prospective, current and previous patients. 2. Run a clinic that is adequately staffed by competent, knowledgeable, caring individuals with a positive attitude and good communication skills. 3. Ensure that patients have privacy at sensitive times (semen production, etc.) and are physically comfortable when undergoing investigations and procedures. 4. Practice shared decision-making, autonomy and personalised care. 5. Ensure confidentiality of personal information and data. 6. Patients expect to receive emotional support from doctors and nurses, and most are able to cope with the stresses of treatment. However, a significant proportion (~20%) have specific vulnerabilities and are at risk of psychological distress. These patients will require professional support before undergoing fertility treatment.
Be a forward-looking organisation	Staff and effective team building: – Have a formal recruitment, on-boarding and cross-training process for the entire team, not just clinical staff; – Ensure that there are sufficient technical resources; – Invest in continuous education and professional development, encourage research and cooperation with other facilities. Leadership and management: – Encourage shared and distributed leadership to build a culture that supports inclusion, responsibility and continual improvement; – Ensure fluid, agile, adaptive management.
Continual iterative improvement	1. Process map the patient journey and perform an information gap analysis and audit. 2. Use patient feedback to ensure a dynamic iterative information creation process. 3. Improve organisational digital health literacy. 4. Make use of social networks, regularly checking that the overall online information is clear, concise and accurate. 5. Perform key performance indicators, collect and use the clinic’s own healthcare data to improve patient engagement and lead the quality improvement strategy.

Conclusions

Both patients and clinics have welcomed the advantages of virtual healthcare. However, clinics should be aware that, in adopting these new methods of interaction, they must continue to encourage patients to be in control of their treatment decisions. Ensure that informed consent is obtained, reduce stress and lessen the patient workload. This will improve the overall experience and protect both the patient and the clinic.

References

1. Where will telemedicine go from here? Rotker, K., Velez, D., Fertility and Sterility® Vol. 114, No. 6, December 2020
2. Building the case for Health Literacy. Alper et al., 2018. Available at: https://www.nap.edu/catalog/25068/building-the-case-for-health-literacy-proceedings-of-a-workshop. Accessed 15/06/21
3. Nonverbal Communication (eBook). Burgoon et al., Boston: Allyn & Bacon, 2010
4. Can You Hear Me? How to Connect with People in a Virtual World. Morgan N., Harvard Business Press, 2018
5. Vulnerability and the Consenting Subject: Reimagining Informed Consent in Embryo Donation. Hewer, R., Feminist Legal Studies (2019) 27: 287–310
6. Fertility education: what's trending on Instagram. Peyser et al., Fertility Research and Practice 2021. Available at: https://doi.org/10.1186/s40738-021-00095-6
7. The impact of anecdotal information on medical decision-making. Jaramillo et al., 2019. Available at: https://cogsci.mindmodeling.org/2019/papers/0100/0100.pdf
8. Promoting patient comprehension of relevant health information Kreps, G.L., Isr J Health Policy Res 7, 56 (2018). https://doi.org/10.1186/s13584-018-0250-z
9. Tackling burden in ART: an integrated approach for medical staff. Boivin et al., Human Reproduction, Vol.27, No.4 pp. 941–950, 2012
10. Good Clinical Treatment in Assisted Reproduction – An ESHRE position paper. June 2008.
11. Patients' memory for medical information. Kessels, R.P.C., 2003. Available at: https://pubmed.ncbi.nlm.nih.gov/12724430/.
12. 'Your hopes can run away with your realistic expectations': a qualitative study of women and men's decision-making when undergoing multiple cycles of IVF. Copp et al., Human Reproduction Open, Vol.00, No.0, pp. 1–8, 2020
13. The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. Harper et al., Human Reproduction, Vol. 31, No.6 pp. 1135 –1140, 2016
14. Understanding the burden of ovarian stimulation: fertility expert and patient perceptions. Huisman et al., Reproductive BioMedicine Online, Vol . 19, Supplement 2, 2009
15. Patient perceptions and understanding of treatment instructions for ovarian stimulation during infertility treatment. Barrière et al., Reproductive BioMedicine & Society Online 2019 Available at: https://doi.org/10.1016/j.rbms.2019.08.003.
16. Cultural competence in fertility care for lesbian, gay, bisexual, transgender, and queer people: a systematic review of patient and provider perspectives. Kirubarajan et al., Fertility & Sterility 2021. Available at: https://dx.doi.org/10.1016/j.fertnstert.2020.12.002
17. How organisations contribute to improving the quality of healthcare. Fulop, N., Ramsey, A. BMJ 2019; 365: l1773.
18. Patient-centered infertility care: a qualitative study to listen to the patient's voice. Dancet et al. Human Reproduction, 2011. Available at: http://dx.doi.org/10.1093/humrep/der022

4.3

Learning what and where to research

Introduction

Several studies report that most people are misinformed about reproductive health (1-6) and the age-related fertility decline, and that providing this information has the potential to affect unintended childlessness (11,12,13,14,15). Other studies also suggest that only a small proportion of patients seeking fertility treatment are aware of the dramatic impact of age and other factors on fertility, suggesting that current information provision is insufficient (11,12,13).

The reality is that most people who want to conceive in the future and those who are already trying to conceive, require and actively seek information and advice to assist them in meeting their reproductive goals. Several studies report virtual communication as a common source of information (1-6). These sources include the Internet as well as fertility clinics and official bodies' websites, social media platforms, forums and apps. A study researching the use and perceptions of online education material by fertility patients found that 42.6% (106/249) looked at the online material. Of those who viewed the online information, 99.1% (115/116) found the information helpful or somewhat helpful and 67.6% (73/108) felt better prepared for making fertility decisions during their consultation after reading the material online (1).

However, accessing online information has been described as a complex process (6). This is particularly evident among women from low-income, socio-culturally diverse communities (3). One study showed that women from low-resource, largely immigrant communities, seeking fertility care have greater disparities in fertility knowledge and lower health literacy compared to women from high-resource clinical settings (3).

This guide aims to reduce reproductive e-literacy inequalities, by reviewing and clarifying what information should be provided to patients by fertility clinics, in which format patients prefer this information and where to direct patients to learn about that information.

Content topics

(information sought by patients)

The content of information sought by patients differs at every stage of their journey. Patients typically search for general information, often related to causes of infertility, as they embark on their journey. As they become more informed and engaged with services and treatment, they look for more bespoke information which is also more challenging to find (6). The main purpose of obtaining information is to assist patients in the decision-making process and to prepare them for consultations with healthcare professionals. Moreover, patients often take information from their consultations back to online communities in order to assess options and develop their understanding (6).

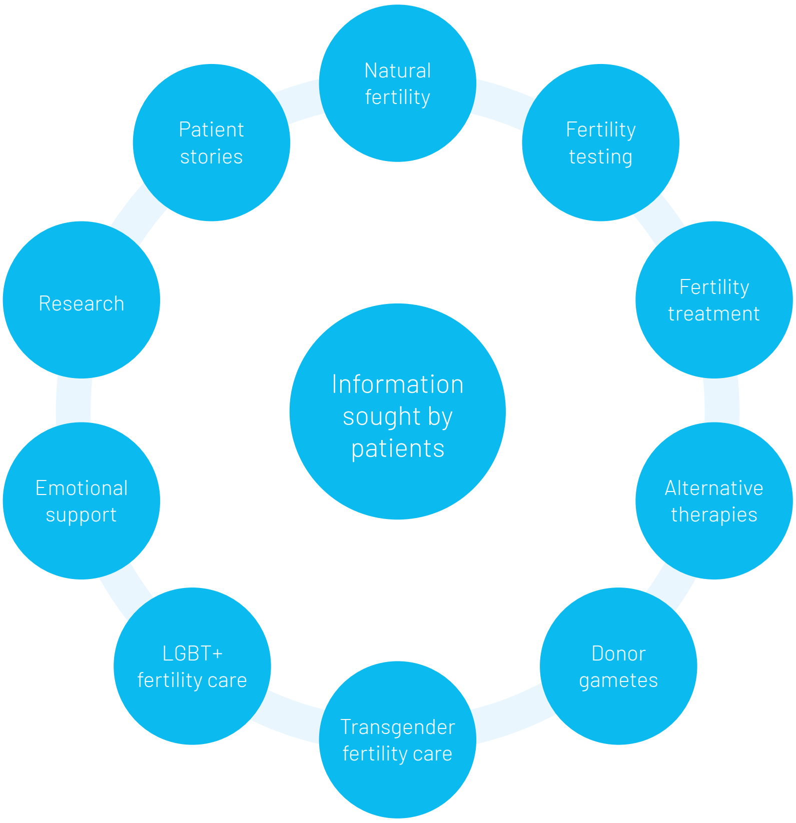
A qualitative analysis on education material sought by patients highlighted the following themes: detailed information on infertility, fertility testing and fertility treatment (28.6%), improving natural fertility and use of alternative therapies (17.9%), donor gametes and transgender fertility care (14.3%), step-by-step approach (14.3%), emotional support and counselling (10.7%), patient stories (10.7%), lack of certainty (10.7%) and other topics (14.3%). Examples included: "how to prepare for appointments and what to expect from the procedures", "How-to videos" and "Videos that explain process, concerns that individuals may have" and the use of "interactive tools". Patient stories were suggested by 3 participants who recommended "real patients speaking about their journey", including accounts of both "successes and failures" (1).

Apart from the educational content, many patients are also looking for emotional support and a sense of community, wanting to find people in similar situations and form support networks (6, 18, 19, 20). One study looking at online support found that the latter was preferred by some over real-world friends and family, because of the shared experience and ability to discuss issues openly and anonymously (6).

Another study looking at fertility-related content on Instagram found the following types of content: educational, patient experience, outreach, advertisement, research, personal (unrelated to a diagnosis), and other (2). Educational posts included posts where the primary goal was to provide education on fertility issues (e.g., a physician describing the basic fertility workup). Outreach posts involved posts where the author was trying to engage the user (e.g., "comment below if you have heard of anti-mullerian hormone!"). Advertisements included a clear promotional goal (e.g., an office offering a free initial fertility consultation) (2). In this study, 60% of posts related to patient experiences, 10% to advertisements, 10% to outreach, 8% were educational and 6% were personal posts unrelated to diagnoses. Only 15% of all posts were written by physicians, allied health professionals and professional societies, and there were zero posts related to research and only 8% related to education. Physicians were more likely to write posts related to planned oocyte cryopreservation compared to IVF, while patients were more likely to write posts about IVF, their experience with treatment, success and failure (2). There seems to be a discrepancy between the content being published by clinics and the content patients are looking for.

Another relevant aspect relates to the trustworthiness of information that patients find online. This is described as an important issue for patients and it is suggested that online information is translated into plain language but linked to the main information source so that patients can access it should they want to (6).

Taking these findings into consideration, it is recommended that fertility clinics provide more online content and ensure that the said content meets different patient needs, ranging from basic educational content on natural fertility to more detailed, personalised information about fertility testing and treatment, as well as stories of success and failure.



Content format

(how do patients want the information displayed)

Different online formats can be used to display the content described above. It is important to choose the format that not only matches the information but which also meets the patient's needs. If the content is in the wrong format, patients may not be able to find it or may not engage with it in a way that empowers them with knowledge to be active participants in their fertility treatment plans.

When considering written information, a study suggested that this should be translated into plain language but still have links to the main information source so that patients can access it should they want to (6). Special consideration should also be given to sentence construction, making it as simple as possible, and free from complex words. The font size should also be large enough to be legible, and the font colour should provide enough contrast with the background colour to be easy to read. Audio recordings of written communication, correctly tagging the content on the website in order to be detected by screen readers that convert on-screen information into speech or Braille, will make information more accessible to people with visual impairments.

Regarding video content, this has been preferred, over text-based content (65.6% vs. 11.3%) (1). Other studies also acknowledge that although videos cannot replace the importance of counselling from a physician, patients tend to favour videos over written hand-outs and verbal instructions (23, 27, 28). When creating videos, it is important to consider subtitles and inclusion of sign language to make these as accessible as possible.

Taking these findings into consideration, fertility clinics are advised to create online content in various formats that meet the needs of their patients, ranging from written format to video/audio content, paying particular attention to details that make the content more accessible to the wider population.

Writtern online content

- Plain language
- Simple sentence construction
- Avoid complex words
- Legible font size
- Contrast font colour
- Detectable by screen readers

Video online content

- Plain language
- Avoid complex words
- Subtitles
- Sign language

Content sources

(which platforms are patients using to access information)

Different platforms are being used by patients to access online information. These include search engines such as Google as well as the fertility clinic's website, social media, apps and the websites of official bodies including ESHRE and ASRM.

A study investigating the patient-reported usage and helpfulness of education material on clinic websites found that online information can often be biased in favour of a discussion of benefits over risks. There is also a lack of evidence-based research to back up recommendations and failure to disclose conflicts of interests (16, 17, 24, 26). In this study, 72% of participants stated that they would like to see more information posted online (1).

This guide reviews and clarifies which platforms are preferred by patients to access online information, so that fertility clinics can post more content where patients are likely to find it, and clinicians are able to guide patients to trustworthy sources of information.

Search Engines

(e.g. Google)

A study researching reproductive e-literacy found that all participants had accessed the Internet as one of their first sources of information. The researchers confirmed that those searching for information inevitably began their search in a web browser, typically Google, and searching was generally described as unstructured, with participants finding useful sites by chance (6). However, frustration was expressed at the limited information provided by health professionals, especially when first contacting them about fertility issues (6).

Given that search engines are often the first point of search, fertility clinics have an opportunity to create high-quality content available on search engines. This can be done on various platforms such as the clinic's website and blog, tagging the content to allow it to be discovered, as well as creating content in other platforms that contribute to search engine ranking.

Clinic Website

As described previously in this chapter, the fertility clinic's website is one of the main sources of information for patients. In a recent study, the majority (95.8%) of respondents who viewed online information stated that they accessed it through the clinic website (1). However, patients often find that this information can be biased and incomplete with little discussion of safety and risks. Several studies also highlighted that most online medical information is written at an educational level that is too high for the average patient to understand (6,8,9,10).

The way the information is presented on the website is also important. In one study, patients expressed a preference for clean, simple, uncluttered, professional sites. Adverts were viewed very negatively along with sites that were too impersonal and made use of chat-bots. The addition of a personal element to the website to give some idea of who is behind the website and their motivation were also considered important (6).

Based on these findings, fertility clinics should use their website as a source of trustworthy, easy to understand, easy to find, unbiased information. Adding a personal team touch and describing their skills and motivation can help patients feel connected and engaged.

Social Media, forums and apps

Several studies have found that patients use social media for both educational content as well as a resource for dealing with the emotional consequences of infertility, helping them to feel less isolated and abnormal (1,2,6). The main networks appear to be Instagram, Facebook, Twitter and forums. One study investigating the role of social media for persons affected by infertility found that over 60% of the respondents had taken part in discussions about infertility on social media over one to three years, and 39% participated more than once a day. Half of the participants spent one to three hours every week on the forums and wrote 1–5 postings per week. The forums offered participants information, solidarity, and the opportunity to receive and give support. However, one of the criticisms raised was that the advice given was not necessarily evidence-based (7).

In another study, 80% of patients highlighted that social media improved their overall patient experience in the fertility clinic and the majority (60 %) of respondents used Instagram (21). Another study suggested Instagram attracted patients with infertility due to the possibility of anonymity and the fact that they would be able to find others experiencing similar problems with whom they had more informed conversations (6). A recent poll showed that the average user spends 21.2 minutes on Instagram each day, with the 18–29 age group spending the most time (30 minutes) (16).

A study looking into fertility posts on Instagram found that most posts were written by patients (67%), followed by physicians (10%), for-profit commercial groups (6.0%), allied health professionals (4.5%), professional societies (1%), and others (11%) (2). Attitudes from healthcare-regulating organisations on the use of social media are also changing and the American College of Obstetricians and Gynaecologists

(ACOG) recently revised their committee opinion in 2019 stating that social media is "not only acceptable for the modern practicing physician but has become a necessary element for relating to patients and practicing medicine" (22).

For these reasons, fertility clinics can and should use social media to connect and engage with patients. There is an opportunity for fertility clinics to use social media as a platform to share evidence-based medical education and inform the public (16,29,30,31).

Official Bodies

Websites of governmental and official bodies in the reproductive health sector, such as ASRM and ESHRE can also provide reliable information for patients. Ideally, the information presented on these websites should be written in plain language that is easy for patients to understand. This would also make it easier for fertility clinics to recommend them.

Conclusion

Many people are misinformed about reproductive health. The provision of adequate information would empower patients to be active participants in their fertility treatment plan. This guide reviews the information to be provided to patients by fertility clinics, and specifies appropriate formats and resources.

References

1. https://fertilityresearchandpractice.biomedcentral.com/articles/10.1186/s40738-020-00083-2
2. https://fertilityresearchandpractice.biomedcentral.com/articles/10.1186/s40738-021-00095-6
3. https://fertilityresearchandpractice.biomedcentral.com/articles/10.1186/s40738-020-00084-1
4. https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-00912-y
5. https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-017-0352-z
6. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7037703/
7. https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-00964-0
8. https://pubmed.ncbi.nlm.nih.gov/23017508/
9. https://pubmed.ncbi.nlm.nih.gov/22810759/
10. https://pubmed.ncbi.nlm.nih.gov/23098043/
11. https://pubmed.ncbi.nlm.nih.gov/19296943/
12. https://pubmed.ncbi.nlm.nih.gov/16293651/
13. https://pubmed.ncbi.nlm.nih.gov/17056448/
14. https://pubmed.ncbi.nlm.nih.gov/24927291/
15. https://pubmed.ncbi.nlm.nih.gov/26611499/
16. https://www.jmir.org/2013/4/e85/
17. https://pubmed.ncbi.nlm.nih.gov/28214492/
18. https://journals.lww.com/greenjournal/Fulltext/2020/01000/Instagram_Users__Experiences_of_Miscarriage.22.aspx
19. https://journals.sagepub.com/doi/10.1177/1049732316680203
20. https://academic.oup.com/jamia/article/18/3/298/699704
21. https://doi.org/10.1007%2Fs10815-018-1189-2
22. https://journals.lww.com/greenjournal/Fulltext/2019/10000/Professional_Use_of_Digital_and_Social_Media__ACOG.49.aspx
23. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5491980/
24. https://pubmed.ncbi.nlm.nih.gov/22918796/
25. https://pubmed.ncbi.nlm.nih.gov/26541372/ old [5]
26. https://pubmed.ncbi.nlm.nih.gov/27570129/
27. https://pubmed.ncbi.nlm.nih.gov/27153169/
28. https://pubmed.ncbi.nlm.nih.gov/27440499/
29. https://www.comscore.com/Insights/Presentations-and-Whitepapers/2010/Women-on-the-Web-How-Women-are-Shaping-the-Internet
30. https://www.jmir.org/2009/4/e48/
31. https://link.springer.com/article/10.1007%2Fs11764-011-0179-5

Chapter 5

The future of patient care

Andreia Trigo
Dimitris Kavakas
Karenna Woods
Bola Grace

Abstract

It has been over 40 years since the birth of the first IVF baby and since then, rapid advances in assisted reproductive technology have taken place. Technology has evolved, facilitating microfertilisation, cryopreservation with higher thawing survival rates and embryo monitoring and selection. Despite these advances, take home baby rates remain low (approximately 20%).

In this chapter we reflect on the new emerging era of Artificial Intelligence and Machine Learning solutions that can interpret large health data sets. This has the potential to be the next significant advancement within reproductive medicine, particularly in the areas of triage, screening, and diagnosis, predicted outcomes, personalised treatment and monitoring, and imaging interpretation.

In the patient care and support sector, telehealth, telemedicine, mobile apps, connected devices, wearables and trackables also herald a new era in patient engagement that cannot be underestimated.

5.1
Emotional Support Toolbox

The digitalisation of communication offers clinics innovative ways of communicating and supporting patients. Indeed, some progress has been made by various clinics in providing virtual communication channels to their patients through apps, patient-only areas on websites and via community groups on social media or via forums.

Preliminary caution

Caution should be exercised first and foremost regarding the security and privacy of data held in such channels and clinics are advised to have full ownership of these settings and data. For example, Facebook groups share data with personal profiles and advertisers. Even in some purpose-built community apps such as Mighty Networks, the data is owned by the corporation, not the individual clinic account. Moreover, individual clients should at least have access to account settings such as profile, password and communication preferences. Secondarily, clinics are advised against over-digitalising patient care information. Face-to-face communication is still preferable, backed up by digital communication . In any event, communication channels where the patient can interact directly with clinic staff are preferable to one-way data relay and support tools or a combination of the two should be available.

Telehealth

Telehealth and virtual appointments bridge the gap between digital and traditional care models. As a result of the recent COVID-19 pandemic, these approaches have become routine practice and are now highly accessible.

It is crucial to give patients a choice in how support is delivered as one size does not fit all. Clinics are expected to shift towards a hybrid support care model over the coming years – hence the provision of secure systems and storage is paramount.

Examples in practice

Considerable research has been conducted into the efficacy of digitally-based interventions in mitigating distress, as psychological markers and in patient care (see studies outlined below).

The work of Dr Alice Domar is internationally acclaimed as the leading programme in infertility psychosocial interventions. The mind and body programme run in conjunction with Boston IVF for the last 30 years has had excellent results in improving stress reduction and decreasing anxiety and depression levels. The 10-week programme consists of an individual assessment, several face-to-face sessions and group/therapist support.

In 2020, PLOS ONE published a journal article about the similar success of a digital version of the programme, paving the way for more research and services in this area.

Similarly, an online psychoeducational programme offered to 190 women from 3 US fertility clinics also had beneficial effects:

“This evidence-based eHealth program for women experiencing infertility suggests that a web-based patient education intervention can have beneficial effects in several psychological domains and may be a cost effective resource for fertility practices”
(Cousineau *et al.*, 2008)

Aarts *et al.* (2012) assessed 20 Internet-based programmes and concluded that many were successful in providing information and support, as well as in promoting mental health but lacked interactivity.

“The interventions could be improved by using more interactive and dynamic elements as their key components.”
(Aarts *et al.* 2012)

These examples and the following additional references provide insight into emotional support areas, generally outside the current scope of the predominantly implication-based counselling provided by clinics. They also highlight concepts for future development either by clinics per se or outside services.

Current research has taught us that the introduction of programmes has been beneficial in many individually-assessed areas and that greater interactivity and group settings would provide additional benefits.

Contents of the emotional support toolbox

The research reveals key psychosocial or psychoeducational tools that have proved beneficial in patient mental health and overall patient care. These include:

- Providing evidence-based knowledge of stress, lifestyle and fertility
- Relaxation techniques including breathing and yoga
- Mindfulness
- Cognitive restructuring
- Stress-reduction strategies
- Listening and communication skills
- Relationship skills
- Strategies for emotional expression and effective coping with tricky emotions such as anger, guilt, blame and shame emotions
- Assertiveness training and goal setting
- Group support - meeting others in the same situation and having access to interactivity channels within the group.

Complementary support tools - the role of the clinic

A vast range of emotional support tools and providers is now available for patients outside the clinic setting in the form of podcasts, support and social groups, forums and allied health and alternative health professionals. The choice is so wide that individuals often struggle to navigate their way through various programmes and practitioners, incurring costs at each stage.

Patients are undoubtedly reliant on these services and benefit enormously from them. It would be hugely beneficial to patients if these tools and services were directly available from the actual clinics given their integration with medical care and delivery from a trusted source.

Clinics are now tasked with including increased patient care services either digitally or through partnerships with external organisations or a combination of both.

Conclusion

These guidelines set out practical examples of digital support tools that can enhance the patient care experience. Suggestions are also provided regarding the contents of and interaction with the emotional support toolbox available to patients.

Although potentially challenging for clinics to facilitate initially, the immense value and considerable impact on individuals are undeniable.

References

1. Clifton, J., Parent, J,, Seehuus, M., Worrall, G., Forehand, R., Domar, A., An internet-based mind/body intervention to mitigate distress in women experiencing infertility: A randomised pilot trial. PLOS ONE. 2020; 15(3): e0229379
2. Cousineau, T., Green, T.C., Corsini, E., Seibring, A., et al., Online psychoeducational support for infertile women: a randomized controlled trial. Human Reproduction. 2008; 233: 554–66
3. Pasch, L.A., Holley, S.R., Bleil, M.E., Shehab, D., Katz, P.P., Adler, N.E., Addressing the needs of fertility treatment patients and their partners: are they informed of and do they receive mental health services? Fertil Steril. 2016; 106 (1): 209–15. pmid:27018159
4. Boivin, J., Scanlan, L.C., Walker, S.M., Why are infertile patients not using psychosocial counselling? Hum Reprod. 1999; 14 (5): 1384–91. pmid:10325300
5. Wischmann, T., Implications of psychosocial support in infertility - a critical appraisal 1. J Psychosom Obstet Gynecol. 2008; 29 (2): 83–90.
6. Aarts, J.W.M., Van den Haak, P., Nelen, W., Tuil, W.S., Faber, M.J., Kremer, J.A.M., Patient-focused Internet interventions in reproductive medicine: A scoping review. Hum Reprod Update. 2012; 18(2): 211–27. pmid:22108381
7. Hämmerli, K., Znoj, H., Berger, T., Internet-based support for infertile patients: A randomized controlled study. J Behav Med. 2010; 33 (2): 135–46. pmid:20039196
8. Van Dongen, A.J.C.M., Nelen, W.L.D.M., IntHout, J., Kremer, J.A.M., Verhaak, C.M., e-Therapy to reduce emotional distress in women undergoing assisted reproductive technology (ART): a feasibility randomized controlled trial. Hum Reprod. 2016; 31 (5): 1046–57. pmid:26965429
9. Domar, A.D., Clapp, D., Slawsby, E., Kessel, B., Orav, J., Freizinger, M., The impact of group psychological interventions on distress in infertile women. Heal Psychol. 2000; 19 (6): 568.
10. Domar, A.D., Zuttermeister, P.C., Seibel, M., Benson, H., Psychological improvement in infertile women after behavioral treatment: A replication. Fertil Steril. 1992; 58 (1): 144–7. pmid:1623995
11. Clifton, J., A randomized pilot trial: An internet-based mind/body intervention to mitigate anxiety in women experiencing infertility. 2015.
12. Andersson, G., Carlbring, P., Berger, T., Almlöv, J., Cuijpers, P., What makes internet therapy work? Cogn Behav Ther. 2009; 38(S1): 55–60.

5.2
Digital technology to boost confidence

Telehealth for patients

Like much of healthcare, telehealth replaces medical appointments when and where possible, reducing costs and creating greater access. The recent COVID-19 pandemic has accelerated the global demand for digital technology, including telehealth for fertility treatment. Digital technology addresses costs for fertility patients by facilitating ways of receiving information. For example, home testing kits for both men and women, which are fully supported by fertility specialists, can be ordered by patients online, with full information and support also available via the Internet.

Digital consultation can also be provided by clinics using online video technology. This reduces the number of visits to the clinic and generates an automated matching and booking system. This can then be followed up by a detailed medical consultation with one of the clinic's fertility consultants. These services provide easier access to care.
Digital technology promises a better user experience (UX) across the entire healthcare sector. It can personalise care and provide continuity, not to mention support 24/7. Today's experience is highly impersonal and is mostly self-managed outside the doctor's consulting rooms, including the administration of medication. Thanks to telehealth and digital journeys, customers can benefit from connected, on-demand support using the app of their choice.

However, the digital technology boom comes with important data protection and cyber security considerations. The European GDPR requirements for personal data protection have significant implications for fertility clinics, healthcare providers and patients. This means that providers need to adopt a more holistic approach towards data management. Fertility clinics must have effective procedures in place that can be implemented immediately in order to meet GDPR requirements. This requires a more cautious approach to the handling of personal data and thorough knowledge of where the information is being stored and how it is being processed. This applies to hospitals and clinics, diagnostic laboratories, online shops and every organisation that processes health-related data.

Mobile apps, connected devices, wearables and trackables

Mobile apps linking patients to healthcare providers range from reference to communication tools including electronic health records, providing continuous access to personal health-related information. Initial evidence shows that these mobile applications improve the patient experience by increasing compliance, efficiency and accuracy in terms of documentation, information retrieval, and coordination of care. Patients can access their personal fertility information, profile and documents all in one place.

Partners are able to share and connect their information to create a holistic overview. Patients are sent reminders and have medication tracking to ensure that they are following their fertility treatment plans more efficiently. This is a key benefit as men are often left out of the process or are not given as much consideration.

Infertility can be a significant source of psychological distress. Mobile applications also allow patients to obtain support by connecting to online forums. Finding an egg or embryo donor or a surrogate is a simple, digitally supported exercise in matchmaking instead of the manual process that has existed to date. Connected devices can be used to track hormones, sperm count and symptoms, etc. with data to be shared directly with doctors.

Fertility healthcare professionals are also turning increasingly to mobile applications to help improve patient care. Regulators in the US and Europe have gradually approved applications which have benefited the fertility industry. These applications now support decision-making for healthcare professionals and patient-management. From the patient's perspective, these apps are invaluable in managing modifiable lifestyle factors during treatment such as the management of medication, booking appointments and accessing online support.

References

1. Rotker, K., Velez, D. 2020. Where will telemedicine go from here? Fertility and Sterility. VOLUME 114, ISSUE 6, P1135-1139, 2020 DOI: https://doi.org/10.1016/j.fertnstert.2020.10.050
2. Gay, V., Leijdekkers, P., Bringing Health and Fitness Data Together for Connected Health Care: Mobile Apps as Enablers of Interoperability. J Med Internet Res. 2015; 17 (11): e260. Published 2015 Nov 18. doi:10.2196/jmir.5094
3. Earle, Sarah, Marston, Hannah, Hadley, Robin, Banks, Duncan (2020), The use of menstruation and fertility app trackers: a scoping review of the evidence. BMJ Sexual & Reproductive Health (Early Access). DOI: https://doi.org/10.1136/bmjsrh-2019-200488
4. Radin, J. et al. The healthy pregnancy research program: transforming pregnancy research through a ResearchKit app. NPJ Digit Med. 2018; 1:45.
5. Curchoe, C., Smartphone Applications for Reproduction: From Rigorously Validated and Clinically Relevant to Potentially Harmful. EMJ Repro Health. 2020;6[1]:85-91
6. Yu, S., Rubin, M., Geevarughese, S., Pino, J.S., Rodriguez, H.F., Asghar, W., Emerging technologies for home-based semen analysis. Andrology. 2018; 6: 10-1
7. Roshonara, Ali., Zeynep, B., Gürtin, Joyce, Harper, C., Do fertility tracking applications offer women useful information about their fertile window? Reproductive BioMedicine Online, Volume 42, Issue 1, 2021, Pages 273-281, ISSN 1472-6483, https://doi.org/10.1016/j.rbmo.2020.09.005.
8. In-Depth: Digital health innovation in fertility and women's health – not so niche anymore | MobiHealthNews
9. https://www.mobihealthnews.com/content/depth-digital-health-innovation-fertility-and-womens-health-%E2%80%93-not-so-niche-anymore
10. The new EU Regulation on the protection of personal data: what does it mean for patients? (eu-patient.eu)

5.3
Artificial Intelligence in ART

Introduction

'Big data' analytics solutions are key to what the future has in store for ART professionals. These solutions are already here and the specialised technology platforms that use such solutions are currently operational or under development. The main advantage of big data analytics is that they can accurately predict individual patient success rates based on specific circumstances. In order to be effective, these platforms require an effective database containing thousands of patient profiles with very detailed information on medical history and fertility examinations as well as outcome data. Platforms use these data to find similarities and to draw conclusions regarding potential patient outcomes, thus estimating individual success rates.

The large amounts of data available for each type of treatment and fertility problem create an obstacle that platform developers have to overcome. However, the collection of data from a variety of sources/clinics/countries is vital in order to accurately predict the chances of success.

If big data analytics is paving the way to the future, Artificial Intelligence (AI) solutions are the future. AI builds on big data analytics to further enhance technology platforms that estimate IVF success rates. The ability of 'machine learning' and the identification of data patterns that are accurately interpreted by AI systems to reach conclusions potentially beyond the realms of human intelligence, are major challenges when it comes to using technology to estimate success.

AI can help us not only to estimate success rates but also to recommend treatments, methods and protocols to maximise the chances of success. It can also recommend the best locations/clinics for optimal individual outcomes.

AI systems are currently at the research and development stage. They can impact three main areas of fertility. The first is outcome prediction, where the further development of AI algorithms will allow systems to estimate outcome percentages more accurately, as discussed above. The second is the development of clinical decision systems capable of providing a better patient service, selecting the appropriate patient protocol, and evaluating suitable types of treatment and laboratory methods to optimise results. Finally, AI systems can be used to assess cost-effectiveness and reduce unnecessary expenses from failed cycles.

Robotic surgery is one of the areas in which AI has been widely applied and is still under research. It has not yet been applied to fertility but maybe this is the next step in assisted reproduction.

Different uses of Artificial Intelligence in ART

The lack of automation and the vast array of clinical presentations and treatment options in ART lead to considerable inter-user variability in terms of healthcare provision. This variability can lead to poor outcomes and may be confusing for patients. Artificial Intelligence can be used to reduce this variability by learning from vast amounts of clinical, demographic, pathological, imaging and laboratory data, and making connections and recommendations to guide health care decisions. Automating and streamlining the entire process should reduce the overhead costs for fertility practices and increase patient access (1).

Artificial Intelligence applications are emerging in different areas of ART (3):

- Triage, screening, and diagnosis
- Prediction of outcomes
- Treatment personalisation and monitoring
- Image interpretation

Use of AI in triage, screening and diagnosis

AI is used to efficiently interpret large health datasets in the context of clinical triage, screening, and diagnostics, These AI systems are trained on external health data that have usually been interpreted by humans and that have been minimally processed before exposure to the AI system, for example, clinical images that have been labelled and interpreted by a human expert. The AI system learns to execute the interpretation task on new health data of the same type, which in clinical diagnostics is often the identification or forecasting of a disease state (4).

It is particularly useful for clinicians with triaging patients who might need fertility treatment sooner, when screening for potential problems or for investigating factors that can affect reproductive health. It could even be used to diagnose specific conditions such as endometriosis, polycystic ovary syndrome or diminished ovarian reserve.

Use of AI in prediction of outcomes

Prediction of outcomes and estimating success in IVF is a complicated task that requires new technological solutions if it is to be done effectively. Traditionally, success rates are estimated by medical experts based on the medical history and current examination findings of the patient in question as well as on the expert's experience and knowhow. However, this can never be accurate and can vary depending on the clarity of mind of the expert at the point of consultation, factors such as tiredness, ability to remember data from past cases, and potential to analyse and evaluate statistical data, etc.
Current developments in technology are providing us with important tools to eliminate human errors and miscalculations and to provide accurate estimated success rates easily and quickly. Patients can already identify clinic websites in different countries that offer simple solutions. This quickly gives them an idea of their chances of success based on broad categories such as age group, type of treatment and main fertility problem, etc. These solutions are widely available and constitute the first step in showing what technology can offer in terms of accurately estimated IVF success rates. One problem with these solutions is that they are too broad and generalise findings without examining individual patient specifics.

Some research has been conducted in this area. Gil *et al.* looked at utilising various AI networks to analyse the association between environmental factors and/or lifestyle habits and the potential impact on semen quality (5). Some of the variables assessed included smoking, alcohol consumption and body mass index (BMI). The data obtained displayed a high predictive accuracy (~ 86%) for sperm concentration, and (73–76%) for motility. Another example is presented in a study by Candemir *et al.* in the form of an alternative algorithmic model to predict semen quality based on a similar questionnaire with additional variables including season of analysis and history of genitourinary trauma (5). A radial basis function neural network was used in this model, and success rates of up to 90% were reported in estimating semen quality. This was deemed to be the most accurate for predicting semen quality compared to previous models (5). El- Shafeiy *et al.* have also demonstrated further optimisation of an ANN for predicting fertility quality by coupling an additional optimisation algorithm, termed the Sperm Whale Optimisation algorithm (5). Predictive models for semen quality could be used as the initial step in screening men who may need an infertility evaluation. Earlier identification of men potentially presenting sub-fertility by recommending a semen analysis would lead to earlier intervention for couples desiring pregnancy.

In the fertility treatment context, a different study reviewed 95, 868 medical records and created a dynamic grading system that considered seven indicators, namely age, body mass index, follicle-stimulating hormone level, antral follicle count, anti-mullerian hormone level, number of oocytes and endometrial thickness to predict treatment outcomes (2). The system graded the patient's infertility on 5 levels ranging from A to E with A corresponding to a pregnancy rate of 53.82% and E to a 0.90% pregnancy rate. The cross-validation results confirmed system stability of 95.94% (95% CI, 95.14% - 96.74%) (2). The authors point out that this machine learning-derived algorithm may assist clinicians in making an efficient and accurate initial judgment on the condition of infertility patients (2).

Use of AI in treatment personalisation and monitoring

Different patients respond differently to fertility drugs and treatment protocols. Personalised treatment therefore has significant potential to improve the outcomes that matter to patients. However, many factors need to be considered when attempting to personalise treatment protocols including age, body mass index (BMI), hormone levels and ovarian reserve capacity, to name but a few. This can prove challenging (2). Artificial intelligence and machine learning can be used to automate the complex task of analysing all of the individual factors, to compare against a benchmark and make personalised treatment protocol recommendations. Similar algorithms can be used to monitor the patient's response during treatment, assessing, for example, the risk of OHSS or poor ovarian response.

Use of AI in imaging interpretation

Imaging interpretation is potentially the most advanced area of Artificial Intelligence. However, although obstetric and gynaecological ultrasound scans are two of the most widely performed imaging studies, AI has had little impact on this field so far. Nevertheless, there is huge potential for AI to assist in repetitive ultrasound tasks, such as automatically identifying good-quality acquisitions and providing instant quality assurance (3). In this area, for each ultrasound task, there are several image acquisition and analysis capabilities that can be met by an AI application, including classification ('what objects are present in this image?'), segmentation ('where are the organ boundaries?'), navigation ('how can I acquire the optimal image?'), quality assessment ('is this image fit for purpose to make a diagnosis?') and diagnosis ('what is wrong with the imaged object?') (3). In obstetric and gynaecological ultrasound, promising workload-changing advancements include automatic detection of standard planes and quality assurance in foetal ultrasound, detection of endometrial thickness in gynaecology and automatic classification of ovarian cysts.

Perhaps the most important application of Artificial Intelligence is in the IVF lab. Historically, embryo selection for transfer has been based on human experience and expertise. The skills and seniority of the embryologist would play a vital role in selecting the best embryo for transfer, thus speeding up the process and eliminating any unnecessary, unsuccessful attempts. This problem has been addressed to a certain degree by expensive infrastructure, such as time lapse incubators that provide extra tools and scope for embryologists. However, this remains a personal human decision. AI offers a system that learns from embryo development patterns and the implantation success of those embryos. In this way, the AI system would be able to effectively grade embryos according to real success potentials and thus standardise the embryo selection process and eliminate human error. Furthermore, AI systems operate algorithms that compare input data with output data and develop a process known as 'Machine Learning'. Provided that good quality data are available in sufficient quantities, this process allows Artificial Intelligence to learn to improve itself, thereby providing more accurate predictions over time.

The application of AI solutions is available not only at the embryo selection stage but also one step earlier, i.e. the selection of eggs and sperm. Although the selection of eggs for fertilisation is not such an issue as all available eggs are usually fertilised, the selection of sperm is of vital importance. Research is currently underway and solutions are being tested on how to select the best available sperm using AI algorithms. This is particularly important in cases of sperm samples with low normal morphology, high fragmentation and altered DNA.

In conclusion, artificial intelligence is currently being applied in several areas to improve clinical decision-making. Further research and development is ongoing so that these systems can become more proficient, improving success rates and reducing errors as well as generating cheaper, faster and more accessible results.

References

1. https://www.fertstertdialog.com/posts/ai-will-revolutionize-assisted-reproductive-technology-if-we-work-together
2 https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2772681
3 https://obgyn.onlinelibrary.wiley.com/doi/10.1002/uog.22122
4 https://genomemedicine.biomedcentral.com/articles/10.1186/s13073-019-0689-8
5 http://website60s.com/upload/files/5-artificial-intelligence-in-reproductive-urology.pdf
6 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6733338/
7 https://healthmatters.nyp.org/behind-the-latest-advance-in-ivf-treatment/
8 https://link.springer.com/article/10.1007/s10815-020-01881-9

About the authors

Giuliana Baccino

Dr Giuliana Baccino is a leading expert in health and fertility field with more than 15 years of experience. She is international advisor for Europe and Latin America in public and private sectors. Also Giuliana is lecturer in several Universities and Coordinator of the Psychology and Counselling group of the European Society of Human Reproduction and Embryology (ESHRE). Previously she worked as head of private fertility clinics. Giuliana holds a PhD in Health Sciences.

Sarah Banks

Sarah Banks is a qualified Personal Development Coach, and author of the IVF Positivity Planner, which is a unique support resource, that combines coaching exercises and coping strategies with a journal to fully support people through IVF. Through her work coaching patients and running support groups, Sarah has gained a deep understanding of the points of treatment that people struggle with, and these insights lead her to develop the planner, to support them through treatment and enable them to take control and improve their emotional wellbeing.

Andrew Coutts

Andrew Coutts is one of the fertility industry's best travelled individuals having visited and worked with over 150 clinics worldwide. He is a regular speaker, writer and commentator on fertility travel and the male experience of fertility treatment. Andrew is the CEO of the International Fertility Company, an independent consultancy which advises both patients and treatment providers. He is a PhD researcher at the Centre for Reproduction Research at the De Montfort University (DMU) in Leicester, UK, working on his specialist area, male factor fertility.

Karin Hammarberg

Dr Karin Hammarberg is a Registered Nurse with 20 years' experience as clinical co-ordinator of IVF programs. She completed a PhD in 2006 is now Senior Research Fellow at Monash University and Senior Research Officer at the Victorian Assisted Reproductive Treatment Authority in Melbourne Australia.

Ana Oliveira Pereira

Ana Oliveira Pereira was graduated in clinical psychology from the Higher Institute of Applied Psychology in 1996. Master's degree in health psychology in 2004, with a thesis on the personality and motivations of candidates for donation, in the first Portuguese Egg Donation Program. Ana Oliveira Pereira completed her postgraduate in integrative cognitive behavioral psychotherapy from APTCCI. Since 2000 she collaborates with Ava clinic – Lisbon fertility center, with functions of evaluation and counselling of donors.

Bola Grace

Dr Bola Grace has over a decade's leadership experience working on Women's Health in multiple settings, and is passionate about empowering women. Bola's research interests lie in SRH, Digital Health, Health Economics, Translational Research and Global Health. She is a Fellow of the Royal Society for Public Health, Chartered Fellow of the CMI and member of several global reproductive health societies.

Sandra Greenbank

Sandra Greenbank graduated as a nutritional therapist from the prestigious Institute for Optimum Nutrition in 2009 and has gone on to further her studies with the Institute for Functional Medicine. Over the last 12 years she has specialised in working with couples to enhance their fertility by natural means. Using proven and effective nutritional and lifestyle strategies, she works with clients globally to make small changes that drive lasting and powerful results.

Mandy Rodrigues

Mandy Rodrigues is a Clinical Psychologist registered with the Health Professions Council of South Africa. Mandy holds the degree BA (Honours)(SA), MA (Research) (Cum Laude)(SA), MA (Clin. Psych)(Cum Laude)(SA). She has been in private practice since 1995, and battling with her own miscarriage, infertility and cancer journey ignited the passion for her to specialize in the field. Her Master's degrees were both about the field of psychoneuroimmunology and the effects of stress and exercise.

Stephanie Toulemonde

Stephanie Toulemonde is a certified professional coach specialized in emotional support during fertility treatments. Stephanie is also co-founder of the patient association She Oak, in Barcelona. She has undergone fertility treatments (IVF) and she is now the happy mother of 2 wonderful kids. Stephanie Toulemonde knows that fertility treatments come with a lot of different emotions that are difficult to deal with. As a coach, her passion is to help fertility patients live the process in a more positive and serene way.

Olivia Montuschi

Olivia Montuschi is a parent to two donor conceived adults born in 1983 and 1986. She and her husband founded the Donor Conception Network in the UK with four other families in 1993. Olivia trained as a teacher and counsellor and for many years worked as a parent educator and trainer, writing materials and running parenting education programmes. She is the author of all the Telling and Talking booklets for parents of donor conceived children of different ages and has written many articles about parenting children conceived by egg, sperm and embryo donation.

Veronica Montgomery

Veronica has over 16 years of experience in the fertility sector working for a JCI accredited IVF clinic. She started her career at the Royal College of Nursing Publishing Company, within the marketing and advertising team. She went on to became a director for a leading London advertising agency who specialised in healthcare. Veronica often speaks at international conferences on fertility tourism and has also had her work published in scientific publications on how IVF clinics can market themselves to reach infertility patients.

Julie Morgan

Julie Morgan RGN, MSc, APM (PFQ) is an experienced Assisted Reproductive Technology (ART) practitioner from the United Kingdom. She has extensive experience of the Clinical, Operational and Human Resources Management of fertility clinics and is a member of multiple ART and Project Management societies together with the Chartered Institute of Personnel & Development. Currently working as a consultant in ART research and development, she has a particular interest in Femtech and developing algorithms for individualised controlled ovarian stimulation.

Andreia Trigo

Andreia Trigo RN BSc MSc is a multi-awarded nurse consultant, lecturer, researcher and TEDx speaker. Andreia's mission is to improve accessibility to fertility care and support worldwide at minimal cost to populations. Combining her medical experience and her own infertility journey, Andreia founded the Enhanced Fertility Programme App. This is an evidence-based programme that improves accessibility to fertility education, support and care.

Dimitris Kavakas

Dr Dimitris Kavakas is an international business development consultant with long experience in the fertility travel sector. Currently owns his consultancy company, Redia Ltd, based in London, with which he specifically focuses on the fertility travel sector. He runs the ivftravel.com portal which offers unique services to fertility patients, including refund guarantee packages and instalment payment financing so as to better support them in traveling abroad for treatment.

Karenna Woods

Karenna Wood is an international fertility coach, founder of Your Fertility Hub.com and a passionate advocate for more emotional support and information for women trying to get pregnant. She's an expert in mind-body tools and has supported over 1600 women all over the world in learning relaxation and stress-reduction techniques, relationship tools, mindset techniques and coping skills. She uses a combination of cognitive behavioural therapy, professional personal and relationship coaching, proven relaxation techniques and visualisation/mediation to transform the experience of infertility.

Jakub Dejewski

Jakub Dejewski has over a decade's experience working on support and treatment abroad in the fertility field. He is international advisor in public and private fertility sectors. The cofounder and the Chairman of the European Fertility Society. Also CEO at IVF Media Ltd, the network of websites supporting and helping patients in their fertility journey. Jakub is experienced in the reproductive genetics market, with a particular focus on pre implantation diagnostics. He deeply believes in the power of fertility education that's why he develops projects like a FertiAlly and myIVFanswers.

Version 01. Feb. 2022

FERTILITY PATIENTS CARE GUIDANCE

Authors

Giuliana Baccino, Sarah Banks,
Andrew Coutts, Bola Grace, Sandra Greenbank,
Karin Hammarberg, Dimitris Kavakas,
Veronica Montgomery, Olivia Montuschi,
Julie Morgan, Mandy Rodrigues,
Stephanie Toulemonde, Andreia Trigo,
Ana Oliveira Pereira, Karenna Woods,
Jakub Dejewski.

With the collaboration of:

www.temos-worldwide.com
www.prideangel.com
www.masola.org

EFS
EUROPEAN
FERTILITY
SOCIETY

www.europeanfertilitysociety.com

The European Fertility Society C.I.C.
2 Lambseth Street, Eye, England, IP23 7AG
Email: info@europeanfertilitysociety.com