

Digital Experiences – Patient’s Patchwork Knowledge in Health-Related Online Forums

Abstract: Patients undergoing infertility treatment are constantly confronted with complex decisions requiring scientific knowledge. Referring to scientific knowledge, which often is tentative and conflicting, however, frequently impedes the patients’ decision-making. Against this background, we analyse how infertility patients perceive and utilise other patients’ knowledge which was communicated and gained in infertility forums. A guiding premise of this article is that the characteristics of digital media help to bring scientific knowledge to a conclusion and, in this way, to translate it into an everyday decision-relevant resource. In a multimethod design, we carried out qualitative telephone interviews with 32 people with an unfulfilled desire to have children, a standardised online survey of 1,216 users of infertility forums as well as a standardised content analysis of three German-language infertility forums. Our study shows that patients’ online forums constitute a place where scientific knowledge and lived experiences intertwine. In order to increase their chances of a pregnancy, infertility patients using online forums interweave scientific knowledge and personal experiences, go back and forth in this process, and form patchwork knowledge enabling them to go on in decisions involving uncertainty.

1 Scientific Knowledge in Everyday Life

Nowadays, scientific knowledge is increasingly considered as the guiding principle of almost every sphere of life (Collins 2014, Nowotny 2016, Weingart 2013). Unlike religious or traditional knowledge, however, scientific knowledge is preliminary, controversial and therefore presents no simple certainty. Thus, if everyday life is based upon scientific knowledge, the opportunities of choice proliferate: Life, death, sex, religion, marriage, parenthood – everything becomes decidable, in a way has to be decided (Beck/Beck-Gernsheim 1994:16 f.). Knowledge societies then construct a “social world, in which things are more and more ‘made’ to happen” (Stehr 2001 b:10).

This holds especially true for human reproduction. Due to new medical possibilities, such as birth control and reproductive medicine, as well as the societal acceptance of new forms of family, reproductive choices are constantly and significantly rising (McNeil 1990:11). Particularly assisted reproductive technologies, which have been developed over the last four decades, have pulled human reproduction into the scientific domain. Apart from adopting, fostering or changing partners, men and women seeking to fulfill their desire to have a child can pursue different ways of reproductive medical treatment. Even if Assisted Reproductive Technologies are widespread today, it is still the case that “fertility (...) is both unpredictable and

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prone to turbulence” (Nowotny 2016:91). This means that scientific knowledge on infertility treatments is tentative, conflicting and complex, too. However, at the same time, laypeople are chiefly interested in the practical utility and applicability of their knowledge. For patients, scientific knowledge first and foremost has to be sufficient to satisfy the interests of everyday life. From their perspective, the nature of scientific knowledge diminishes its relevance as a resource in everyday life, as it is not possible to make a clear decision on a tentative and conflicting knowledge base. Thus, the interpretations of scientific knowledge “must come to a ‘conclusion’” (Stehr 2001 a: 90) – only then does scientific knowledge have any practical value in patients’ decision-making.

Against this background, we analyse how infertility patients perceive and utilise other patients’ knowledge which was communicated and gained in infertility forums. A guiding premise of this article is that the characteristics of digital media help to bring scientific knowledge to a conclusion and, in this way, to translate it into an everyday decision-relevant resource.

2 Internet, Infertility and Experiential Knowledge

A meta study shows that in case of infertility, the Internet serves as a central, if not the most important source of information (Zillien et al. 2011). Besides information needs, the main reasons especially for the use of social media in case of infertility are needs for emotional, social and psychological support and for self-guided improvement (Epstein et al. 2002; Haagen et al. 2003; Kahlor/Mackert 2009; Malik 2010; Malik/Coulson 2008; Rawal/Haddad 2005; Weissman et al. 2000; Wingert et al. 2005). A qualitative study by Hinton et al. (2010) emphasises that the Internet is modifying the handling of infertility by giving sufferers targeted access to the experiences of others facing the same problem (Hinton et al. 2010: 440). Furthermore, Malik (2010) explicates that infertility forums enabled patients “to understand exactly what it was like to undergo treatment from those who had first-hand experience of infertility” (Malik 2010: 308).

Analyses of the self-help movement have already illustrated that learning about other patients’ experiences affects health-related decisions, perceptions and actions (Borkman 1976). In general, there is a growing body of literature on the empirical examination of patients’ experiences (e.g. Akrich 2010; Brown 2004; Pols 2014; Rabeharisoa et al. 2014; Whelan 2007; Ziebland/Wyke 2012). These studies argue that patients’ experiences can provide knowledge which is valued by itself. However, while these empirical investigations put a focus on political activities of patient communities and analyse how groups concerned engage in science to change their situation (e.g. Akrich 2010, Brown 2004, Rabeharisoa et al. 2014), the study at hand adopts a mainly epistemological point of view.

Whelan (2007), who analyses knowledge processes in (offline) groups of endometriosis patients, takes this perspective, too. Endometriosis is a hormonal and

immune system disease with pelvic pain as the main but not universal symptom. For this enigmatic disease, there is often no correlation between the severity of the pain about which patients complain and the observable symptoms, so that the perceptions of patients and physicians may diverge. Physicians often dismiss the endometriosis patients' narrations as hypochondriacal descriptions of menstrual problems (Whelan 2007: 957). Against this background, patients try to handle the uncertainty of medical knowledge by relating it to their experience: "Experience', then, becomes the arbiter of medical truth" (Whelan 2007: 962). On the basis of their experiential knowledge, endometriosis patients thus collaboratively define "what counts as 'good knowledge' in order to challenge medical authority" (Whelan 2007: 959). Experiential patient knowledge, then, is mainly seen as corrective of expert knowledge.

In contrast, Pols (2014) illustrates for a community of patients suffering from lung emphysema – a severe lung disease – that their knowledge does not principally aim at a correction of physician knowledge, as lung emphysema is a widely researched, incurable disease that is usually cared for adequately (Pols 2014: 76). In this case, experiential patient knowledge consequently rather aims at managing everyday life with the illness: Patients for instance (collaboratively) learn how to deal with frequent breathlessness. This experiential knowledge is not positioned against but conglomerated with expert knowledge and presents as such "a profound mixture of homegrown concerns and values, with elements of medical knowledge and technology" (Pols 2014: 76).

Infertility patients do not start their medical treatment because of acute physical pain, nor are they fatally ill. They rather, in the beginning, define themselves as patients in order to find a medicalised solution for an unfulfilled wish to have children. Infertility is then defined as a medical problem and as such can be defined as a socially constructed process; thereby, patients come to find reasonable ways of handling their problem of infertility (Greil et al. 2010: 141). This medicalisation of infertility can be seen as typical of a knowledge society in which infertility is no longer a matter of fate. In a knowledge society, it is possible "to 'fix' the infertility and produce a pregnancy" (Becker/Nachtigall 1992: 460) through medical means. As a consequence, at some stage in their course of treatment, infertility patients are confronted with complex decisions requiring scientific knowledge: They have to decide, for example, how they are going to approach infertility treatment, whether they are willing to accept specific stresses, and whether they want to undergo another treatment option after unsuccessful therapy. Besides these decisions, in infertility treatment, there is often no clear-cut indication for or against a medical intervention, so that there is ample scope for different opinions on treatment possibilities (Rauprich et al. 2011). Thus, infertility patients have to handle tentative and conflicting scientific knowledge, they have to learn to cope with uncertainty (Nowotny 2016:xiii).

In the following, we start from the premise that emotions, personal stories and subjective judgements gain relevance in social media. Our thesis is that the architecture, the material composition of social media virtually encourages personal exchange: As Papacharissi argues, “[m]edia technologies afford affect” (2015: 20). Accordingly, a reevaluation of subjective assessments in public exchanges can be observed; in large part, this development is due to the availability of digital media: “Due to the new technological tools now available, it has become possible to compare and share the life world experience with others” (Nowotny 2016: 131). Furthermore, we assume that the technological affordances of Internet forums enable the supplying, sorting and evaluating of massive amounts of heterogeneous sets of information. Users “can quickly browse through the account, break off at any point, or go back and review a section in more detail” (Ziebland/Wyke 2012: 233). While these actions would cause offence in offline communities, online patient communities allow this behaviour and therefore offer a technological structure suitable for the exchange of knowledge between persons concerned.

Against this background, our empirical investigation explores patients’ perceptions of knowledge processes in infertility forums. Here we assume that the technological architecture of Internet forums implies mechanisms which contribute to the closure of the knowledge discussed in the forums. In other words, through the closing mechanisms inscribed in the digital media, the fragile and conflicting knowledge of reproductive medicine is transformed into an individual knowledge resource for information-seeking laypersons.

3 Patients’ Patchwork Knowledge: Empirical Results

In a multimethod design, we carried out qualitative telephone interviews with 32 people with an unfulfilled desire to have children, a standardised online survey of 1,216 users of infertility forums as well as a standardised content analysis of three German-language infertility forums. At its core, the data collection dealt with the search for information on infertility, the Internet use with regard to this topic, the course of the fertility treatment and the doctor-patient relationship. The telephone interviews were conducted between November 2009 and February 2010, took 15 to 49 minutes and were audio-recorded and transcribed verbatim for computer-assisted analysis. First, the material was read, re-read and systematically structured along broad categories derived from theoretical assumptions and the interviews themselves. This means that the interviews were analysed both for issues already known from corresponding research and for emergent issues. According to the qualitative content analysis by Mayring (2008), subcategories were then identified from the interviews and the full text was coded using the new categories. The sample includes 30 women and two men. Even if this vast majority of women was not intended, it reflects the composition of the infertility forums. Thus, 98.6 percent of the 1,216 participants of the online survey conducted in April and May 2010 are female. Par-

ticipation in the survey was encouraged in three different infertility forums. The largest German-language infertility forum, which was also included here, was further subjected to a standardised content analysis. Within the frame of this analysis, we examined closed threads which had been started between August 2009 and July 2010; every hundredth thread was incorporated into the sample. Ultimately, 171 threads were evaluated with the aid of a text analysis programme; on average, one thread consisted of seven contributions. On the whole, 537 authors were communicating in 1,281 analysed contributions across all 171 threads.

3.1 Tentative Nature of Scientific Knowledge

In general, our respondents in both surveys express a strong need for information. Reasons for this are the complexity of treatment options, the often strong desire to have a child and the demand for patients' active participation in fertility treatment (for instance the self-injection of hormones). Respondents' knowledge surrounding the unfulfilled desire to have children originates in large measure from the Internet. For 49.5 percent of those polled, the other users of the infertility forum are a highly significant source of information for the topic; only close to one third of the respondents consider their attending infertility doctor a similarly meaningful source of information. However, as a common strategy in dealing with conflicting information, most interviewees mention the option of asking your doctor. As a qualified expert, the physician is usually considered to be able to clarify situations of uncertainty.

"I asked my doctor. And she said she found it funny that I asked her this, because she would have almost written a study on the subject... The results there are so contradictory that she rather kept her hands off it... So, I just talked to my doctor about it, who ultimately couldn't give me any detailed information" (Journalist, female, 32, in treatment for two years).

Thus, even though the success rates of reproductive medicine have increased significantly, physicians still act upon the assumption of a relatively uncertain success in some questions of infertility treatment. At the same time, physicians have to make specific decisions, which leads to an "unsolvable dilemma of legitimation" (Honer 1994: 58): Medical authority rests primarily on its scientific base, but scientific findings by definition only have a provisional validity. This does not necessarily challenge the expert's competencies. Rather, patients have come to terms with the fact that contradictions are implicit in scientific knowledge.

"One doctor thinks better of EmbryoGlue or – what's it called? – assisted hatching. And the other one says in turn, 'Well, I don't think much of it. And there are not enough studies that could prove it yet'" (Industrial Clerk, female, 41, in treatment for two years).

“Because the field simply isn’t all that well explored, you can’t draw any conclusions. It’s a bit like, well, someone thinks of it as a good thing, the next person disagrees. So you have to think for yourself a little ... Perhaps this somewhat hinders decision-making. That you don’t know – and can’t know – what’s best for yourself” (Industrial Manager, female, 41, in treatment for two years).

In terms of conflicting information of experts, one respondent summarises: “This is ultimately a matter of trust or belief” (Teacher, female, 40, in treatment for 15 months). In general, talking to someone about your infertility and its treatment seems to be a matter of trust. Just a few of our respondents deal quite openly with their infertility, but the majority – beyond their forum usage – talk about their problem solely to their close family and friends; one third of our sample speak about their infertility treatment face-to-face with two or three confidants only. The online survey further reveals that – beyond doctors’ consultation hours and Internet forums – seven percent of interviewees talk about their infertility treatment exclusively with their partner. The main reason for this is the delicate and private topic itself, but also the anticipation of incomprehension. Furthermore, interviewees doubt that talking to non-affected people could be beneficial, since they lack both medical knowledge and empathy. The Internet, today, enables an exchange with people who used to be difficult or even impossible to access in former times. That is why other users of online forums are often the most important contacts in infertility issues of all kinds.

3.2 Everyday Experiences and Scientific Knowledge

Using infertility forums, patients learn that other persons concerned share similar experiences and get to know ways of coping with infertility and its treatment. In the frame of our online survey, it turns out that respondents consider other forum users’ personal experiences the most helpful forum information: 59 percent of interviewees describe them as very helpful. The analysis of the forum, too, shows that the narration of personal experiences plays an important role: In a third of the contributions, persons concerned comment on their own reproductive medicinal treatment. If questions are raised on the part of users, in half of the analysed cases these explicitly aim at the subjective judgements and experiences of other persons concerned. Other patients’ experiential knowledge is then considered to be authentic, tested in everyday life and pragmatic. Thus, most of our respondents are exceedingly interested in personal experiences of other women and men with an unfulfilled desire to have children. Furthermore, the ability to understand an infertile person’s situation is frequently exclusively attributed to other people concerned.

“It’s a good community... where you are in the midst of like-minded people who actually understand. Actually, that’s the most important thing. Among one another, you know what you are talking about and how you feel. You don’t have to explain yourself comprehensively. And this is the main reason why I am there, why I like it

so much and why I definitely need it” (Journalist, female, 32, in treatment for two years).

Even if friends and family are interested and insightful, other patients online are often exclusively credited with real empathy. Our interviewees underline that they made a lot of contacts or even friends in the forums, whom they partly meet face-to-face on a regular basis. Forum users are bound together by the assumption that they have the essential experience and others are not able to understand. But using infertility forums is not dominantly driven by an affective motivation.

According to many respondents, the often long-term infertility treatment on its own leads to a process of self-professionalisation, “simply because it was our life – well, the last two or three years the topic has been very intense” (Nurse, 35, in treatment for five years). This is mirrored in the forum analysis: In a third of the 1,281 contributions, technical terms of reproductive medicine are used. Accordingly, in the online survey, 43 percent of the 1,216 respondents refer to themselves as experts on their own account – a further 41 percent state that they possess expertise even beyond their own specific case. This is why they see themselves as a knowledgeable guide for others. Several of our respondents cite friends, family members or physicians who commented on their expert status and especially their technical language regarding infertility issues. In forum communication, in addition to the extensive use of technical language, a minimisation or alienation of medical terms takes place. Thus, forum communication is characterised by a specific language including medical terms and a lot of forum-specific abbreviations and slang. In consequence, forum-specific expressions pose an obstacle to access for novices, which means that newcomers are required to slowly grow into the language of the community.

“Later on, we understood this gobbledygook... and as we had some experiences, you can – thank goodness – impart something” (Office clerk in parental leave, female, 36, in treatment for 3 months).

Accordingly, “old stagers” – a label which is used several times in our interviews – feel the responsibility to introduce novices to the forum’s language, knowledge and community. Introducing newcomers is defined as kind of a collective duty. Thus, by regularly using the forum, patients are “learning to tell the story” (Ziebland/Wyke 2012), which is important to make sense of one’s own situation, to talk to professionals or even to open oneself to friends and family.

All in all, regarding their form of forum usage, many of our respondents describe a certain pattern along their course of treatment. Most patients describe the first time period after their diagnosis as a downright learning phase in which they investigate the basic concepts of reproductive medicine and adopt medical terms.

“At first, it’s learning vocabulary. Then, it’s a process of orientation: Which clinic is right for me? ... Then an exchange about your diagnosis takes place. Then you discover that you are not the only one... This means that step by step, you learn not

to feel alone and isolated with that anymore, to get to know others going through the same thing. Somewhere down the line, you start to share your treatments, so that you are really excited about the outcomes of other people’s treatments” (Course coordinator, female, 29, in treatment for one year).

Firstly, couples trying to get pregnant for months or having a diagnosis of infertility usually use online communities for information. But after a while, motives of emotional and social support gain in importance. Finally, informational, social and emotional support start to mix. Especially long-term users have a lot of scientific expertise, while they are also equipped with experiences, insights and bodily sensations. This suggests that there is a blurred line between patients’ scientific and experiential forms of knowledge. Experiential and scientific knowledge are intertwined, whereby medical knowledge forms an integral part of patients’ experience.

3.3 Robust Nature of Experiential Knowledge

While a lot of forum users value experiential knowledge, there is no doubt that infertility forums also contain more or less wrong and misleading information, unintentionally given by others or even perhaps intentionally given for example by a fake user who abuses the forum for advertising. Thus, misinformation, confusion and an overload because of the diversity of information are assumed to be problematic aspects. Furthermore, unlike scientific studies, experiential knowledge primarily refers to a singular case, namely one’s own, which entails certain risks. This means that information given by laypeople could be wrong, biased or distorted. Close to 70 percent of forum users who participated in the survey deem the factual information provided by other persons concerned trustworthy. Nevertheless, this information is viewed critically: Far less than half of the respondents are confident that the information is overall (rather) correct contentwise. This is something a lot of our respondents are aware of but which they mainly describe as a third-person-effect: They predominantly characterise themselves as informed and critical users of information given online, whereas they are concerned about other users’ informational competencies.

Many of our respondents found a strategy to deal with potentially misleading information. They check the given sources of information, compare it with other sources and consult friends, acquaintances and their doctors. In case of conflicting information, many respondents also rely on their gut feeling or think about the plausibility of the information provided. But as diverse experiences can be explained by the uniqueness of individual situations, experiential knowledge in particular enjoys a special status in forums.

“If you prefer to read reports on experiences ... and then this one [woman] recounts for example – somewhat – she got her menses four weeks after an abortion and curettage. And another one says, yes, that’s after one year. Thus, there are rather different experiences” (Consultant, female, 37, in treatment for 10 months).

“‘How long did it take with you until the treatment started?’ One simply has to accept the fact, if people say, ‘two months’ or ‘three months’ or ‘one month’” (Research Assistant, female, 29, in treatment for five months).

In comparison to contradictions in scientific knowledge, differences in personal experiences tend to be condoned. Contradictions in different patients’ experiences are accepted as such; they can be explained by the singularity of experiences. Personal experiences and especially bodily sensations are a type of knowledge that is undeniable.

“If someone who perhaps did not have endometriosis and doesn’t know anything about it at all responds to me, then I suppose I might not take the answer as seriously as that of someone who had it and knows it herself” (Course Coordinator, female, 29, in treatment for one year).

Forum users look for contributions by other patients as similar as possible, in order to draw parallels to their own situation. In this context, forum users referring to very similar conditions have a special status as informants. Hence, infertility patients online want to compare, for example, the chosen course of treatment, the drug dosage, the chances of success or even their own emotional state. Therefore, similarities in age, diagnosis, and treatment history increase the value of someone’s post.

Accordingly, most of our respondents know that there are other forum users who value their contributions and so they display their expert status with confidence. However, several respondents dissociated themselves from their self-professionalisation during our interviews.

“You become an expert in that field. Well, that is very dreadful” (Course Coordinator, female, 29, in treatment for one year).

“Well, you become like a specialist in a way, unintentionally” (Journalist, female, 32, in treatment for 28 months).

“Yes, as upsetting as it is, you catch on pretty quickly... And yes, it becomes kind of second nature, unfortunately” (Project Assistant, female, 33, in treatment for 30 months).

These patients declare their expert status, but at the same time regret their self-professionalisation and describe it as unintended, unfortunate, dreadful; they undergo a kind of reluctant self-professionalisation. Although self-professionalisation is deeply rooted in the tentative nature of scientific knowledge, for patients, it seems to be inappropriate to gain an expert status – at least it is regarded as something deplorable.

4 Conclusion

In conventional public communication, medical knowledge is usually presented as objective text-book knowledge, that is, as “objective” knowledge generally accepted

by experts (Fleck 1935; Bucchi 2008). Thus, although scientific knowledge is tentative in nature, in public, it becomes fact. For the communication of medical knowledge in online forums, the opposite is the case: The juxtaposition of scientific and experiential knowledge reveals contradictions and confronts patients with opposition. At first glance, then, communication of laypeople in online forums might be expected to generate uncertainty, rather than straightforward facts.

However, today, patients online go through a process of self-professionalisation and therefore tend to have kind of a scientific habitus. Consequently, our interviewees think and act in a scientific manner in multiple respects: They look out for a broad range of medical knowledge of diverse origin, compare different sources, use technical language, reflect on the tentative and conflicting character of scientific knowledge, and discuss their state of knowledge. Unlike scientists, though, they do not pursue pure scientific knowledge as an end in itself. Instead, they prefer a more pragmatic approach informed by a process of knowledge acquisition which clearly incorporates non-scientific features as well: Our interviewees consider experiential knowledge an important source, assume that others who know from experience are the only ones who really understand and use similarities as heuristics.

Thus, patients’ online forums constitute a place where scientific knowledge and lived experiences intertwine. Infertility patients using online forums are then not only experienced in living with infertility and going through infertility treatment, but also gain interactional expertise (Collins/Evans 2009:14) – this means that they learn to understand and discuss scientific knowledge on medical treatments (but they are not able, let alone allowed to carry out these treatments). Thus, we assume that in health-related online forums, we find “expertise mixed with experience” (Collins/ Evans 2009:9), which can be of use in decision-making situations of uncertainty. In order to increase their chances of a pregnancy, infertility patients using online forums interweave scientific knowledge and personal experiences, go back and forth in this process, and form patchwork knowledge enabling them to go on in decisions involving uncertainty.

The Internet forums themselves are understood as a technological structure which, on the one hand, suggests a subjectivation of the communicated knowledge and, on the other hand, facilitates the systematic processing, researching and filtering of the individual statements available online. Thus, subjectivity, concern, body knowledge, intuition and experience are inscribed into the digital media, which are conceived to invite an exchange between patients as similar as possible. Through a reference to experiential knowledge, the conflicting scientific knowledge is then transformed into a resource on which everyday decisions can be based.

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