Online Health Communities as a resource for collective sensemaking for men who experience fertility difficulty.

Dilisha Patel, UCL Interaction Centre, London, UK. dilisha.patel@ucl.ac.uk

ABSTRACT

Online health communities (OHCs) are dedicated spaces where users discuss specific topics in an anonymous virtual and asynchronous environment. This space can be valuable for men who experience fertility difficulty by providing a safe environment for them to share information and advice to understand their condition and share their experiences. I present findings from our study investigating men's use of online communities. 603 posts from OHCs were qualitatively analysed to understand how men use online health communities when they experience a fertility difficulty. We found that peer support within these communities facilitated men to navigate a process of collective sensemaking to understand and accept a "new normal" within their fertility prognosis.

KEYWORDS: Online Health Communities; Men; Fertility; Finding a New Normal; Sensemaking.

INTRODUCTION

Online health communities (OHC) are often utilised to create virtual spaces for like-minded individuals. Users of these communities can have several motivations for participation in these sometimes asynchronised online communities. These include the need for advice, information, or support[13, 15]. As many OHCs provide the option of anonymity, they are often used as spaces for users to share private, personal, or sometimes perceived stigmatised feelings and information[8, 9], which is particularly true in the case of fertility. Fertility difficulty can occur in men and women[2, 7], with almost 30% of all fertility difficulties having male-related factors[1]. Fertility concerns are seen as private and personal and not often openly shared[5]. Men are found to engage with OHCs to help make sense of fertility prognoses[6]. Sharing and discussing with similar others can help validate information, and the advice attained can be beneficial to support individual and collective sensemaking, especially where information is perceived to be harder to find[12]. Collective sensemaking is when people congregate to use their own experiences and knowledge to support one another[10]. This can be the case with a sensitive topic such as fertility. This research aimed to explore how men use OHC when they experienced fertility difficulties.

METHODS

We collected data from several online forums to understand how men used online health communities when experiencing fertility problems. A total of 603 posts were qualitatively analysed from OHCs dedicated to people navigating their fertility journey. We specifically analysed posts from men only from the OHCs. The extracted posts were anonymised before analysis. The data underwent a number of iterations to ensure the content was fully explored. In this research, we use the term "men" to refer to all people who self-identify as men and discuss trying to conceive to become fathers in the OHC comments. For detailed methods of this study, please see our work [11].

ETHICAL CONSIDERATIONS

We carefully considered the ethical issues of carrying out this research prior to its commencement. As it is was not practical nor technically possible to gain explicit consent from all users of the OHCs selected, we ensured the moderator rules allowed for research to be undertaken in the public OHCs. All OHCs were accessible without registration. We understand that whilst a user may have posted something in a public forum, certain expectations around how that data will be used exist [3]. We drew on The British

Psychological Society Code of ethics [14] and ACM Code of Ethics and Professional Conduct [4] to inform our study development. To ensure we protect the privacy of these users and not indirectly reveal their identities, the OHCs are never named. Moreover, to secure the sensitivities and vulnerabilities of these users and reduce the potential risk of anonymised quotations being deanonymised, each quotation used was paraphrased by the lead researcher, which was then checked by another researcher to ensure there was no misinterpretation. The UCL Interaction Centre ethics committee granted ethical approval.

RESULTS

For the purpose of this paper, I will present selected findings in accordance with three of the six proposed workshop topics.

What have we learned about the reasons people join OHCs and the kind of support members seek and provide to each other?

While I could not probe why people joined these particular OHCs, I found that users used OHCs for many reasons. These included finding information and advice either for themselves or for others, for emotional support, wanting a safe space to share personal feelings, and finally, to find others who were in a similar situation to them to feel less alone.

Posts looking for information and advice were direct and clear in their intention. These ranged from wanting medical advice, “I am writing on here to see if what my Dr is suggesting is normal? Is there anything else I should suggest to my Urologist” (722731), to wanting to understand the cause and impact of their fertility difficulties, “Is it likely that my hormone investigations will be positive? How true is it that if your hormone levels are high, it will negatively affect my chances (to conceive)?” (291291). These posts were met with advice based on personal experiences from other users within the OHC.

When looking for emotional support, posts were usually quite long with their medical and personal history detailed. Occasionally, these posts would describe their feelings of isolation of having no one else to share with who could understand and empathise. “This group has given me so much more than anyone else I have tried to talk to. Thank you and I really appreciate all of you for listening to me and taking the time to reply. I just feel so alone, and I don’t know what else to do” (726737).

We found a lot of men were using these OHC to find similar others and not feel alone. “Anyone else have this experience? I would really appreciate it if you guys would share your stories and advice, especially success stories.” (721344). Another way users tried to emulate not feeling alone was by asking similar others to share how they were coping and feeling in their circumstances. “I don’t know anyone else who has experienced this kind of thing, so I joined this group, so I don’t feel so alone.” (724865).

What are the underlying processes and consequences of collective sensemaking?

We found that men used OHCs to make sense of their fertility diagnosis, understand their fertility journey and determine what was “normal” in their situation. We found through the, sometimes asynchronous, conversations, men were able to go through a collective sensemaking process that helped them accept their fertility difficulty as normal for them. We present details of this finding in our work, [11], and demonstrate the information journey in the model below (Fig 1).

Men would enter the OHC when they had a knowledge breakdown of what they accepted as normal, this could be a fertility diagnosis or that conception has not occurred as expected. Next, through the OHC, men would gather information and make sense of the advice and information attained to construct a socially accepted normal. This would be what was normal for the population of users within the OHC. Understanding of their “new normal” could be taken out of the OHCs and translated into their daily lives. There is also the potential for further knowledge gaps as men progress through their fertility journey, within or external to the health services, which could lead men back to the OHCs for additional support.

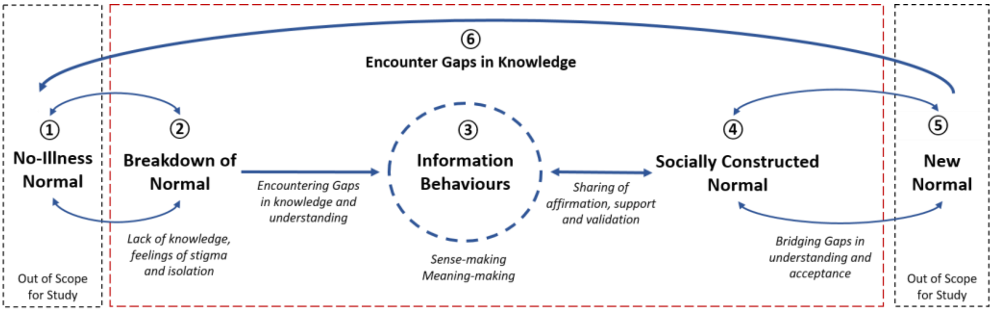

Figure 1: Finding a New Normal Model elaborated to the context of Fertility.

How is medical knowledge exchanged and generated within OHCs and what are the consequences of potential propagation of misinformation?

As mentioned above, medical knowledge and advice was freely sought and provided in the OHCs. Men would share details of their medical investigations and then ask for users' opinions and advice based on the results. This shows an explicit trust within the OHC. There was a perception that this community would have had similar experiences with health professionals and lessons learned that could be valuably shared. "I have a condition where my Doctors tell me I need surgery, without it, I can't conceive. Is this true? Welcome your advice and information." (307188).

We did not find clear examples of misinformation being detected or raised by users within the OHC. Conversations seemed to occur in harmony and with support. If users disagreed with advice or information shared it was not openly discussed. We can assume the consequences of misinformation in these OHC could be particularly damaging for the users. It can be seen that users are using these OHC in desperation and when they are feeling particularly vulnerable.

CONCLUSIONS

We have found that users of fertility online health communities look for support from their peers. Through this support network, users use collective sensemaking techniques to acknowledge and accept a "new normal" for their fertility prognosis. OHC are a rich virtual space where users can make sense of their experiences. Researching these spaces can help us understand users' concerns and to better support communities with their healthcare. In addition, by collating lessons learned from different OHC we have a great opportunity to understand how to address the ongoing challenges within OHC and healthcare in general.

REFERENCES

1. Agarwal, Ashok, Mulgund, Aditi, Hamada, Alaa, and Chyatte, Michelle Renee, *A unique view on male infertility around the globe.* Reproductive Biology and Endocrinology, 2015. **13**(1): p. 37.
2. Arya, S. T. and Dibb, B., *The experience of infertility treatment: the male perspective.* Hum Fertil (Camb), 2016. **19**(4): p. 242-248.
3. Doyle, Tony, *Helen Nissenbaum, privacy in context: technology, policy, and the integrity of social life*. 2011, Springer.

4. Gotterbarn, DW, Brinkman, Bo, Flick, Catherine, Kirkpatrick, Michael S, Miller, Keith, Vazansky, Kate, and Wolf, Marty J, *ACM Code of Ethics and Professional Conduct.* 2018.
5. Hanna, Esmée and Gough, Brendan, *Emoting infertility online: A qualitative analysis of men's forum posts.* Health:, 2016. **20**(4): p. 363-382.
6. Hanna, Esmée and Gough, Brendan, *Searching for help online: An analysis of peer-to-peer posts on a male-only infertility forum.* Journal of health psychology, 2016: p. 1359105316644038.
7. Hinton, Lisa, Kurinczuk, Jennifer J, and Ziebland, Sue, *Infertility; isolation and the Internet: A qualitative interview study.* Patient education and counseling, 2010. **81**(3): p. 436-441.
8. Larkin, Marilynn, *Men open up in online forums.* The Lancet, 2001. **357**(9254): p. 487.
9. Maestre, Juan F, MacLeod, Haley, Connelly, Ciabhan L, Dunbar, Julia C, Beck, Jordan, Siek, Katie A, and Shih, Patrick C. *Defining through expansion: conducting asynchronous remote communities (arc) research with stigmatized groups*. in *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. 2018. ACM.
10. Mamykina, Lena, Smaldone, Arlene M, and Bakken, Suzanne R, *Adopting the sensemaking perspective for chronic disease self-management.* Journal of biomedical informatics, 2015. **56**: p. 406-417.
11. Patel, Dilisha, Blandford, Ann, Warner, Mark, Shawe, Jill, and Stephenson, Judith, *" I feel like only half a man" Online Forums as a Resource for Finding a" New Normal" for Men Experiencing Fertility Issues.* Proceedings of the ACM on Human-Computer Interaction, 2019. **3**(CSCW): p. 1-20.
12. Shah, Chirag and González-Ibáñez, Roberto. *Evaluating the synergic effect of collaboration in information seeking*. in *Proceedings of the 34th international ACM SIGIR conference on Research and development in Information Retrieval*. 2011. ACM.
13. Shi, Xiaolin, Zhu, Jun, Cai, Rui, and Zhang, Lei. *User grouping behavior in online forums*. in *Proceedings of the 15th ACM SIGKDD international conference on Knowledge discovery and data mining*. 2009. ACM.
14. Society, British Psychological, *Ethics guidelines for internet-mediated research.* Leicester, UK: British Psychological Society. Google Scholar, 2013.
15. Zhang, Thomas, Cho, Jason HD, and Zhai, Chengxiang. *Understanding user intents in online health forums*. in *Proceedings of the 5th ACM Conference on Bioinformatics, Computational Biology, and Health Informatics*. 2014. ACM.