



HAL
open science

Fertility and medically assisted procreation: forms of exchange and relationships between patients via forums and blogs in South Africa

Emmanuelle Simon, Brigitte Simonnot

► To cite this version:

Emmanuelle Simon, Brigitte Simonnot. Fertility and medically assisted procreation: forms of exchange and relationships between patients via forums and blogs in South Africa. International symposium Biomedical Technologies in Sub-saharan Africa, Mar 2014, Lisbonne, Portugal. hal-01322259

HAL Id: hal-01322259

<https://hal.univ-lorraine.fr/hal-01322259v1>

Submitted on 26 May 2016

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

**Fertility and medically assisted procreation:
forms of exchange and relationships between patients *via* forums and blogs
in South Africa**

Emmanuelle Simon, Brigitte Simonnot

emmanuelle.simon@univ-lorraine brigitte.simonnot@univ-lorraine

Centre de recherche sur les Médiations

University of Lorraine, France

Introduction

(Diapo 2) This research is part of a multidisciplinary research program in anthropology and information and communication sciences about medically assisted procreation in three African countries: Cameroun, South Africa and France. The research is undergone by four laboratories: CEPED, Centre Population et Développement (UMR 196 Université Paris Descartes – INED – IRD); CEMAf, Centre d'études des mondes africains (UMR 7161 – CNRS- Paris1-EPHE); CEAN Centre d'Etudes d'Afrique Noire (UMR 5115 – IEP Bordeaux); CREM Centre de recherche sur les médiations (CREM – EA3472 Metz).

In this communication, we will focus on South Africa.

(DIAPO 3) For us, online forums and blogs about Assisted Reproductive Techniques are social spaces for African women, and they build some communities to make sense of their situation. In blogs and forums, women submit personal data and exchange information between them. Identities, considerations about selves and relations (how to live with others) are built up through those technical settings.

To understand how women exchange together in online blogs and forums, we have observed and analyzed in detail “the organization, production and processing of specific sequences of interactions” (Licoppe, 2013), and have tried not to follow only actors but also sequences of interactions, crossed between several websites where they are “expressed, evoked, cited.” This double process helps to “grasp something in the production of identities” (Licoppe, 2013).

So, we have carefully analyzed some journeys of infertile women, especially one of them during several years. In social sciences, the internet is often studied as a social space through the notion of network, but we have rather chosen to reconstitute some paths and biographies of online women. We have tried to observe how they gradually build a relation with their bodies, the drugs and assisted reproductive techniques. Utterances in forums and blogs are worthy of analysis as they don't include only *a posteriori* speeches about the course of their lives: individuals can be followed as they evolve and broadcast their thoughts live. We tried to capture the complexity of their routes (e.g. how women handle failures), with their discrepancies and developments, and the steps to make sense of fertility issues through subjective experience.

On the other end, to better understand how such interactions appear from one place to another, we have undertaken to follow these women in various online spaces. Here, we have followed these South-African women between forums and blogs.

1. Our corpus

(DIAPO 4) During the research project, we analyzed African blogs, written in French or in English. Usually women are from upper middle class with various situations of social vulnerability. We have collected 26 blogs from South African people. Only one is written by a man (his wife has also a blog). Women who blog are between 29 and 42 years old, they are from the white community. They have very good positions, they have jobs as manager; training consultant; national account manager; freelance designer and wedding stationer. These women live in Cape Town, near Johannesburg or near Nelspruit in the east.

Women who blog in English about infertility are not so many, and it's worse for French blogs in Africa. We can identify a very strong tie between writing a blog and being registered in Fertilicare¹ forums: on 26 blogs, 19 ones are linked to Fertilicare, with the logo of the association or links to the website. 16 women have been identified in both supports. Most of them registered on Fertilicare forums first and then have created one blog. 12 of them are very active on forums (from 1500 to 3000 posts). None of them is just a reader (at least 200

¹ **Fertilicare** (<http://www.fertilicare.org/>) is a website with online forum about fertility. The web site has been created in 2007 by 2 South-African women who coped with infertility. One of them has found a donor centre, *Nurture*.

messages posted in forums) when it is a common practice in French or English speaking forums.

In our biographic perspective, we don't aim to present some women's routes as exemplary ones. Women of our corpus are from a minority in a double way: white people in South Africa and people writing online in blogs and forums. However, the underlining idea is that people, even from a minority, always say something about the whole society.

(DIAPO 5) Usually, blogs of women trying to conceive begin just after they start treatments for IVF, and ends when the project is over. Some women have several blogs, each one being dealing with a specific topic. We have followed one woman we will nickname Rose. We have analyzed her blog throughout, with comments and also her comments on Fertilicare. Even if she writes with her real first name on her blog, we prefer to hide her real identity. Rose, like most of bloggers (not to say all of them) doesn't link her blog to her pseudonym in Fertilicare. In forums, women use pseudonyms as they speak about very personal issues.

Rose created her blog in February 2009, she was trying to conceive from 2001, has been pregnant 3 times but each time it ends in miscarries. In 2008, she had her first IVF, got pregnant but miscarried at 6 weeks. She explains the reasons why she creates a blog by her need to understand and to get support:

“I embarked on my spiritual journey looking for answers and found a wonderful place for my intuition and self-awareness to grow”.

She writes every Saturday in the afternoon, except when there are special events; for example, she writes almost every day in period where she waits for results, and she stops writing for 15 days or one month after failures. Nevertheless, she tries to be positive and doesn't complain too much about her fertility issues.

2 Kind of sources for information about infertility issues

(Diapo 6) In forums and blogs, we have found many tracks of information practices about fertility issues. One dominant topic is uncertainty: outcomes of treatments are unpredictable. To face uncertainty, women seeks actively for information. They use a large diversity of media. Women read books about infertility. Rose is interested in scientific discoveries, some of them could be described as para-scientific. For instance, Rose, when she changes her strategy and think about egg donation, reads books about genomics and human evolution.

From the books, she concludes that even if she conceives with eggs from another woman, the fact that embryo will be in her “tummy” (as she says) can change many things.

DIAPO 7 Figure 1- Blog of Rose, Saturday, December 4, 2010

(DIAPO 8) Women watch specific TV programs on various channels and notify them to others on forums threads. For example, Rose notifies on her blog a program on BBC Knowledge "A child against all odds", and she says that she appreciated it a lot because each episode talks about 2 cases: one which worked and another one which failed. On TV, women watch also American series, medical dramas like *Greys anatomy*, *Private Practice* and *Brothers & sisters*. Even during leisure time, they keep in touch with fertility issues and medical circle with books and TV programs.

Another common practice women refer to in their blogs and forum is googling. They mainly use web search engines to ask “Dr Google” about their symptoms, to understand the pieces of information for diagnosis, to go further after discussions with their fertility specialists or to understand the meaning of numbers or rates in medical records when they receive results of their biological tests. They search to understand how normal are theirs results, and what they mean. But they also search further on the web after watching a TV program or reading a newspaper to verify and to know more about what has been said.

(DIAPO 9) They turn to forums to ask other women about specific questions and to get advices in order to make some choices. During fertility treatments, they are faced with many choices, and they discuss them with their Fertility Specialist but they also seek advices from women with similar experiences. Rose asks: how many days before egg transfer, 3 or 5? Or what kind of IVF to do, ICSI, PICSI? She talks about drugs used for stimulation and the possible side effects. Other women try to help in the forum answers or in comments of the blog by reporting their own experience, their doctor advices, and so on.

In her interactions with others, women also refer to websites they have found during their googling: often, they find information on websites in USA, Canada or the UK. They mention some fertility practitioners' blogs they read. They also refer to scientific magazines like *New Scientist* (online), for example about a paper announcing a new treatment against infertility which has been developed by a doctor in the USA, the doctor coming from South Africa. Their information practices cross-reference facts from other women experiences and information from classical sources.

And last, they share and discuss information they have found during doctor-patient appointments:

Prof wasn't very complimentary about Dr Sher when I arrived armed with loads of his articles from his blog last time we chatted - said that not a lot is based on true scientific studies yet...so maybe SA is behind or he has a point...

Figure 2- Rose, in Fertilicare forum, May 25th 2010

3. ICT for organizing and making sense of individual situations

(DIAPO 10) The blog is a kind of self-recorded information that the author can search in when she wants to compare her current situation with past results in treatments. So women use ICT both to organize their “plans of action” and as self-reflexive tools. Our blogger, Rose writes a lot in Fertilicare forums first and then she writes a blog post where she is more staid or serene. For example, on the 10th of December 2009, she posts in the Fertilicare forums about a “prescription for hope” her fertility specialist wrote out during her last appointment; on the 16th of December, she writes a blog entry with the same title but a rather different content that shows ideas have caught on in her head. This blog entry is a testimony of the work done on herself, to rebuild a unified self and to overcome the risk of fragmentation of her identity, a work that she wants to benefit others. So some blog entries are not only written for expressing oneself at the time, but to give an account she thinks will be useful for other women. That the reason why, when the infertility journey is over, women stop blogging (and often open another blog) but some of them leave their old blog open.

Blog and forums are means to get in touch with a community of people who are concerned with the same topics and who can understand what patients feel during fertility treatments.

(DIAPO 11) In the case of South African bloggers, women use forum and blog to express their discomfort and to describe how they feel, physically and much more psychologically. For instance, some threads are about “The most insensitive comments” those women have been faced to. One thread, beginning in August 2009 on Fertilicare forum, had fifty or so answers from women with their own anecdotes, the last one being posted in November 2010. In Fertilicare, women expect especially emotional support and we can see an emphasis on their subjective experience. They ask others for news about their IVF and worry when a woman doesn't visit online spaces for a while, which could be a sign that she is discouraged. This unconditional support which always invites them to continue is ambivalent because it implicitly expresses the commonly held idea of impossibility "of being childless" (Inhorn,

2002). At the same time, individuals are supported by the community to build her selves and identities, and on the other side, they are watched by the community and encouraged to go on the journey and constrained by the norms.

4. Forums and blogs as technical settings which promote the appropriation of ART

(DIAPO 12) Mixing emotional support and information seeking about Assisted Reproductive Techniques, digital social spaces are important places for women to incorporate the process of medically assisted procreation.

We first mention their information seeking episodes and biomedical sources they use. Rose has a sharp knowledge about infertility, its causes, the treatments and she puts forward each step protocols with a high precision. The questions she asks for demonstrate a high level of knowledge of the processes of ART but, more generally speaking, of human biology. Is it possible for an immature egg at time X to be fertilized? What are the determiners of nesting? And so on. This level of expertise remains very uncommon and can be linked to the social category of those women who blog, which suppose some level of education. This education allows her to ask the necessary questions in her relations with the staff and the doctor of the fertility clinic.

By the time, many of those women have developed a kind of expertise: they experienced a great number of tries to conceive (6 IVF for Rose, up to 9 IVF for another one), each one being different from the previous one, with, sometimes, slightly different protocols, and each detail is important for them. For Rose, her expertise is also built through a complex relation with her fertility specialist where clinical and experimental relations are mixed up: in a classic case of “therapeutic misconception” (Appelbaum, 1982).

(DIAPO 13) Thus, the reports of the progress of Rose’s IVF look like a medical file where the patient is reduced to a set of equations. For example, she compares the outcomes of her stimulation on Cycle Day 8 of her current IVF with the previous one. On her blog, she begins to update a comparison, step by step, between protocols.

(DIAPO 14)

July:

CD2 - 3 x Femara tabs

CD3 - 3 x Femara tabs / 4 amps Menopur

CD4 - 3 x Femara tabs / 3 amps Menopur

CD5 - 3 x Femara tabs

CD6 - 3 x Fenara tabs / 4 amps Menopur & Scan

CD7 - 2 amps Menopur / 1 amps Fostimon

CD8 - 2 amps Menopur / 1 amps Cetrotide

CD9 - 2 amps Menopur / 1 amps Cetrotide

CD10 - 2 amps Menopur / 1 amps Fostimon & 4 day Cetrotide & Scan

CD11 - 2 amps Menopur / 1 amps Fostimon

CD12 - 2 amps Menopur

CD13 - 2 amps Menopur & Scan

CD14 - 2 amps Menopur / 1 x Cetrotide

CD15 - 2 amps Menopur / 1 x Cetrotide

CD16 - 2 amps Menopur / 1 x Cetrotide & Scan & Trigger in the pm

CD17 - No meds

CD18 - Aspiration = 4 eggs

CD19 - One fertilised, rescue ICSI on 3

CD20 - One stopped, 1 out of 3 fertilised

CD 21 - The 1 embie stopped

CD22 - The 1 embie started again

CD23 - The 1 embie stopped again and ET cancelled

October:

CD2 - No stims & Scan

CD3 - 2 amps Menopur / 150 Gonal F

CD4 - 2 amps Menopur / 150 Gonal F

CD5 - 2 amps Menopur

CD6 - 2 amps Menopur

CD7 - 2 amps Menopur

CD8 - 2 amps Menopur & Scan

CD9 - 2 amps Menopur / 3 day Cetrotide

CD10 - 2 amps Menopur

CD11 - 2 amps Menopur

CD12 - Scan - 2x 13mm follies on RHS and 2x 20-22mm follies, 1 x16mm on LHS!!! / 2

Menopur & Trigger shot at 11pm

CD13 - No meds

CD14 - Aspiration = 3 Eggs (!!!???)

CD15 - One egg fertilised. Waiting to see if immature one matures & fertilises

CD16 - Immature egg fertilised. First egg divided.

CD17 - First egg only a 5 cell on day 3 (should be 8 cell). Second egg stopped.

CD18 - First egg still only 5 cell :(Second egg started diving again and is now a 4 cell...

CD19 - Going in at 11am and praying there is something to transfer

(DIAPO 15) Later, when she will use an egg donor, as she will learn the number of follicles of the donor after the stimulation, she will calculate the probabilities to go to the transfer (I let you read the slide):

« *I read that a good donor should have 15-25 antral follicles. Also, you can calculate how many eggs you will get with a simple calc: $EGGS = 0.8 * FA$ (Antral Follicle Count)+2. So if our donor had 15 antral follicles then hopefully we will get 14 eggs!! That would be great, if one considers only about 50% fertilise. I would be completely thrilled to have 7 embies. They also say that approx 30% make it to blast, so if we get 7 embies, then hopefully hopefully, hopefully we will get 2 healthy blasts to transfer, maybe more* ». (blog: 18 February 2010).

(DIAPO 16) The promise to be pregnant takes the form of the results from biological tests (BETA test) as well (just an extract):

« *And the number is.....*

1985!!!

So relieved! »

(blog & forum : 14th of March 2010)

Putting in numbers the path according to the number of stimulations, of produced follicles, of biological results is pushed to the extreme here. But we can find a similar tendency, more generally, in profiles and signatures in forums. And we can say it is the same for a large majority of African women who are active on forums – either French or English speaking.

(DIAPO 17) Here is the way Rose's profile is displayed in the forum:

TTC: 13 yrs Me: 39 DH: 52

98-01: Tried...

01 & 04: Lap endo x 2, PID

05: 3 Chlo & 3 AI's - BFN

06&07: Preg: Rupt ectopic & 2nd ectopic

08: IVF#1 BFP, MC 6 wk, July: IVF#2 no ET

Nov: IVF#3 no ET, poor embryo qual

2010: Mar: IVF#4 - cancl'd. May: IVF#5 - no ET, embies stopped. Oct: IVF#6 - BFN

2011: Feb: IVF#7 DE - BFP! (Betas: 10d5dt 264, 14dp5dt 1985, 18dp5dt 9756, 22dp5dt 26356) 😊

TWINS!!!!: A boy and a girl! 😊 Rebecca (1430g) and Finn (1940g) Hospitalised for severe pre-eclampsia, born at 31 weeks 3 days. 4 Weeks in NICU...

(It's difficult to read, because of the online infertility lingo)

Profiles and signatures are like identity cards, sometimes displaying a diagnostic but mainly a series of steps in an infertile woman's life, with ART at the center.

Rose biography seems reduced to the different IVF succeeding each other, without or with egg donor, some are simple IVF, some ICSI or PICSI. It can be seen like a process of embodiment of assisted reproductive technologies.

But, in our biographical approach, it's important not to focus on a single step of the trajectory. The ultimate aim of these women is to have a child and to become a mother. Usually, women inscribe their new born in their signature and then, they change the category of forum where they write: they post in the forum which is dedicated to mothers.

At the same time, we would like to nuance the idea of embodiment of ART because we don't want to join in feminist criticism about ART, when they say ART is a new biomedical mean to constrain women bodies:

(DIAPO 18) (Greil, 2002: p. 113) « *The experience of infertility is an experience of failure of body and self, and the experience of infertility treatment is an experience of frustration, loss of control, and mortification. But these women do not present themselves as passive victims content to be treated as objects. Rather they appear as active strategists and negotiators who have learned to work the system in such a way as to maximize the control they do have* ».

These women adopt biomedical representations of their bodies, and they enroll themselves in a project which leads to monitor and watch their bodies, putting aside the invasive therapies and treatments. But we may suppose, with Greil, that they are ready to do such effort to satisfy their wish of having a child and to gain, finally, the legitimate status of a mother.

Conclusion

(DIAPO 19) After this online fieldwork, we can say that Information and Communication Technologies (ICT) play a role in the way women deal with their infertile status; through their

writings, both in blogs and forums, they try to overcome heavy treatments. Moreover, they build social identities. Online, they find places where they are recognized and can rebuild self-esteem. But, the online community is also normative in the way it gives support. And, for a large part of infertile women, the ultimate aim is to recover a legitimate social role: to be a mother.

To clarify the relationship between subject, procreative norms and ART embodiment, they are several other questions that we want to explore through our corpus, for example:

- When a woman decides to make a break (not stop, a break) during infertility treatments, how are such conflicts handled in forum exchanges? It could be also explored with the question of adoption. Does the community of women just give a normative support? Or new norms could arise from such online interactions?
- One South African woman, who was infertile and finally became a mother, created Ferticare website and an Egg Donor center. She writes: “when you have been an infertile woman, you will be one for your whole life”. When women conceive with assisted reproductive technologies, does the embodiment process of biomedical technologies still exist after babies’ births?

To conclude, Isabelle Gobatto was bringing out, in *Les pratiques de santé dans un monde globalisé [Health practices in a globalized world]*, that « all the women are not exposed in the same way and with the same degree to the process of globalization” “material and immaterial conditions which determine part of their life and their capacity to subjectivize their experience, to modulate it as they wish, vary from one group of women to another.” p. 163.

We could adopt this remark for web tools. The ability to juggle with social logics specific of the internet, its settings, and its tools is not shared equally. Is our corpus representative of infertile women in South Africa? To write a blog, someone needs to be educated and fluent with ICT. Now, in South Africa, there are black women in the upper middle class. But we couldn’t identify black women who write a blog. Perhaps black women are less ready to display themselves online. We shouldn’t think the issue just in term of equipment, stable connection, but rather to keep in mind the social conditions of existence of people who face infertility in our study and their unequal relation towards the practical sense, specific of the internet.

APPELBAUM PS., ROTH LH., LIDZ CW. [1982], «The therapeutic misconception: Informed consent in psychiatric research». *International Journal of Law and Psychiatry*, 5, p. 319-29.

GREIL, A. [2002], Infertile bodies, medicalization, metaphor, agency, In Inhorn, M. et Van Balen, F (dir.). 2002. *Infertility around the Globe: New thinking on childlessness, gender and reproductive technologies*, Berkeley, University of California Press. p. 101-113

GOBATTO, I. [2003], *Les Pratiques de santé dans un monde globalisé*, Karthala, 240 p.

INHORN, M. et VAN BALEN, F (dir.). [2002]. *Infertility around the Globe: New thinking on childlessness, gender and reproductive technologies*, Berkeley, University of California Press.

LICOPPE, C. [2013]. Formes de la présence et circulations de l'expérience, de Jean-Jacques Rousseau au « quantified self » *Réseaux*, 6, 182 : 21-55.