Terms of Engagement: Re-Defining Identity and Infertility On-line

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Abstract

This article focuses on the identity work that takes place on the biggest Polish Internet forum for infertile people (www.nasz-bocian.pl). It is an example of a wider trend of "digital groupings created by and for those who struggle with the physical and emotional burden of a disease or disability, and through blogs, chats and forums contact others who have similar experiences, while staying anonymous. Participating in on-line discussions often leads to various forms of social engagement, both on-line and off-line. The sick, their family members, partners and friends cooperate in order to change the public discourse, as well as the regulation and financing of research and the treatment of certain diseases. Emergence and proliferation of such digital groupings raise questions such as: what ails these communities? How the collective identity is constructed on-line? This article examines "boundary work, which is a specific element of collective identity construction processes. The analysis concerns how the borders are established between the different sub-groups within the digital community, and how this process involves producing novel forms of identity based on a fragmented "socially legitimized childlessness. It focuses on a sub-forum "Conscious Childlessness and is based on qualitative analysis of the posts placed there. This sub-forum was established by users who do not necessarily share the dominant collective identity around which the social mobilization on infertility in Poland coalesces. They refuse to see themselves as sick people, or as patients, attempting to construct a new collective identity based on the idea of choice and the pursuit of happiness.

Keywords: infertility, identity, boundary work, on-line activism, assisted reproductive technologies

Introduction

"You will become a mother, you will cuddle your own children. We have dreamed of your children" – that is how, according to one Internet forum user, other infertile people reacted when she stated that she wants to end an unsuccessful infertility treatment. This happened on "Our Stork", the biggest Polish Internet forum for people with infertility (<u>www.nasz-bocian.pl</u>). The user whose nickname is "bloo" is not only a member, but a moderator. She stresses that she posted the above quote to show that the boundary between support and pressure is sometimes trespassed by the members of the virtual community; that the encouragement of others to keep up the fight when in vitro fertilization (IVF) fails may easily turn into coercion.

"bloo" concludes her post by saying that receiving such reactions did not change her own decision, but that such responses may deepen the sense of guilt and shame felt by others. Because of this, she initiated the Our Stork sub-forum "Conscious Childlessness", where the negative aspects of being a member of virtual community of the infertile can be discussed.

This sub-forum has become a space for women who identify themselves as infertile, but who do not share the dominant collective identity around which the social mobilization on infertility coalesces. They do not necessarily see themselves as sick people, or as patients. Rather, they define themselves as women who happen to be infertile but who are able to make conscious decisions concerning their engagement with reproductive technologies. Thus, they challenge the official types of identity promulgated by the Our Stork group, attempting to construct a new one based on the idea of choice and the pursuit of happiness. This article focuses on the identity work that takes place on Our Stork's "Conscious Childlessness" Internet forum, and examins the strategies used for establishing boundaries between different groups of infertile people when their life trajectories, emotional responses and needs differ.

Activism Around Infertility and Access to IVF

The Polish Our Stork forum is an example of a wider trend of "digital groupings" created by and for those who struggle with the physical and emotional burden of a disease or disability (Rose & Novas 2005). Through blogs, chats and forums, the sick and their partners or friends can contact others who have similar experiences. New communication technologies allow people from all over the world to discuss what they live through, to express their hopes and fears, and to share information, while staying anonymous. Furthermore, participating in on-line discussions often leads to additional forms of social engagement, both on-line and off-line. People cooperate in order to change the public discourse, as well as the regulation and

financing of research and the treatment of certain diseases (Rose & Novas 2005; Brown & Zavestoski 2008; Callon & Rebeharisoa 2008).

This trend also applies to people suffering from infertility, even though it is not always possible to discern whether the problems with conceiving a child are health-related or stem from other environmental or social factors. Today, there are many organizations focusing on infertility and assisted reproductive technologies (ART), most of which originated on the Internet.¹ Examples include the Çider Association in Turkey, which has been studied by Polat (2012), and the Association for Medical Treatment of Infertility and Supporting Adoptions Our Stork (*Nasz Bocian*), whose members have created and managed the forum discussed here. The situation of the infertile is special because people, especially women, who do not have children are often subject to social stigmatization, no matter what their state of health is. This stems from the fact that motherhood is seen as a key to women's "normal" social identity, and so being childless is regarded with disdain and/or pity. The Internet is often the only place where childless and infertile women can discuss their feelings and experiences freely (Allison 2011).

This may be still more the case in the Polish context due to the hegemonic discourses on femininity as based on motherhood (Hryciuk & Korolczuk 2013). Moreover, while in Poland the childless are often stigmatized and considered egoistic, the people who use assisted reproduction are regarded with still greater suspicion. They are condemned by representatives of the Catholic Church and by conservative politicians, both of whom accuse such persons of defying God's laws and thus of immorality and indecency (Radkowska-Walkowicz 2012; Korolczuk 2013). In fact, the Church's opposition to IVF influences both discourses and practices. Consequently, assisted reproductive technologies, such as IVF, are not regulated by the state, and Poland did not ratify the Convention on Human Rights and Biomedicine of 1997, despite the fact that ART have been offered in Polish hospitals and private clinics since the late 1980s and today there are over 40 clinics where such procedures are performed. The situation has improved while this text was written: on the 1st of June 2013, the Ministry of Health introduced a three-year plan for state-funded IVF treatments, which will partially cover the costs of procedures, if not hormonal treatment and diagnostics, for a total of 15,000 heterosexual couples. However biotechnologies in general remain unregulated.²

The example of "bloo", cited above, shows that while there are advantages attached to being a member of a virtual community of people grappling with infertility, there are also challenges. These concern issues such as the construction of a shared identity and the definition of a common goal. Infertile people in Poland have to cope not only with the social consequences of infertility, such as exclusion, feelings of inadequacy and reproductive failure, but also with negative opinions on ART disseminated in the media and public sphere (Korolczuk 2013). This requires constructing a new type of embodied identity based on a desire to become a biological parent, which gives the infertile the status of a patient and a citizen. The problem is that some members of the community may experience the identity of a parent *in spe* or a patient as oppressive. This happens, for example, when, as in the case of "bloo", IVF fails.

British sociologist Karen Throsby (2006), who examined the experiences of IVF failure, points out the fact that infertile people whom ART did not help

find themselves ambiguously located between often contradictory norms of gender, technology and the reproductive body: they have a strong desire to be biological parents, but are no longer actively pursuing that desire, and they have technologised the "natural" reproductive process but without a subsequent baby to counterbalance anxieties about technological corruption of the natural order. (83)

Throsby stresses that the failure to achieve the desired result – the baby – does not mean that people's bodies and identities remain unaltered. My study examines the ways in which this ambiguous location is expressed on the Internet forum which is dedicated to people who are using or have used ART. I am interested in how website users who have undergone ART but decided to stop the treatments, define their position vis-à-vis those who refuse to "give up". The latter, openly or implicitly, brand the former as losers if not traitors; yet they all remain a part of a larger Internet community of the infertile. Moreover, there are people like "bloo", who stay active on the forum, although they no longer pursue the goal of becoming a parent. How is the boundary between these two groups drawn? How is the boundary drawing process facilitated by the medium?

In this article I examine "boundary work" (Hunt & Bedford 2004: 442), which is a specific element of collective identity construction processes. My analysis concerns how the borders are established between the different sub-groups within the digital community, and how this process involves producing novel forms of identity based on a fragmented "socially legitimized childlessness" (Throsby 2006).

Methodology and Ethics

The analysis presented here is based on the outcomes of a research project, which examined the institutional, legal and discursive framework concerning infertility and assisted reproductive technologies (ARTs) in contemporary Poland.³ It involved qualitative analysis of the posts which are placed on the internet forum <u>www.nasz-bocian.pl</u>, which is the biggest Polish virtual community concerned with infertility and ART. As of March 2013 there were 6,548,993 entries, organized around almost 50,000 threads, and 76,838 registered users. The main themes include: "Ask the expert" (with threads such as: Infertility, Men's infertility, Miscarriages, Infertility for beginners), "Infertility, let's share information" (e.g. How to get treatment, Where to get treatment, The sperm etc.), "Adoption, let's share information" (e.g. Places and procedures, Dilemmas, My road to adop-

tion), "Foster families", "I need to talk about it" (Space for some psychotherapy, Good and bad news, Our dearest) and "Technical and organizational stuff", and finally, the focus of the present study, the "Conscious childlessness" sub-forum. I have analyzed the posts on the "Conscious childlessness" sub-forum, looking for specific key-words on the whole forum. Critical discourse analysis has been an important inspiration for the present study, as I attempt to re-constructing the ways "infertility" and "childlessness" are framed in these on-line discussions, and how internal hierarchies are (re)produced through discourse (Fairclough 1995; van Dijk 1997). Data gathered in the semi–structured interviews conducted in 2013 with key activists of Our Stork Association living in Warsaw has been used as an additional source of information.

The analysis of Internet forums raises some important ethical questions, especially concerning privacy and informed consent. The forum of Our Stork is open to the general public, which means that all posts are available to all Internet users, without registering. Those who register providing a nick name and an e-mail address get access to more functionalities, e.g. they can publish posts, establish new threads etc. There is no verification process during registration.

Also, the number of people using the community is large – there are thousands of users and posts. Thus, I regard the forum as public and decided that informed consent for my passive analysis of the postings was not needed. However, the researcher is obliged to make sure not to put the informants in a situation where they might be at risk of psychological harm, which is especially important concerning issues related to health and sexuality. Thus, I informed the activists from Our Stork of my project, its goals and of how the outcomes will be used, and invited them to an open seminar where I presented the preliminary outcomes of my analysis. I am very grateful for their comments and generosity, and hope that my work will be helpful in their struggle towards social change.

Boundary Work and Social Activism in Virtual Space

The Internet forum, which is the focus of my analysis, is linked to the Association Our Stork (*Nasz Bocian*), the most vocal social actor fighting on behalf of the infertile in Poland.⁴ This is a politically engaged lobbyist group, which supports people, collaborates with doctors, educates the public, engages in cooperation on the international and local level and fights for regulations that would mandate safe, state co-financed treatment.⁵ The Internet forum to which the Association is linked, on the other hand, offers a space for interaction and emotional support. At times, the Internet forum users also engage in social activism, mostly in reaction to potential threats, such as aggressive and demeaning utterances concerning infertile people publicized in the media, or in order to support new laws regulating ARTs. On such occasions they alert the media, write open letters to newspapers, sign petitions to politicians and representatives of the Church, or express their

opinions on the social media. In a few instances small groups also took to the streets.

In some respects the Association functions as a typical Social Movement Organization (SMO), while the users of the Internet forum mobilize only occasionally, and some – perhaps even most – do not engage in social activism. Nevertheless, they influence public discourse and the political sphere not only via direct actions, but also through the production of knowledge and promulgation of novel interpretations of infertility, ART and human reproduction. Thus, I interpret the engagement of the active members of Our Stork forum as a case of on-line social activism, and take my theoretical starting point in collective identity theory (Polletta & Jasper 2001) as well as and the body of work done on social activism related to health (Brown & Zavestowski 2005; Rose & Novas 2005; Polat 2012).

I focus specifically on boundary work, which is usually interpreted as the marking of social territory by stressing differences between those who belong to a specific group or a movement and those who do not (Hunt & Benford 2004: 442). The goal of such work is to strengthen a sense of togetherness, solidarity and commitment, by producing both a collective "us" and a collective "them" through a variety of practices and activities. Hunt and Benford point to the fact that boundary work occurs also within a movement, for example when the most engaged members of a specific SMO attempt to mark boundaries between themselves, and more casual activists. Analyses of animal rights activism demonstrate how this dynamic works in a specific context. Here, the demarcation lines can be drawn between activists who are vegan and those who are vegetarians (Jagger 1992 in: Hunt & Benford 2004: 444, Jacobsson 2013). Following less strict rules concerning one's diet is interpreted as a sign that a person lacks commitment, that she is not truly engaged. According to Jacobsson (2013), the division between those who promote veganism and those who stick with vegetarianism forms a major source of division within the animal rights movement in Poland, and causes its "bifurcation into the two strands of animal welfare and animal rights proper" (30).

The analysis of the Our Stork forum suggests that establishing borders between the groups within a larger community may also serve other goals. It may, for example, enable people to challenge the official identity of the group from within and to manage the problem of divergent goals, without the necessity to leave the group altogether. In sub-groups people can voice desires, emotions and interests which are not shared by the majority, while remaining connected to a bigger community.

In this specific case, the social terrain where boundary work takes place is the Internet. The Internet has proved to be "a congenial host territory" for people who want to share knowledge and information, exchange their feelings, and campaign for their rights (Rose & Novas 2005: 449). Thus, it is often perceived as an instrument which not only facilitates communication and reduces the costs of coop-

eration, but also promotes collective identity and creates new communities (Norris 2004; Garret 2006: 204). Such a vision has significant social currency. Other scholars, however, point to the fact that the loose networks created on the web are often temporary, and easy to opt out of. Thus, they cannot generate the commitment, persistence, and solidarity that characterizes successful social movements (Garret 2006). Technologies such as the Internet enable communication or recruitment but do not necessarily lead to mobilization, or as Wall (2007) argues, they may facilitate specific organizational activities, but have less impact on the symbolic aspects of action.

Recent works on the relation between new communication technologies and contentious activities demonstrate that the influence of new technologies depends on a variety of interrelated factors, for example the nature of the existing social movement organization (Diani 2000; Garrett 2006). Bennett and Segerberg (2012: 756) distinguish between formal political organizations and groups, which follow the logic of collective action, and which are based on high levels of organizational resources and the formation of collective identities; and digital media networks that follow a different logic – the logic of connective action – based on personalized social networking among followers. Bennett and Segerberg define three modes of technologically enhanced activism: self-organizing networks and organizationally enabled networks that follow the logic of connective action, and organizationally brokered networks that follow the rules of collective action.

What makes this distinction interesting for the present analysis is that it addresses the problem of collective identity. Bennett and Segerberg agree that new types of Internet-based mobilizations do not require the strong, fixed types of identification, which according to many scholars, including Snow were traditionally employed to "activate adherents, transform bystanders into supporters, exact concessions from targets, and demobilize antagonists" (2008: 385). Today, the activists prefer "using resources to deploy social technologies enabling loose public networks to form around personalized action themes" (Bennett & Segerberg 2012: 757). These new networks embrace a rather eclectic sense of identity, which enables cooperation between different groups and organizations and makes digitally mediated collective action formations more flexible "in tracking moving political targets and bridging different issues" (ibid: 742).

This article focuses on this type of "connective" and "eclectic" approach of social movement identity. The case of Our Stork differs from those analyzed by Bennett and Segerberg, but the perspective they propose, which links the use of ICTs to the specific type of identity work employed by a group, may be helpful in understanding the dynamic of the identity construction process within a heterogeneous on-line community of the people travelling down the road called "infertility".⁶

Together, Yet Apart – The Case of the "Conscious Childlessness" Sub-Forum

In this article, I focus on Our Stork's "Conscious childlessness" sub-forum, which is one of the newest on the portal, established in 2011. Today, it has close to 600 entries in three different active threads, which had, in turn, over 6500 views. The users consist of people (mostly women) who have not managed to have a biological child through ART, and have considered stopping or did end the treatments, but nonetheless remain active members of the portal. How do they relate to the rest of the community; how do they re-negotiate their identity?

Scholars of social movements observe that the identity that a group projects publicly is sometimes not the same as that which its members experience, and that some members challenge the collective identity imposed on them (Polletta & Jasper 2001: 285). This is the case of "Conscious childlessness" sub-forum members. They challenge the collective identity promulgated by the activists from Our Stork. As I have argued elsewhere, the official collective identity – as formulated in official statements, press interviews, open letters and on the Internet site itself – is that of patients-citizens protesting the state's violation of their right to medical treatment (Korolczuk forthcoming). They accuse the state of insufficient support and lack of regulations, and very actively encourage each other's quest for effective treatment. In the process, infertility is constructed discursively as a disease, a biological fact, and/or a difficult emotional experience, embedded in a specific social context. Analogously to other patient organizations (Polat 2012), people active in the association Our Stork and connecting through the Internet bond by sharing the emotional, intellectual and physical experience of grappling with infertility. It is a negative experience, but also something to fight, to overcome.

Hence, the underlying assumption is that all members share a common goal, an overriding desire: to have a biological child (Franklin 1997; Allison 2011). This is exactly the assumption that the users who established "Conscious Childlessness" sub-forum challenge.

Analysis of the posts on this sub-forum demonstrates that while support from other members is often badly needed, other members' strong emphasis put on perseverance and commitment can be perceived as oppressive. Hence, some women who decided to end unsuccessful infertility treatments established a space for members of Our Stork community, who seek escape from the portal's culture of "fighting for a child". They carved out space for their own experiences and needs, at the same time attempting to challenge the dominant collective identity of the infertile as patients-citizens, driven by the desire to have a biological child.

As explained by the moderators who created the sub-forum, it was launched in reaction to constant pressure to reproduce exerted not only by the "outside world", e.g. family members or friends, but also by other Our Stork members. One of the moderators – the same "bloo" cited above – claims that at one point she realized

that the emphasis on having biological children at all costs was becoming simply unbearable:

It scares me that so much energy goes into constant stressing SUPPORT, which we have to show each other constantly, in the name of patients' solidarity. We have no right to say "no, we will go no further" and "yes, this is the end of the fight for a child". If someone stops fighting it is interpreted as "stopping others". If someone doesn't have the strength anymore, it is interpreted as "going astray". If someone says "I don't have energy for more", "it's over" [...] others claim that you just need some time before another attempt. [...] The boundary between support and pressure is very often trespassed. (bloo, capitalization in the original)⁷

Most of the women who posted their opinions on the new sub-forum shared the perception that the users of Our Stork portal tend to pressure others to continue the fight for conception, regardless of the personal situation, health condition and emotional needs of the addressee. Assistance and encouragement thus easily turn into coercion, and those who want to stop treatments for reasons other than financial difficulties can feel bullied and/or marginalized. Their decisions are interpreted as undermining the struggle and commitment of others. They are sometimes accused of being lazy, of being neither truly committed nor serious (see also Korolczuk forthcoming). Such views are confirmed by the posts on other threads, such as "Infertility, let's share information" or "I need to talk about it". Moreover, the language used on the main forum is full of militaristic comparisons and phrases. The expression "to fight for a child" is often used on the forum, as many infertile persons perceive their experiences as a battle or a war against the limitations of their bodies and/or modern technology (see Radkowska-Walkowicz 2013).

The question of when to stop trying to become a parent through reproductive technologies is problematic, as there are no clear, objectively identifiable boundaries. Throsby (2006) points out that one of the most fundamental problems for those undergoing treatment is "that while a given amount of treatment may, in retrospect, become constituted as definitive, what actually constitutes the end of treatment is never clear" (85). Moreover, the engagement in assisted reproduction generates a post-IVF body. In the case of failure, it requires further the construction of a new (or yet another) form of socially legitimized infertility. The process of making sense of IVF failure, and constructing such novel forms of identification is often long and inconclusive (Throsby 2004, 2006).

These factors strengthen the pressure to continue fertilization treatments until the desired goal – pregnancy and the birth of a child – is reached. This is exemplified by the post of one of the moderators who had decided to stop seeking medical help, and adopted a child. Her initial happiness and confidence were overlaid with doubts after visiting Our Stork forum and reading posts by people, who encouraged others to fight against all odds:

I came back on the forum in February, after years of absence. And I started to have doubts [...] I have read all those posts encouraging others to fight and I began think-

ing that I was LAZY, and that's why I let it go so easily! I started to think of IVF [...] I started to pester my husband, fight with him, tell him how egoistic he was, at times I was full of hatred. (Bobetka, capitalization in original)

As several scholars have pointed out, constant encouragement from others during IVF treatment can make it even more difficult to fight the social stigma attached to being infertile. Such support is based, after all, on the idea that everyone can have a child; that it is just a matter of commitment and will. The pressure is especially effective in the case of women, for the effort and commitment put into trying is interpreted as the litmus test of their engagement in (potential) motherhood (e.g. Inhorn & van Balen 2002; Throsby 2006). But when technology turns out to be ineffective, the process undermines the women's struggle for emotional stability and happiness. Thus, it is not a coincidence that most users on "Conscious Childlessness" sub-forum are women, and that they are interested in redefining the meaning of infertility.

The posts of people who support the seemingly endless "fight for a child" reinforce the sense of those who quit as being "losers"; only this time not only in the eyes of society, but in the eyes of other infertile people, the very people who are supposed to provide them with a sense of acceptance and understanding. This makes this group "homeless", in more ways than one, as they find understanding neither among their family, neighbors and co-workers, nor among other infertile people. The post by "mija77" expresses the feelings of guilt and remorse that such a situation evokes:

On one of my favorite threads I saw a title once "You are a winner, if you fight." That receedly made me feel as a loser ⁽²⁾, because I stopped "fighting". (mija 77, "misspelling" and emotive in original)

Several women active in the "Conscious childlessness" sub-forum openly argue that the continual emphasis on not giving up "the fight" and on trying more advanced medical procedures, in fact serves the people who write the posts rather than their addressees. As a person with the nickname "Agaaaa" puts it, "all this 'you should fight this battle' serves the person who writes this, as she wants to feel that what she does is right".

The case of "Conscious Childlessness" demonstrates that when sharing the desire and the intention to have biological children becomes normalized within the community, it becomes a very powerful tool for disciplining those who want to renegotiate their engagement with technology. The resulting sense of being under constant pressure puts in question the sense of solidarity and cohesion within the group. In the case of Our Stork, this conflict has been resolved by a resource perhaps unique to the Internet: the creation of a semi-separate space where users can be free from peer pressure, where they can challenge the dominant collective identity, and yet can remain a part of the collective, active, so to speak, on shared virtual domain.

The sub-forum examined in the article became a safe space where people who choose not to pursue medical treatment and/or adoption can experience comfort and safety within the community of the infertile, and yet be free from the judgmental remarks of fellow Our Stork members.⁸ Sub-forum moderator "yasuko" makes it clear, indeed, that "this is the place where [infertile] people who decide to be childless should be protected from being persuaded to try adoption or another IVF cycle." Importantly, some of the people who opt out from treatment apparently do not want to opt out of the community. Rather, they want to re-negotiate the terms of belonging. As one woman ("lenox", who initiated one of the threads on "Conscious childlessness") puts it, "I want others to respect my decision, my arguments and I want others to admit that my way may also be good, that I can be happy with what I have." lenox" wants to be recognized as a legitimate member of the community. Her desire is shared by others who emphasize that they also identify themselves as the infertile, but still want their individual decisions to stop pursuing treatment to be recognized as valid and legitimate. They argue for this not only on an individual but also on a collective level.

According to "yasuko", such a strategy would ensure wider membership, as well as strengthen in-group solidarity and engagement. "This is why we have this sub-forum, so that the girls [sic!] would not escape, nor disappear from Our Stork, so that they have their own space."

Notably, while this on-line space is presented as safely free from intervention, it is also under strict supervision. The interactions are controlled by the moderators, some of whom were once engaged in the association but are no longer able or willing to undertake any responsibilities off-line. They have established rather strict rules for the forum users, removing posts which they consider repetitive and/or irrelevant to the thread's main theme.

General organizational rules are rather strict on what can and cannot be said in specific threads, and it is stressed several times in the Regulations that the users need to be very specific and stick to one issue or theme, posting their opinions in threads devoted to particular issues (e.g. infertility treatments, adoption, men's infertility or pregnancy after infertility treatments).⁹ Already in the second point of the Regulations, the administrator warns the users to "Think of what theme you are going to develop and find the thread that fits best. Any threads that do not fit the main theme will be closed and removed by the moderators." (sylwia30)

The activists whom I interviewed claim that the moderators of "Conscious childlessness" are correspondingly strict, actively counteracting any attempts at introducing topics which they consider either oppressive or irrelevant. This is confirmed by the warnings posted on the forum. Users are often warned that their freedom to discuss specific topics is limited: "Any posts that include suggestions concerning adoption will be removed" (yasuko). The boundaries of the alternative space are thus patrolled by moderators who act as the gate keepers. These interactions take place in a controlled environment, where power and decision-making

processes are not fully transparent. The gate keepers manage the flow of information by deciding on what is important and what is not, and thus play a key role in the process of negotiating collective identity within the digital community. One of the activists whom I interviewed claimed that such sub-forums become "voluntary ghettos", where people isolate themselves from the world, seeking instead the company of a selected group of those who have the most comparable experiences and most similar views (see also Allison 2011). Thus, participation in the subforum may also be interpreted as a process which undermines solidarity within the larger group, and leads to fragmentation of the movement.

Boundary Work – From Infertility to Conscious Childlessness

The sub-forum, thus defined and policed, establishes its own discursive field. The question of what it is exactly that "ails" the infertile is *the* common topic of discussions here. Most posts concern the definition of infertility and childlessness, the questions of who can belong to the newly created group and what differentiates this group from the rest of the Our Stork community. Instead of stressing infertility as a bodily condition or painful experience (Inhorn & van Balen 2002), the women who initiated the sub-forum propose the counter-notion of "conscious childlessness".¹⁰ This concept encompasses not only their experience of not being able to have biological offspring, but also their agency in making conscious decisions about infertility renounce the language of desperation and the hope for a miracle which are often described as characteristic for women undergoing infertility treatment (Franklin 1997: 202; Inhorn & van Balen 2002). They no longer concentrate on their desire for a technological miracle, rather, they stress their agency even when technology fails.

This re-definition of the collective identity of the infertile poses significant challenges. Some Our Stork users doubt whether they can belong to the "Conscious Childlessness" group at all, for they perceive their situation as something beyond their own control, and/or are not able to come to terms with IVF failure:

Is conscious childlessness the situation when life made that decision, not me? I wanted and still want to have children, but can't have them, and I don't want another IVF attempt. I just don't believe it would work. And adoption? Maybe, I think yes, but my husband doesn't want that. [...] Is this "conscious childlessness"?? (mija77)

Another example of the challenges involved in the re-negotiation of the meaning of infertility / childlessness is the discussion initiated by user "EWA1794". This user states "I've been living with the awareness that I am childless⁽²⁾ Now I have an adopted son." (EWA1794). Such posts are, in fact, emphatically not welcomed on the sub-forum, and the moderator reacted immediately:

We are focusing on childlessness, which was consciously chosen as a way to escape the viscous circle of infertility. This is childlessness, which is based on coming to terms with our fate, childlessness which does not hurt and does not cause this sad face, which you placed in your post (9) (yasuko)

In her post, "yasuko" objects to the idea that being infertile involves a failure of agency. She counters with the vision of conscious childlessness as a decision, an identity which offers "a way out" of the vicious circle of guilt and anger.

The affirmation of certain emotional attitudes towards one's condition – most particularly, acknowledgment of the members' inability to be happy as infertile persons – constitutes an important part of the larger Our Stork community's identity work. This identity work confirms "infertility" as a core, and sorrowful, element of one's perception of the self. Such an assumption is challenged by "Conscious Childlessness" initiators, who stress the difference between being "happy despite of one's childlessness" and being "happy as a person who is – among other characteristics – also infertile and childless". Users, such as "yasuko", stress people's agency, the desire to have children need not be a determining, essential, or even enduring aspect of one's identity:

Me and my husband made the decision to end treatment and stop trying to have a child 12 years ago. We are happy not "despite of," we are just normally happy. I didn't have a child before, I didn't try to have one and I was happy, why should I stop being happy when my attempts failed? (yasuko)

She and other users insist on interpreting infertility as one of life's many experiences, not necessarily the constitutive one. This opens up a different temporal perspective. Most importantly, it challenges the collective identity endorsed by Our Stork, that of people who are allies because of their status as patients, bonded by their common hope for successful treatment.

This analysis of the discussion on "Conscious Childlessness" provokes a question: why do some people stay active on the Our Stork portal when they no longer identify themselves as patients and reject the culture of "fighting for a child"? "yasuko", for instance, has stopped treatments long ago, yet she remains involved, and helps manage the forum. Others, such as "bloo", left the forum after adopting a child, but came back after several years and have remained active members ever since. We return here, in fact, to Throsby's conceptualization of the post-IVF experiences as an ambiguous location between "often contradictory norms of gender, technology and the reproductive body" (Throsby 2006: 83). Those who, however unsuccessfully, attempted pregnancy through IVF treatment have "technologized" the reproductive process, and thus placed themselves outside the "biological" mainstream; in Poland, indeed, this has involved withstanding a public polemic about being egoistic and godless. And yet, as Throsby puts it, these people have no baby with which to "counterbalance anxieties about the technological corruption of the natural order" (Throsby 2006: 83). The failure of IVF requires a fundamental reinterpretation of one's goals and desires – yet again.

It is a process based on experiences and emotions related to "grappling with" or "fighting" infertility, but in which the meaning and emotional significance of these experiences are redefined. As a result, although the inability to have biological children is no longer the center of one's self-identification, one is different nonetheless. He or she becomes someone who has undergone unsuccessful IVF treatment.

This process of choosing to end attempts to get a child also requires a shift in collective identity. Many Our Stork members who decided to stop treatments understand and have shared the experience and desires of other infertile persons, and can, to some extent, still identify with them. This produces a deep emotional commitment, a sense of solidarity – the affective bonds which motivate long-term participation (Polletta & Jasper 2001). At the same time, ending the treatment endangers the collective sense of solidarity, challenging the conviction that infertile share the same goals and fight for common interests. Such decisions symbolically undermine the efforts of others who keep investing their emotions, health and money in "the fight for a child". Thus, the terms of belonging have to be renegotiated. Arguably, the engagement of people such as "yasuko" and others attests to the power of collective identity. Even when challenged and re-defined, it remains an important basis for personal engagement.

Conclusions

The case of the "Conscious Childlessness" sub-forum confirms the view that the identity a group projects publicly is not necessarily the same one its members experience (Polletta & Jasper 2001). Some members of Our Stork resisted the idea that what bonds people experiencing infertility is, first and foremost, their status as patients and the desire to become a biological parent. They started to contest the organizationally generated action frames and proposed a different way of framing infertility, coining the notion of "conscious childlessness". The article has discussed how borders are established between different sub-groups within the digital community, and how this process involves producing novel form of identity, based on what Throsby (2006) interprets as "socially legitimized childlessness". Throsby points out that the amount of energy, time and effort invested in the fight for a child is supposed to legitimize technological interventions, as in the context of IVF

reproductive belonging is rewritten [...] as defined not by actual reproduction, but by the desire and the intention to reproduce; it is having tried [...] that produces the socially-legitimized post-IVF body (85)

"Having tried" and having invested a lot in the process of becoming a parent is something that unites the group. The analysis of the Our Stork sub-forum suggests, however, that in the context of social activism people may want to distance themselves from "the desire and the intention to reproduce" imposed upon them by others, and seek a new form of socially legitimized childlessness. "Conscious Childlessness" becomes an identity which is related to the experience of struggling with infertility, but which involves a re-definition of the emotional, cognitive and temporal aspects of this process – from the past to the present, from desperation to hope, from being focused on infertility to concentrating on other aspects of one's life.

This analysis demonstrates that boundary work serves different goals than what is often assumed in social movement literature. It not only allows for separating "us" from "them", and for strengthening the engagement of a core group of most committed activists, but also helps to bridge the differences in emotions and selfidentification, and to keep people involved when interests and needs diverge. I found this was accomplished through a process that involved (1) identifying the elements of the dominant identity that did not fit the experiences and needs of some members of the group, (2) strategic deployment of emotions aroused by being oppressed and excluded by the group, (3) constructing an alternative collective identity, and (4) establishing a semi-separate space with well-guarded borders while remaining connected to the larger community via other threads and subforums. Thus, boundary work enables people to challenge the official identity that the group promulgates from within, without having to abjure the group altogether. In carefully gated sub-groups people can voice desires, emotions and interests which are not shared by the majority. This helps them to feel safe and accepted, among "others who are like me". At the same time, the fact that this takes place in a relatively isolated space within, and not outside the community, allows them to remain a part of a larger group – the infertile. This provides room for communication and negotiation, and, moreover, enhances their ability to influence the public discourse on infertility.

The technology used, the Internet, arguably has been key to this process. The "Conscious Childlessness" sub-forum is a relatively isolated, autonomous space, yet at the same time connected to other sub-forums and the on-line community of the infertile as a whole. The technology which allows the creation of such "safe havens" enables group members to cope with differences in goals and interests by offering different levels of proximity and communication. The medium provides people the opportunity to act on the fragmented nature of human identity.

These findings dovetail with Bennett and Segerberg's (2012) suggestion that the ways in which social movements construct and promulgate collective identity changes with technological development. In some respects the Our Stork forum fits the second model, which they termed "organizationally enabled networks", because the organization provides a social technology outlay and a loose coordination of actions. At the same time, the communication content on-line centers on personal expressions rather than organizationally generated action frames, and most members of the collectivity shun involvement in Our Stork's parallel formal organization, which is characteristic of self-organizing networks. The sub-forum's heavy-handed moderation, in turn, is characteristic of organizationally brokered networks, as opposed to networks based on a logic of connective action. This shows that tools and modes of action which we associate with specific organizational types, e.g. the high level of control associated with hierarchical organizations, may also be used by groups which are structured differently, or by individuals who are not necessarily recognized as leaders. This hybridity suggests that certain conceptual tools, e.g. the differentiation between social movement lay members and social-movement organization (SMO), may not be as useful in the case of on-line activism.

This insight raises further questions, in turn, concerning the mechanisms of control which influence the process of establishing the personal action fames, and consequently, an eclectic type of collective identity. The fact that these frames are produced by lay members, not the representatives of an organization, does not mean that all have access to creating the content. In the case of Our Stork, which in many respects functions similar to the self-organizing networks that follow the logic of connective action, the communication content centers on personal action frames which are primarily ramified by the moderators. This confirms the fact that if we wish to understand the interplay between technology and collective action, we should move from a generalized discussion of how the Internet influences social movements to the specificities of different processes and types of interaction on Internet sites.

The question as to the probable success of a minority's attempts to challenge the dominant collective identity of a larger community is an open one. But even if such attempts fail, boundary work within the movement has positive outcomes. Our Stork forum users can be interpreted as using a strategy which enables those who feel that their self-identification and interests cannot be accommodated within the dominant group identity to remain engaged. The notion of "conscious childlessness" facilitates alliances between different groups, for it encompasses various categories of people, e.g. those who are infertile and are undergoing treatment (or not); those who had to stop treatment but did not give up hope; and those who refuse to engage in assisted technology even though they did not manage to become parents. Also it highlights people's agency and ability to make sense of difficult experiences, which may be an incentive to mobilize. Nevertheless, the challenge of mobilizing in the Polish cultural and political context, where women's reproductive choices are severely limited and reproductive rights are marginalized in public discourse, remains enormous.

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Notes

- ¹ A comprehensive list of such groups and networks can be found at the Internet site of Infertility Network UK: http://www.infertilitynetworkuk.com/?id=502
- ² The main criteria concern age and medical records stating that IVF is recommended by doctors. See also http://www.reuters.com/article/2012/10/22/us-poland-fertilityidUSBRE89L1BJ20121022
- ³ The project entitled 'We are not second-rate quality citizens'. Negotiating biological citizenship in social mobilizations around infertility issues and access to in vitro in Poland has been funded by the Foundation for Baltic and East European Studies 1555/42/2011. This article has been read and commented upon by people I would like to thank for their comments and suggestions. This includes Kerstin Jacobsson, anonymous reviewers, the members of the social movements seminar at University of Gothenburg (especially Abby Peterson), and last but not least, Madeleine Hurd who has been a dedicated editor of this special issue.
- ⁴ This text and my chapter "'Those who are almost full would never understand the hungry'. Negotiating collective identity in social activism around infertility in Poland" in The Identity Dilemma (eds A. McGarry and J. Jasper), should if possible be read in relation to each other. They cover some common ground concerning the construction of collective identity based on infertility but develop different aspects of this process. While in the latter I analyze social activism concerning infertility and assisted reproductive technologies in relation to social, cultural and political context of contemporary Poland, in the present article I focus specifically on boundary work employed by the people who did not manage to become biological parents via ART, but who are still engaged in the on-line community of the infertile.
- ⁵ The association has been established in 2002. Today it has around 60 members, but only a few are active on a daily basis.
- ⁶ Our Stork is a small-scale national mobilization, which does not address highly contentious political issues such as globalization or environmental effects of economic development. Another difference concerns the fact that Bennett and Segerberg (2012) analyze the cases, where activists used many different ICTs, e.g. Twitter, Facebook or mailing lists, while in the present text I focus mostly on just one communication platform the Internet forum, which places specific limitations on the types of actions that can be undertaken via technology. However, the association has also a Facebook profile and this digital technology works differently than the forum it is more interactive, engages people more and thus is a much better platform for promulgating political views and potentially contentious opinions.
- ⁷ All the quotes from Internet forum has been translated by the author.
- ⁸ The issue of adoption is also controversial, as many opponents of IVF claim that people who are infertile should adopt "poor, abandoned children" rather than attempt at having a biological offspring themselves, at the expense of fellow citizens. Sometimes, this is also a source of conflict for the users of Our Stork forum, as for some people who happen to have problems with fertility it is one of acceptable options, while others do not want to adopt a child, even if IVF fails. The representatives of the Association often stress that they represent also people

who adopted or want to adopt a child, and that ART are not the only way out from involuntary childlessness, but most their activities center around access to ART.

- ⁹ <u>http://www.nasz-bocian.pl/phpbbforum/viewtopic.php?f=75&t=76960</u>
- ¹⁰ While in English there is a difference between being "childless" and "childfree", no such distinction exists in Polish.

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