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## Internet Use of Fertility Patients: A Systemic Review of the Literature

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FÜR KLINIK & PRAXIS

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# Internet Use of Fertility Patients: A Systematic Review of the Literature

N. Zillien, G. Haake, G. Fröhlich, T. Bense, D. Souren

Patients undergoing infertility treatment often satisfy their information needs by using the Internet. The objective of this study is to compile the main reasons for and the impact of different forms of Internet usage in case of infertility. A systematic review of literature was carried out including 19 distinct studies in English language published in peer-reviewed journals from 1999 to 2009 identified from PubMed, Medline, Embase, Web of Science, Sociological Abstracts and by using snowball sampling. According to the examined studies, the main reasons for the use of the Internet by infertile couples are the availability of a great amount of diverse information, the emotional, social and psychological support offered, and to seek self-help. The consequences are perceived improvements in knowledge, emotional state, relationships and self-efficacy. However, concerns about the quality of information and possible negative impacts are reported, too. Further research is needed concerning the effects of fertility patients' internet use.

**Key words:** Internet usage, online, information, information needs, emotional support, fertility patients

**Motive und Auswirkungen der Internetnutzung von Kinderwunschpatienten – eine systematische Literaturübersicht.** Die vorliegende Arbeit fasst den aktuellen Forschungsstand zu den Motiven und Auswirkungen der Internetnutzung von Kinderwunschpatienten zusammen. Eine umfassende Recherche in den Datenbanken PubMed, Medline, Embase, Web of Science und Sociological Abstracts sowie eine ergänzende Anwendung des Schneeballverfahrens hat für den Zeitraum von 1999–2009 zu insgesamt 19 einschlägigen empirischen Untersuchungen in englischer Sprache geführt. Die zentralen Motive der Internetnutzung von Kinderwunschpatienten liegen demnach in der Informationsvielfalt des Internets, dem Bedürfnis nach emotionaler, sozialer und psychologischer Unterstützung und dem Selbsthilfepotenzial des Mediums. Als wichtigste Auswirkungen der Internetnutzung gelten ein Wissenszuwachs auf Seiten der Kinderwunschpatienten, eine Verbesserung der psychosozialen Verfassung sowie ein erhöhtes Selbstvertrauen insbesondere in Entscheidungssituationen. Es werden jedoch auch negative Konsequenzen wie Fehlinformation oder emotionale Belastung als mögliche Auswirkungen der Internetnutzung von Kinderwunschpatienten genannt. **J Reproduktionsmed Endokrinol 2011; 8 (4): 281–7.**

**Schlüsselwörter:** Internetnutzung, Internet, Information, Informationsbedarf, emotionale Unterstützung, Kinderwunsch, Kinderwunschpatienten.

## ■ Introduction

Women and men undergoing infertility treatment typically have high information needs. These information needs are increasingly satisfied by using the Internet [1–5]. At least half of all patients use the Internet to gather information about infertility [1–3]. A current online survey even characterizes the Internet as the most heavily relied-upon source on infertility information [6]. At the same time numerous studies document that online information about infertility is often incomplete, misleading or inaccurate [3–4, 7–11]. Against this background the systematic review at hand provides an overview of the reasons for and the impact of different forms of Internet usage in case of fertility treatment.

## ■ Methods

Studies in English language published in peer-reviewed journals between 1999 and 2009 were included in our systematic review if they meet the following criteria: Firstly, the study mainly deals with Internet usage in case of fertility

treatment. Secondly, the content focus of the study is on reasons for and/or the impact of Internet usage. Thirdly, the group under research consists of patients undergoing an IVF or ICSI treatment. Fourthly, the study is an empirical investigation (survey, experiment or content analysis). Consequently the selection criteria exclude studies which for example evaluate Internet sources for infertility patients, deal with Internet-based surveys regarding coping strategies in case of infertility, or analyze the criteria for choosing a fertility centre. Our literature search included the following databases: PubMed, Medline, Embase, Web of Science and Sociological Abstracts. To identify those articles dealing with Internet usage in case of fertility treatment, the search term “Internet” in combination with the terms “infertility”, “IVF” or “ICSI” was used. Additionally snowball sampling was applied.

All in all 350 potentially relevant studies are identified by the literature search. However, 163 of these publications are repetitions, appearing in more than one of the databases. Furthermore the full

text of 13 studies is not written in English. Of the remaining 187 citations 163 are excluded after screening the titles and/or abstracts. Out of 24 articles that appear to be meaningful, further 8 papers are discarded because they are not relevant or specific enough to the study topic. The reference lists of the 16 papers considered relevant are manually searched for additional citations. A total of 19 empirical investigations in English language published in peer-reviewed journals from 1999 through to 2009 focus on reasons for and/or the impact of Internet usage in case of IVF or ICSI treatment and thus are included in our systematic review. Author, year, title, study design, sample and aim of the included studies are listed in Table 1.

## ■ Results

### Reasons for Internet Use in Case of Infertility

16 of the 19 studies included in the systematic review analyze the reasons for Internet use of fertility patients [1–3, 5–6, 12–22]. The main reasons for the use of the Internet by infertile couples are

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**Table 1:** Included studies: method, sample, aim

Author, year	Title	Study design/method	Sample	Aim
1 Connolly et al. [16], 2009	What's on the mind of IVF consumers?	Quantitative data analysis: Exploration of data on Internet search activities (Google Insight)	Data on the search terms 'IVF'/IVF costs' for the USA and the UK from Jan 2004 to May 2009	Understand changes in public interest in IVF over time
2 Cousineau et al. [23], 2008	Online psychoeducational support for infertile women: a randomized controlled trial	Experiment: Solomon-four group design	190 female patients from three US fertility centers	Test the effectiveness of an online education program for infertile women
3 Epstein et al. [13], 2002	Use of the Internet as the only outlet for talking about infertility	Survey: cross sectional survey, Internet-based	589 visitors to the website of the International Council on Infertility Information Dissemination	Compare infertile persons whose only outlets for talking about infertility are online forums with persons who have additional outlets
4 Haagen et al. [1], 2003	Current Internet use and preferences of IVF and ICSI patients	Survey: cross sectional survey, paper and pencil interviews	143 infertile couples awaiting an IVF/ICSI treatment	Characterize Internet use of IVF and ICSI patients
5 Haemmerli et al. [25], 2010 [2009 EPub]	Internet-based support for infertile patients: a randomized controlled study	Experiment: randomized controlled study	124 infertile patients recruited by means of newspaper articles and Internet ads	Evaluate the efficacy and patient acceptance of an Internet-based treatment for infertile patients
6 Himmel et al. [12], 2005	Information Needs and Visitors' Experience of an Internet Expert Forum on Infertility	Survey & Qualitative Content Analysis: Internet-based survey; content analysis of visitors' requests	513 visitors who sent a request to the Internet expert forum; content analysis of 3840 requests	Analyze the needs and information requests of visitors of an Internet expert forum on infertility
7 Huang et al. [19], 2003	Internet use by patients seeking infertility treatment	Survey: cross sectional survey, paper and pencil interviews	200 infertile persons seeking consultation	Evaluate the reasons for Internet use of infertile couples and the effect on their decision-making process
8 Kahlor/ Mackert [6], 2009	Perceptions of infertility information and support sources among female patients who access the Internet	Survey: cross-sectional survey, Internet-based	567 infertile women visiting the infertility web site of a non-profit organization	Evaluate the helpfulness of and reliance on infertility information online
9 Kahn [17], 2006	Making technology familiar: Orthodox Jews and infertility support, advice, and inspiration	Survey & Qualitative Content Analysis: open-ended interviews; qualitative content analysis of a magazine/webpage	Staff of an infertility clinic; a magazine/webpage of an orthodox Jewish fertility support network	Explore how orthodox Jews use new media to cope with infertility
10 Malik/ Coulson [21], 2008a	Computer-mediated Infertility Support Groups. An Exploratory Study of Online Experiences	Survey: qualitative online survey with open-ended questions	95 users of eight different websites about infertility	Explore the motives of accessing online support groups
11 Malik/ Coulson [20], 2008b	The male experience of infertility: a thematic analysis of an online infertility support group bulletin board	Qualitative Content Analysis: analysis of messages within an online forum	728 messages from 53 threads within an infertility forum for men	Obtain a richer understanding of male experiences and needs affected by infertility
12 Porter/ Bhattacharya [5], 2008	Helping themselves to get pregnant: a qualitative longitudinal study on the information-seeking behavior of infertile couples	Survey: 3 year prospective semi-structured interviews	25 couples undergoing treatment at a fertility clinic	Examine infertile couples' perception of the information available from various sources
13 Rawal/Haddad [2], 2006	Use of Internet In Infertility Patients	Survey: cross-sectional survey	106 female infertility outpatients in a District General Hospital	Determine the use of the Internet by infertility patients for obtaining health care information
14 Tuil et al. [24], 2007	Empowering patients undergoing in vitro fertilization by providing Internet access to medical data	Experiment: randomized clinical trial	91 female and 89 male patients undergoing IVF or ICSI treatment	Evaluate the effect of an Internet-based personal health record on the empowerment of IVF patients
15 Tuil et al. [18], 2008	IVF patients show three types of online behavior	Quantitative data analysis/survey: analysis of viewed web-pages/ online questionnaire	1,150 couples monitored, 53 couples questionaired	Examine online behavior of infertile couples using a personal health record; correlation of online behavior and dealing with stress
16 Tuil et al. [22], 2009	Dynamics of Internet usage during the stages of in vitro fertilization	Quantitative data analysis: Observation of the use of a PHR	25,420 page views and 11,403 utterances made by 51 couples	Evaluate the use of the PHR during the different stages of IVF treatment
17 Van Selm et al. [15], 2008	Chat about What Matters Most: An Analysis of Chat Contributions Posted to an Outpatient Fertility Website	Quantitative content analysis: analysis of chat utterances	20 chat sessions, representing 4,042 utterances made by 22 patient couples	Explore the topics discussed by couples and health care providers, the appraisal of the IVF treatment in the chat, and the dealing with it
18 Weissman et al. [3], 2000	Use of the Internet by infertile couples	Survey: prospective anonymous closed questionnaires	150 patients of one private and one public tertiary care fertility clinic	Evaluate and compare the extent of Internet use by infertile couples
19 Wingert [14], 2005	Assessing the needs of assisted reproductive technology users	Quantitative content analysis: analysis of messages posted in an Online bulletin board	6,149 messages posted in an Online bulletin board devoted to ART	Examine decision making concerning ART

their information needs, the emotional, social and psychological support offered, and to seek self-help.

### Information Needs

Many of these studies identify the search for information as one of the most important reasons to use the web. Subjects of the search are a number of different topics that are relevant for infertile patients. 84% of the 150 participants of an early study at two fertility clinics in Toronto use the Internet to look for medical information on infertility diagnosis and therapy [3]. The 106 female infertility patients asked by Rawal and Haddad [2] about their general use of the Internet, their use to obtain information on infertility issues, and their reasons to do so, go online to gather more information on their illness (79%) or treatments (43%). The 513 mostly female visitors of an online forum, who were interviewed by Himmel et al. [12], search for general information as well as for detailed medical advice on specific matters such as questions about their current treatment (45.1%), questions about different treatment options (32.1%), questions about the causes of infertility (25.5%) and questions about diagnostic data (22%). The availability of journal articles and medication information are mentioned as reasons for going online in a survey conducted among 589 persons, who filled in an Internet-based questionnaire on the site of the International Council on Infertility Information Dissemination [13].

In addition to these surveys, studies including a content analysis provide more detailed data about the information seeking behaviour of IVF and ICSI patients. The users of an online bulletin board studied by Wingert et al. [14] search for information and for evaluations of alternative infertility treatments. The outcomes of a qualitative content analysis of chat utterances show that 56% of the utterances deal with psychological aspects, 27% with physical aspects, and 17% with social aspects of the IVF treatment [15]. Using publicly available data from Google Insight, Connolly et al. [16] examined the changes in public interest in IVF in the USA and the UK. As it turned out, the interest in IVF (relative to all searches within the infertility searches) in the USA stayed constant over a five years period. The searches for

**Table 2:** Main reasons for Internet use in case of infertility

Main reasons	Examples
<b>Information needs</b>	<p>Patients look for information on:</p> <ul style="list-style-type: none"> <li>– infertility diagnosis and therapy [3]</li> <li>– their illness [2]</li> <li>– their current treatment [12]</li> <li>– treatments in general [2]</li> <li>– different treatment options [12]</li> <li>– causes of infertility [12]</li> <li>– diagnostic data [12]</li> <li>– medication information [13]</li> </ul> <hr/> <p>Topics of chats and bulletin boards on infertility are:</p> <ul style="list-style-type: none"> <li>– psychological aspects [15]</li> <li>– physical aspects [15]</li> <li>– social aspects [15]</li> <li>– evaluations of alternative infertility treatments [14]</li> </ul> <hr/> <p>Further information needs:</p> <ul style="list-style-type: none"> <li>– look for a second opinion [1]</li> <li>– reading journal articles [13]</li> <li>– compensate dissatisfaction with standard information [1, 5, 19]</li> <li>– reduce anxiety caused by a lack of information [20]</li> </ul>
<b>Need for emotional, social and psychological support</b>	<p>The Internet can provide emotional, social, and psychological support by:</p> <ul style="list-style-type: none"> <li>– easy contact to other infertile patients on the Internet [1, 3, 13–15, 20–22]</li> <li>– contact to (medical) professionals [13]</li> <li>– 24h-availability [13]</li> <li>– asynchronous and anonymous communication [13]</li> </ul>
<b>Self-help reasons</b>	<p>Patients also use the Internet to:</p> <ul style="list-style-type: none"> <li>– make a choice for a clinic [2]</li> <li>– evaluate fertility clinics [3]</li> <li>– purchase fertility drugs online [3]</li> <li>– obtain a better understanding of their fertility problem and medical condition [1, 19]</li> <li>– improve their knowledge, awareness, and sense of control [2]</li> <li>– improve their ability to participate actively in health care decisions [2]</li> <li>– find problem-solving strategies [14]</li> </ul>

“IVF cost” and “cost of IVF” have increased in the USA – especially in US states without mandated insurance coverage – while it decreased in the UK since 2006. Against the special background that orthodox Jewish couples are often seeking for fertility treatments that are compatible with Jewish law and tradition, Kahn [17] analyzed the publication of an orthodox Jewish fertility support network and its significant web-based component. The orthodox Jews who participated use the Internet to make information and educational networks available. Finally, Tuil et al. [18] used a web-based personal health record to observe the online information behaviour of 1150 couples from a Dutch medical centre who visited the clinic’s website. The “generic information style” which is characterised by the usage of

pages with recommended literature or information concerning the IVF/ICSI treatment in general is applied by 29% of the visitors. That means it is a less common behavioural style than the “communication style” (37.8%) or the “individual information style” (33.2%).

One reason for the high need for information satisfied on the Internet is the perceived lack of information provided by traditional sources. Several studies report dissatisfaction with the standard information on infertility. Half of the 25 infertile couples interviewed by Porter and Bhattacharya [5] within a 3-year prospective study about their perception of information available from various sources, had been sent a leaflet explaining what to expect at their first clinic visit. While they expected to be given

**Table 3:** Main impacts of Internet use in case of infertility

Main impacts	Examples	
<b>Information</b>	Patients feel better informed	<ul style="list-style-type: none"> <li>– satisfaction with the information found [5, 6, 12]</li> <li>– improvement of knowledge about fertility problems [1]</li> <li>– better understanding of the patient’s condition and available treatments [21]</li> </ul>
	Risk of misinformation/misunderstanding	<ul style="list-style-type: none"> <li>– information of low quality and poor usability can be harmful or distracting [2, 13]</li> <li>– highly technical medical information can lead patients to follow advice that is based on false or incomplete information [14]</li> </ul>
<b>Emotional, social and psychological support</b>	Emotional support and improvement of relationships	Internet applications can: <ul style="list-style-type: none"> <li>– enable to fill the gap between the patient’s needs and the support offered by a clinic [22]</li> <li>– help to improve patient’s communication with partners [6]</li> <li>– improve the patient-physician relationship [1, 6]</li> <li>– lead to a reduction of social concerns [23]</li> <li>– be a source of emotional support [21]</li> <li>– give patients the opportunity to provide support to others [22]</li> </ul>
	Emotional strain	Negative consequences of Internet usage may be: <ul style="list-style-type: none"> <li>– experience of sadness and distress [21]</li> <li>– addiction or obsessive use of the World Wide Web [13, 21]</li> <li>– isolation from face-to-face communication [13]</li> </ul>
<b>Self-help and decision-making</b>	Facilitated decision-making and improvement of self-efficacy	Online information may: <ul style="list-style-type: none"> <li>– be helpful during patient’s decision-making process [1, 3, 6, 19, 21, 23]</li> <li>– serve as a positive encouragement or empowerment [5, 21]</li> <li>– make the patient feel more in control of the situation [21]</li> </ul>
	Risk of exploitation	<ul style="list-style-type: none"> <li>– exploitation of patients by merchants [5]</li> </ul>

more practical advice by clinic staff they were disappointed by the lack of advice; the given information was perceived as unhelpful. Huang et al. [19] also conclude that couples seek advice regarding infertility access health information on the Internet “due to dissatisfaction with information received from health professionals”. In a survey among 163 couples awaiting an IVF- or ICSI-procedure only 11% are discontent with their health care provider [1]. On the other hand, the lack of information is highlighted as a source of anxiety within 53 threads written by men in an online message board on infertility [20] – lack of information is mentioned as one of the reasons to avail the support group. Whether due to dissatisfaction or just the want for more information: patients also look for a second opinion on the web [19]. According to Haagen et al. [1] this is the case for only a minority of 5% of couples awaiting an IVF- or ICSI-procedure. But among the questions sent to the expert forum analysed by Himmel et al. [12] 38.8% included the request for a second opinion.

Emotional, Social and Psychological Support

Besides the search for information some studies point out emotional, social and

psychological support as important reasons for going online. They often report that patients are looking for contact to professionals or other infertile patients on the Internet: “Reading about how other patients deal with the treatment in everyday life may also be a valuable form of social support” [15]. Epstein et al. [13] also list the search for support by medical professionals and other concerned persons as a reason for Internet usage by patients. The mostly female visitors of infertility-related websites who participated in a qualitative online survey by Malik and Coulson [21] state to engage in online support because the Internet provides easy access to a network of others finding themselves in a similar situation. Further important reasons for accessing the online communities are the 24h-availability and the asynchronous and anonymous communication which allows respondents to express their feelings more openly than in face-to-face interaction. According to Haagen et al. [1] 41% of the participants of their study go online to receive emotional support by other patients. One fourth of the patients interviewed by Weissman et al. [3] search for support groups on the Internet. But only 10% of the 58 women in the survey conducted by Rawal and

Haddad [2] seek emotional support online during the treatment. Content analyses back up the importance of online support. Especially the female users of an online bulletin board studied by Wingert et al. [14] tried to find social support because of their emotionally stressful situation. The male users of the online message board studied by Malik and Coulson [20] also use it to share their hopes and worries regarding the treatment. The study identified the feeling of alienation and isolation from the process of the treatment as a special reason for the Internet usage by men. The Jewish users of the fertility network analysed by Kahn [17] have created supportive frameworks for collaborations among rabbis, doctors and clinic personnel to ensure that their fertility treatments are in line with their religion. The “communication style” as a type of online behaviour identified by Tuil et al. [18] is the dominant behavioural style applied by 37.8% of the visitors and it correlates to the use of discussion forums and chat rooms. In another study Tuil et al. [22] found out that the use of the Internet changes in different stages of the fertility treatment. Especially during the last stages of treatment patients need continued communication and sup-

port. After the period of medical interference the emotionally most strenuous phase is the one in which patients wait for the results of the pregnancy test. Therefore, in the laboratory stage they are most active in the chat room. The high activity at this point is a way to deal with emotional aspects of the treatment.

#### Self-Help and Decision-Making

Sometimes also practical support is requested, for example to make a choice for a clinic [2]. According to Weissman et al. [3] half of the patients evaluate fertility clinics and about one fifth purchases fertility drugs online. Some studies report the general expectations of the patients using the Internet concerning their self-efficacy in the framework of a fertility treatment. For example, Huang et al. [19], who asked 200 infertile persons how and why they access health information on the Internet, learned that they do so “to obtain a better understanding of medical condition”. Haagen et al. [1] come to the same result when they note that couples go online to better understand their fertility problem (72%). The aim of patients asked by Rawal and Haddad [2] was to improve their knowledge, awareness, and sense of control, and their ability to participate actively in health care decisions. This goes along with the hope of interviewees that the perceived information can help themselves to get pregnant [5]. In the study of Wingert et al. [14] especially women mentioned the search for problem-solving strategies as reason for their Internet usage.

#### **Impact of Internet Use in Case of Infertility**

In the following the main impacts of Internet usage in case of infertility are described. The main consequences relate to the level of information, emotional, social and psychological support and self-help and decision-making. 15 of the 19 studies included analyzed the impact of different forms of Internet usage [1–3, 5–6, 12–14, 17, 19, 21–25].

#### Information

Several studies describe positive consequences through the Internet use by infertile couples. Such a one is the improvement of knowledge as a consequence of their search for information. The majority of the visitors of an Internet expert forum on infertility interviewed by Himmel et al. [12] are satis-

fied with the information they find on the page. In the interviews conducted by Porter and Bhattacharya [5] participants evaluated positively the availability of experience-based information on the Internet. Among 71 couples, which responded the questionnaire of Haagen et al. [1], 45 (64%) feel that Internet usage improves their knowledge about fertility problems. According to Malik and Coulson [21] the great amount of information leads to a better understanding of the patient’s condition and available treatments. Kahlor and Mackert [6] also confirm these findings. Participants of their survey believe to be better informed as a result of the online information.

A problem of online information is the difficulty to evaluate the quality of information for patients. Rawal and Haddad [2] point out that information of low quality and poor usability can be harmful or distracting rather than helpful. Epstein et al. [13] agree that the information available online may be faulty or misleading. According to Wingert et al. [14] highly technical medical information exchanged on an unmoderated board can lead patients to follow advice that is based on false or incomplete information. The users may not be aware of the possible unreliability of the source and may have a false sense of security. The author underlines the need for medical personnel to establish a moderated board, on which accurate medical information is provided and patients can share experiences, information, advice and support.

#### Emotional, Social and Psychological Support

Internet usage can also have an effect on relationships between patients and physicians. Tuil et al. [22] note that Internet applications enable to fill the gap between the patient’s needs and the support offered by a clinic. For example, online information helps the female visitors of the website of the National Infertility Association evaluated by Kahlor and Mackert [6] to improve their communication with partners and doctors. This change in relationship between healthcare providers and patients caused by the Internet use may lead to shared decision-making responsibility [1]. Himmel et al. [12] found that “visitors who have a good relationship with their doctor may be more likely to both share the answer from the expert forum

and rate their subsequent treatment as satisfactory”.

Another important impact of infertility – related Internet usage is the emotional support provided by different online sources. Cousineau et al. [23] report a reduction of social concerns among the female patients of three US fertility centres after using an online support program. The participants in the survey conducted by Malik and Coulson [21] experience online groups as a source of emotional support. Apart from that, involving patients in the healthcare process online also has the advantage that it gives them the opportunity to provide support to others [22]. No significant effect of online coaching for mental health outcome measures was found in a survey among 124 patients taking part in a cognitive-behavioural treatment including an interactive self-help guide, a module for patients to establish regular text-based contact with a therapist, a continuous monitoring and feedback system, and online forums to share their experiences [25]. Anyway, most patients assess the treatment as positive although men are less satisfied than women.

Some studies also report negative impacts of Internet usage of infertile patients regarding emotional, social and psychological aspects. One for example is an experience of sadness and distress which patients interviewed by Malik and Coulson [21] experience when reading the stories of other people. Participants from the study of Epstein et al. [13] whose only outlet for talking about infertility is the Internet are more depressed, consider infertility more stressful, report poorer coping strategies, worry more, are less satisfied with important relationships and feel less supported. Epstein et al. [13] also report that Internet usage may lead to addiction to the World Wide Web going along with isolation from family and face-to-face interactions. The risk of obsessive use of online communities is mentioned by Malik and Coulson [21], too.

#### Self-Help and Decision-Making

Another positive consequence of infertility-related Internet use is a facilitated decision-making. 71% of the participants in the survey conducted by Weissman et al. [3] who accessed information on infertility online find it helpful during their

decision-making process. Visitors of the website studied by Kahlor and Mackert [6] confirm this result by reporting that they have made better informed decisions regarding their treatment. Also Malik and Coulson [21] mention that online information plays a significant role in decision-making. But only 39% of the infertile couples interviewed by Haagen et al. [1] feel that the Internet facilitated decision-making about treatment of their fertility problem. According to Huang et al. [19] women are more influenced by online information. Women who participated in an experiment by Cousineau et al. [23] testing the effectiveness of an online support program, called “Infertility Source: Interactive Support Tools When Trying to Conceive”, experienced a facilitated decision-making, too. At the same time they improved their self-efficacy relating to the management of fertility treatment. Because they feel less alone participants in the qualitative survey conducted by Malik and Coulson [21] sense a positive encouragement provoked by their Internet use related to infertility. It also helps them to feel more in control of their situation. Especially couples, who achieved pregnancy, feel empowered by the information they found online and which they think helped them to achieve this goal [5]: “Those who became pregnant, whether spontaneously or as a result of treatment, often viewed their own efforts by information gathering and change of lifestyle as contributing to their success”. No significant effects in patient empowerment between the users and nonusers of the personal health record tested by Tuil et al. [24] were found – although, it is used frequently and users are satisfied with the functions offered. A general risk feared by the users of online information on infertility is the exploitation of patients by merchants [5].

## ■ Conclusion

Our results show that the Internet is an important source of information for patients undergoing fertility treatment. Regarding the reasons for Internet usage most studies point out the high information needs that fertility patients try to satisfy online. While patients in the pre-treatment stage are the least active, they become more and more active online information seekers in the course of the treatment [22]. There are certain specific

reasons for this behaviour, for example the availability of a great amount of diverse information such as journal articles and asynchronous and anonymous communication properties. Patients seek information on infertility in general: the causes of infertility, treatment options, cost of treatments, and fertility clinics. Standard information given to the patients apparently does not satisfy their needs and is often perceived as unhelpful. The surveys report dissatisfaction with information from traditional sources such as health care providers among ten up to fifty percent of their participants. By going online a minority of patients tries to find second opinions. Beyond that, participants of the included studies also use the Internet to get emotional, social, and psychological support by other patients or experts and hope to overcome feelings of depression, anxiety and stress. For this reason they seem to engage in chats and forums where they get easy contact to other persons concerned and to experts even more than in the search of information on other websites. By actively seeking this information and support online they hope to help themselves by gaining a better understanding of their situation and feeling empowered as patients in the process of the treatment.

Regarding the impacts of Internet usage in case of infertility the analysed studies report both positive and negative effects. Furthermore, two experiments report no significant effects on mental health and empowerment – Tuil et al. [24] mention a small sample size, Haemmerli et al. [25] assume a lack of statistical power to detect small to medium effect sizes. The main positive impacts found in the remaining studies regard emotional, social and psychological aspects. The Internet provides emotional support and experience-based information, which may reduce social concerns. Relationships to medical staff and partners can improve as a consequence of Internet usage. The majority of patients perceive that the use of the Internet also improves knowledge. They believe to be better informed. Self-efficacy is improved because patients feel more in control of their situation and are able to participate in shared decision-making when using the Internet as a source of information. The main negative effects on the emotional, social and psychological condition of patients are isolation from face-to-face interaction and an

increase in depression. These effects are even stronger among persons whose only outlet for talking about infertility is the Internet and who are in risk to show an obsessive use of online communities. Further concerns were uttered about the quality of online information, so the medical information may be misleading, especially in unmoderated online forums.

A weakness of many studies is the use of samples mainly or only including females. Little can be said about the Internet usage of infertile men. Despite the fact that women are more involved in fertility treatment, infertility and involuntary childlessness affect both partners. Therefore, how men use the Internet to deal with this stigma is an important and interesting object of research.

Apart from this constraint it must be asserted that although over the past ten years a number of studies have been published regarding the Internet use of infertile couples, the differences in research questions and study designs make it hard to compare results and come to a clear conclusion about the reasons for and impacts of their online behaviour. While some studies focus on general Internet usage, others examine the usage of specific websites and online tools offered for patients of certain clinics. In general all these sources of information are used a lot and evaluated positively by the patients. But as the topics asked for in the surveys differ widely, making a ranking of their relevance on the basis of this systematic review is not possible. Similar problems arise in the studies of effects of Internet usage by infertile couples. More positive than negative effects of Internet usage are reported in the included studies. Nevertheless, many studies are based on the self-assessments of Internet users in surveys with small sample sizes. Therefore concerns regarding the quality of online information and possible negative effects of false information must be taken seriously. The results confirm the presumption that the acquisition of medical knowledge by laypersons is often directed towards concrete actions such as the decision for a certain treatment or emotionally dealing with a disease. But the tentative or even conflicting nature of scientific knowledge complicates the understanding and activation of medical information in everyday life [26]. This may be one reason why patients look for infor-

mation based on the personal experiences of others because it is understandable, practically tested and authentic. On the one hand, future research should therefore systematically investigate which kind of information regarding topic and mode of presentation is used by fertility patients. On the other hand, further research should focus on the effects of specific forms of Internet usage in case of fertility treatment.

### ■ Relevancy to practice

The corresponding results may provide health care professionals with a better understanding of the kind of scientific knowledge their patients refer to for decision-making in the framework of their treatment. It can also give them an idea of what kind of additional information and emotional support should be provided online, because the results of this systematic review show that in any case, health care providers can satisfy some of the patients needs by offering additional, especially interactive services online.

### ■ Conflict of interest

The authors have no conflicts of interest to declare.

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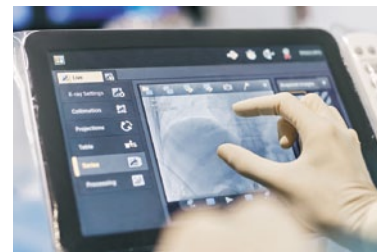
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