

E-Health Communication: Reaching out through the Internet

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E-HEALTH COMMUNICATION: REACHING OUT THROUGH THE INTERNET

Abstract: The impending use of internet open up a broad spectrum of usage. Among those are the use of sharing platform such as facebook and blogging system for particular communities. Support groups are essential part of health recovery, in particular people with acute, chronic or even deadly diseases and disorders. In the age of virtual communities, one can hope to find solace and information through online support group. Support group is important to allow patients or patients' family to receive help and place to open themselves in regard to the illnesses. Online support group enable people from around the globe to communicate, discuss and encourage others with similar condition. This article delves the question of how people use internet-based health support group. The researcher conduct qualitative textual analysis on an online pregnancy support group and various literatures which explores the use of internet-based support group. The findings show that people use online support group that suitable with their online behavior, for example the mode of interactivity and anonymity. Besides the selection of online platform, the types of messages that can be posted, read and replied determine the participation with a support group. In this case, the message of information support and emotional support is shown as crucial reason for the online participation.

Keywords: health, communication, online, support, preeclampsia

Introduction

Health communication, traditionally, was mediated by medical practitioners, administrators and health services organizations. The new development of health communication focus on the subject of multidirectional aspects of communication process, in which the public actively seek health-related information from the most accessible source around them, such as the internet (Corcoran, 2013). People with issues related to their health found assistance from support group in that area. Support group acts for people with similar health issues, problems, and life challenges to find encouragement, solace and exchanging advices in other words social support which include "informational support, emotional support, tangible support, and validation (Wright, 2014, p. 988)." Moreover, Wright (p. 989) concludes that participation in a internet-based support group increase the health quality of the person, health self-efficacy, well-being, coping and symptom management. People seeking advices on online communities also seek information in a traditional ways through traditional media, their families and friends (Hu, Bell, Kravitz and Orange, 2012). In this sense, people with certain conditions combine the traditional and online source of information. Pregnancy is a condition, presumably, wanted by the individuals experienced it. Isupova (2011) found that women on going an IVF (in-vitro fertilization) procedure also relied on other women in the same situation online; the similar experiences help the women involved in decision making about their infertility journey. Pregnancy for woman without medical condition can be the most joyous experience as a woman. However, there are many instances that pregnancy is a difficult moments. High-risk pregnancy is a condition in which the mother, child or both is in danger before, during or after labor; the condition arose from various causes, such as high blood pressure, infection, injuries and others (). In this case, support group, in particular online support forum, can possibly give the push of encouragement for pregnant women. This article discuss three threads of an online forum for pregnancy related issues, *pregnantx.com*. The real name of the website and the posters are changed to ensure their privacy. The issue discussed were fear, worryness, trauma, and loss related pregnancy. Discourse analysis was used to further understand the meaning behind the posted comments, in relations with culture, power, structure and gender.

Support group and online health communication

Social support is key element in the health communication system. Social support has been reported as linked in negatively with depression and other mental and psychological issues; at the same time social support also considered as indices of physical health (Holmstrom, 2014, p.1311). In other instances, social support came in

many forms, one of them is support group that specified in particular problems. Howard Rheingold (2000) stated that "People in virtual communities use words on screens to exchange pleasantries and argue, engage in intellectual discourse, conduct commerce, exchange knowledge, share emotional support, make plans, brainstorm, gossip, feud, fall in love, find friends and lose them, play games, flirt, create a little high art and a lot of idle talk." Online support group can be effective for carers and patient, such as mental health issues, through the participation of peer, family involvement and professional facilitation (Worrall, et.al., 2018). In contrast, online community can also create conflict in terms of the communication pattern and preferences for normativity in interaction, however the same source of conflict act as the source of conflict management (Aakhus & Rumsey, 2010). The advantages of online support group come in the form of alternate choice of functional capacity to face-to-face communication, the support needed for people with health issue and some other advantages such as less feeling of being stigmatized, one's contribution to the group is valued more than her physical appearance, convenient, social comparison and more diverse information about one's health condition (Wright, 2014). One of the key element of online communication is anonymity. However, in the case of online support group for health issue such as breast cancer, anonymity of the poster viewed as untrustable for comment or positive comments from members that are visually identifiable are most likely to be responded (Kang, 2017).

Pregnancy, loss and support

Pregnancy for first time mother can be joyous and also challenging. Carin, Lundgren and Bergbom (2011) found that first time mothers felt the experience of pregnancy as life opening and a sense of holiness; besides that pregnancy urge them to consider their values from a wider perspectives, in which they sometime felt happy but also surprisingly unhappy and lonely. Women who were still trying to conceive also facing stigma and difficulty emotionally. In a research by Isupova (2011) on women going through IVF procedure, the emotional support from other mother in online community with similar endeavour provide a safe haven of empathy and encouragement to make decision about the procedure. The hostile environment of negative relatives and friends are overcome by online support system. Certain health condition can also failed the pregnancy, such as preeclampsia, hellp syndrome, and the likes. Preeclampsia is a disorder that affect 5-8% of pregnancy, happened during pregnancy and postpartum and affect both the mother and the baby; globally, preeclampsia cause maternal and infant illness and deaths and is characterized by hypertension, swelling, the presence of protein in the urine and sudden weight gain (Website, 2019). However rare the conditions are, the deaths of mothers and/or babies can influence the whole perspective on pregnancy and life afterwards. Culpability or the feeling of deserving blame often felt by women experiencing complication or pregnancy loss, to which they might felt the loss were their responsibility; this complex feeling needs to be addressed by medical or psychological practitioners in dealing with the women (Hale, 2007).

Method

Discourse analysis is a qualitative textual analysis which focus on the analysis of written, verbal and visual language. According to Jorgensen and Phillip (2002, p.61), discourse is "a form of social practice which both constitutes the social world and is constituted by other social practices. As social practice, discourse is in a dialectical relationship with other social dimensions." Discourse analysis by Fairclough (Jorgensen and Philips, p. 66) combine three tradition of linguistic, textual analysis, macro-sociological analysis on social practice, and micro-sociological practice on interpretive tradition. In discourse analysis, the units of analysis includes but not limited to,"words, phrases, and sentences to paragraphs or even larger units" (Wood and Kroger, pp. 28-29), moreover, discourse analysis breaks down data and assessing the relationships between the components of the data. Gee (2005, p.29) highlights discourse as "ways of combining and integrating language, actions, interactions, ways of thinking, believing, valuing, and using various symbols, tools, and objects to enact a particular sort of socially recognizable identity." In relations to online communication, the researcher underline discourse analysis from Teun Van Dijk. Van Dijk emphasized conversation as a form of text which can be analyze by the speech act as a form of interaction and also the vertical analysis of the accomplished talk by

accomplishing other talks (p.15, 1997). Moreover discourse analysis define the units or construct of 'language use, cognition and interaction' and formulate the rules of how these aspects used (ibidem).

Findings and Analysis

Thread "Can i have a normal pregnancy after preeclampsia..."*

*Disclaimer: the posts were written in Bahasa Indonesia with slang and informal grammar. The researcher tried to translate them in English in the most formal grammar possible. This can post a problem within the discursive analysis, however the denotation meaning was still the same with the original Bahasa Indonesia. However in this text, the researcher did not put the original text, only the translation.

Medical terms such as hellp syndrome, preeclampsia is written as the posters wrote them, not in the correct spelling. PEB or *Pre Eklampsia Berat* is an Indonesian term for severe preeclampsia.

mom1:

.....

(translation: Last February i lost my baby in my womb, when it was 7 month pregnancy, i got severe preeclampsia/PEB. Are mommies out there experiencing normal pregnancy after preeclampsia??? I am scare to conceive again mums, the trauma and fear of losing is still looming.

I am scare i will kill may baby again..it's hurt...)

mom2:

.....

(translation : In 2014, i gave birth with preeclampsia mom. In 2016 i have a normal pregnancy. Alhamdulillah the birth was normal without preeclampsia. My baby is now 16 month and i am currently 9 weeks pregnant. Keep the spirit mom.)

mom1:

.....

(translation: Alhamdulillah...thank you mom for the sharing...i want to send a personal message to mom, but can't because i am still a new member, i forgot my old account's password. Mom, is there any tips for food/beverage for a healthy next pregnancy? There was a history of high blood pressure in my family and my sister also experiencing preeclampsia in her third pregnancy. So, i am super worry mom...)

Mom1 open up a thread by sentences revealing her traumatic pregnancy loss. She posted the sentence on March 2018, but the content mentioned her factual event occurred on February. The one month time frame shows that there was a time in which she needs to recuperate before she took her issue online. She start by saying that she loss her child before being born, while the gestational age (this information was not clear) of the pregnancy was 7 months old. She explained the loss, the cause of the loss which are preeclampsia and the consequence of the loss. The consequence was revealed as emotional trauma, which she highlighted by saying "I am scare to conceive again mums, the trauma and fear of losing is still looming". More so, the consequence of the unnatural death of the child induce guilt in the mom1 for fear of having her 'killed' her unborn child. In this case, she experienced culpability (Hale, 2007). The fact that preeclampsia is rare and hard to detect did not lessen the guilt of the mother. Mom2 replied the thread by narrating the similar event with a different ending. Mom2 experienced the same loss in 2014, however she got pregnant again in 2016 without preeclampsia and has a healthy child. Her words echoed the same situation, in which it was seen as identifying herself with mom1. Her narration did not end with a loss, her story of another pregnancy, without the complication showed

a different ending of painful situation with hope. She encouraged mom1 to keep her spirit up because mom1 can have a same ending like hers. In this case, mom2 can be seen as an authority of the issue, in which she came out as a survivor physically and mentally. Mom1 conveyed her gratitude and the possibility of further personal communication through the thread, in which she could not do because of the rule of the forum. However, she did not continue to ask mom2 for personal contact. She directed the conversation towards things that can be seen as a physical effort to have another pregnancy that is healthy. She further informed mom2 about the history of high blood pressure in mom1 family. Here, mom1 tried to find solution or at least an answer of why she caught preeclampsia. She did not believe in her body's ability to have a healthy pregnancy. Her first thread showcase the guilt of 'killing' the child inside her body.

mom3:

.....

(translation: I've heard there is a big chance of severe preeclampsia in the next pregnancy, as long as we can manage our meal and life style the severe preeclampsia (*PEB-Indonesian term*) can be prevented. Mums, let us encourage each other and try not to have a severe preeclampsia in the next pregnancy. When i was pregnant my blood pressure was always okay, my lab result the same, uhm it turns out i got PEB during labor and got C-section right there and then.)

mom1:

.....

Yes mom, the midwife remind me to be careful, less salty food and if i got pregnant i can not go to midwife, straight to the obgyn for monitoring, because it might happen again, it also might not. Yes mom i hope my next pregnancy will be healthy...lets not repeat it again..but, i don't know when the trauma will be gone away. I can not forget what had happened with my child. Your baby was born safely right? Usually if the gestational age was enough and the child's weight is suffice, the c-section can be performed immediately, the hurdle is like my pregnancy, 7 month and small baby, observation was required for several days.

In the thread, mom3 joined the conversation by adding her story. Mom3 got severe preeclampsia but her baby survived. She was worried for the next pregnancy because of the chances of recurring preeclampsia. Mom3 traumatized (scared) by the event but focus more on the precautionary measurement, by stating a lifestyle involving healthy and drink to be consumed to hinder herself from reccuring event. She emphasized the 'surprise' factor of preeclampsia, by stating that all the medical check up were conducted with good result, but in the end, the preeclampsia still happened. More so, she has to delivered her baby via C-Section to justify the imminent danger she went through. Mom1 responded by agreement to the healthy life style, but once again she revealed her fear. She mentioned the survival of mom3's baby, to which it gave a different ending for emotional stability issue. Mom1 further reminded the thread writers or specifically mom3, that her condition was different. Her ending was different, partly she shifted the guilt on the 'if only' situation, the incompatible with life condition of her baby.

mom4:

.....

(translation: i've just got a severe preeclampsia (*PEB-Indonesian term*) in my first pregnancy. My baby died 2 days old...my second pregnancy was blighted ovum and need to be curetaged. I'm still recovering from the procedure. Please pray for me to be given another healthy baby....amen.)

mom2:

.....

same with me mom, after the preeclampsia i got blighted ovum and had to be curetaged. One month after the DC

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procedure alhamdulillah i got pregnant again and now my baby is 16 month...keep the spirit mums.

Mom5:

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Mums, i got PEB and helpsyndrome. My baby was born 31 weeks, weigh 1.380, length 32 cm. Alhamdulillah now this child is 10 months. My OB said it's better that i am not get pregnant again. Your experience motivated me mom. Nothing is impossible for Allah. I hope next time i have a normal pregnancy. Stay healthy mom.

mom1:

.....

Amen mom, thanks for the well wishes. It's weird that your OB make you feel down like that? You only have one child...by the way what is Helpsyndrome mom?

Mom4 join the conversation by telling her loss and that she was still recovering. Mom2 continued her response to mom4 by stating her second pregnancy loss before her success pregnancy. Mom2 seems to show the height of tragedy she experienced, although she experienced a healthy pregnancy 2 years after the 'physical' loss, she had to go through a chemical pregnancy loss. Different loss, similar pain. Mom5 came into the conversation by quoting mom2 thread. Mom5 narrated her preeclampsia event with other complication (HELLP Syndrome), to which her doctor advised her not to get pregnant anymore. However her doctor statement was contradicted by other mothers' experiences which she perceived as motivation and further surrendering her wishes to her God. Mom1 indirectly reprimanded mom5's doctor who instead of giving motivation, gave a negative closure to mom5. Mom1 further emphasized mom5's only child. This condition ignite sympathy for nonexistent second healthy pregnancy.

Mom5:

.....

Helpsyndrome is complication from PEB mom. An edema. I gain 14 kg, the 12 kg was liquid. The liquid comes out gradually after C-section. Whe i was 28 weeks, i had nose bleed, soon i had blurry eyes, my stomach chest and back starting to feel hurt.....

Alhamdulillah my baby in the NICU for 2 weeks was normal. Eventhough when we took him home he only weighs 1.1. kg with additional height 40 cm...skinny and small..subhanallah. Baby blues for a while alhamdulillah it's already past. Maybe because of my dire condition, the OB suggest me that if it repeated, it will be difficult to keep the pregnancy and start the saving procedure. The internist was nice and supportive. Focus on Allah's power. Keep the spirit up PEB survivor.

mom1:

.....

Astaghfirullah...it's so scary mom. But *alhamdulillah* you and your baby are still receive salvation and long age. Yes mom, you need to rethink for another pregnancy. But, always get back to Allah mom, miracle could happen on His will. But, do you still want to have another baby?

Mom5:

.....

alhamdulillah, i am so grateful mom. I really want another baby mom. We've waited 5 years for the first pregnancy, with this history i really want to rush it. But my husband is the one that still scare. He was more traumatized. We wan to focus to give the best for R, our little babe, we hope Allah will make him into a sholeh child and beneficial for the people. We have plan if R is 3 years old, we would like to find other obgyn who is supportive with my history...but reading your experiences, i am more convinced with Allah's providence

mom1:

.....

Alhamdulillah bun, 5 years of waiting got answered. I have a sister who still waiting to get pregnant in her9 years of marriage. There are other moms whose baby died like mine and still bare , it's sad to see mom, not to mention what people said..

It's good that your husband is worry, it means he really care with you....

The conversation continued between mom1 and mom5. Mom5 explained her complication, her struggle in the hospital and NICU days. She also seen as explaining her doctor advice in order to correct mom1 judgement. Mom5 retelling her hospital stories and postpartum baby blues and also her gratefulness towards her God, showed narration of hurdles and hope at the same time. She was shown as a survivor of multiple struggles and provide comfort for other women with similar situation. The talk continued by telling the power of their God and their belief to God. This showed how they see the situation as God given situation, in which only God who can provide different outcome, despite their effort to change the situation. Mom1 and mom5 compare their condition with other women who are still bare of children or other condition and the realization that they still able to call themselves mother, because of the pregnancy. Mom5 words incites the presence of husband in the picture. Instead of mom5 hesitance of having another pregnancy, her husband was the one being traumatized and pitying mom5 for experienced the ordeal. In this conversation, husband was seen as outsider but also affected by the event. In this kind of situation, the carer experiencing different emotion while not physically gone through the illness. The fact that the husband participate emotionally was seen as a sign of love by mom1.

Discussion

Based on the extract of the posts on the thread, there are 5 mothers involved in the conversation. Mom1 was experiencing preeclampsia and loss her baby because of the incident, she still want to have another baby after the event but was scare and traumatized. Mom1 felt tremendous guilt by stating that she 'killed' her baby through the preeclampsia moment. Mom2 joined the conversation by telling her own experience facing the similar health problem, although she experienced a severe preeclampsia it was not known whether her baby survived, however she continued to have another pregnancy, a blighted ovum pregnancy that needs to be terminated and then have a healthy-without-preeclampsia pregnancy. Mom2 encouraged mom1 by lifting up her spirit through her words. However mom1 still felt pressured, especially with the medical history in her family which might trigger similar incident. Mom3 came into the conversation by hinting that mom1 history did not necessarily induce the incident, her severe preeclampsia occured despite her normal pregnancy check up, but she also raise the issue of food diet and change of lifestyle that might prevent the preeclampsia. Mom5 joined the thread by explaining the complication of preeclampsia and hellp syndrome, her story reiterate the complicated process of experience and recovery process. Mom1 stated her fear but also admiration that mom5 able to pull through the horrendous event which was worse than hers. However, mom5 has her baby alive, but mom1 did not. In this thread, one issue of pregnancy after experiencing preeclampsia was discussed from various angle.

The posts indicate the emotional turbulence facing mothers in the specific situation. Pregnancy that suppose to be joyous was complicated by premature birth and even ended by the death of a child/children. Considering the horror of the situation, the mothers in the post kept claiming fear but at the same time showing encouragement that might be directed to their own selves. By having a hope of a healthy pregnancy, these mothers felt empowered, like what mom1 said, "*But alhamdulillah you and your baby are still receive salvation and long age.*" So, despite the situation they can find something positive from the event. In the discussion, the position of

OB was seen as an advisor but also someone who can induce negative feeling from the consultation. “the OB suggest me that. If it repeated, it will be difficult to keep the pregnancy and start the saving procedure. The internist was nice and supportive” there was a comparison between the ‘actual’ pregnancy doctor and the general internist, in which it was problematic because the obstetrics and gynecologist supposed to be the one that decide the procedure and also seen as the expert. Health providers supposed to have strategies for assisting the patient in facing the guilt, criticism and the conflict that might arise (Gray, 2013). Moreover the mention of midwife appeared as a part of medical solution only before preeclampsia was detected. When the diagnosis was certain the patient should consult an obgyn. Here, the midwife consider as useful in a normal pregnancy, but for high risk pregnancy their roles are dismissed. Online support group mediates the emotional side of the participants, even the discussion of death which usually taboo in a face-to-face communication is considered normal in an virtual community, this fact underlines the need of the carer or caregiver to focus on the emotion management of the patient and to allow her to disclose her feelings on the subject (Malloch and Taylor, 2018)

In all the conversation the mention of *Allah*, *alhamdulillah* and *astaghfirullah* kept appearing. Allah is the calling name of God in Islam (www.allah.org), *alhamdulillah* means “praise be to God” or grateful (en.oxforddictionaries.com), *astaghfirullah* means “i beg for forgiveness from Allah” (Syakuro, 1970). The researcher observed that a lot of times in Indonesia, the latter is said in surprised tone by something and regretful. Without acknowledging their religious background, their mentions of the three words show their religious belief. And, it was perceived as normal to repeatedly mention the name of God as the source of what had occurred and also the source of comfort after the hurdles. Besides that, the occurrence of religious words indicate the profound perception that life, death, and birth are outside the power of human or mother in this case. Human only accept the fate that they supposed to undergo. Nevertheless, the posters did not curse or blame God for their ordeal, they still make effort for pregnancy after the ordeal, but also surrender to the course of fate or God’s will. Religious belief can influence the way people deals with grief in terms of the time period and acceptance of the loss (Cowchock, Lasker, Toedter, Skumanich, & Koenig, 2010).

Based on the style of language used. All the poster use informal Indonesian language, with the use of incomplete words. For example, the word ‘no’ in Bahasa is ‘*tidak*’, it is further shortened with the word ‘*gak*’ and ‘*g*’. The shortened word into only letter is possible in the world of online communication. There are some typing error, but it seems that the posters understood what the poster wrote. It was proven by the flow of conversation established. One example is “*Sma bget bund aq jg stlh peb itu mlh hamil bo + kuret jg.*” The post use nonformal shortened words and medical terms in shortened mode. ‘Sma’ is ‘sama’ or ‘same’; ‘bget’ is ‘*banger*’ or ‘so much’; ‘bo’ means ‘blighted ovum’; ‘kuret’ means ‘curetage’, ‘peb’ in this forum stands for ‘*Pre Eklampsia Berat*’. They called each other as ‘bunda’ in Bahasa Indonesia means mother or ‘mom’ in English. Each poster replied to the chat via replying by quoting the sentence, and call the intended person as ‘mom’ instead of ‘moms’ in plural form. It means that the chat was supposed to be interpersonal to one person, but in a whole also address the mothers who join the conversation. Medical terms with the specific circumstances served as the information source for knowledge. An example of the medical terms, “*Helpysndrome is complication from PEB mom. An edema. I gain 14 kg, the 12 kg was liquid. The liquid comes out gradually after C-section.*” Although the mother who experience the complication did not write the correct spelling of the term, but she said it in the easisest words possible using ordinary words. The reiteration of one ordeal, the effort to overcome it and the knowledge shown from explaining medical terms hinted the emotional communication competence. Participant with emotional communication competence might felt self-efficacy by being able to provide support to other women (through her experience) (Yoo, et.al., 2014). Women who participated in this group can be considered as in the effort of finding answers and gaining support that might otherwise received from their offline surrounding. The dissatisfaction of the offline relationship might push participants to search more in the online relationship (Chung, 2013).

Vertically, the whole conversation can be seen as started by a person who has experienced loss after preeclampsia with loss outcome but followed by women who experience preeclampsia with other complication

with no loss. The position of mom1 was an opener of conversation whom like a snowball, gradually revealing the true impact of preeclampsia. Medically, preeclampsia only occur in 5%-8% of pregnancy, without a diagnosis and happened after 20 weeks of pregnancy (Website, 2019). It is a rare condition which the cause has not been identified clearly. The mystery surrounding preeclampsia for novice mothers and ordinary women, brought a sense of fear of recurring situation. From the women's perspective, if the pregnancy is a gift from God, that can easily taken by preeclampsia then the fate of future pregnancy can not be guaranteed. The uncertain condition mediated by the web community such as this support forum is to provide glimpses of what can be understood from various puzzle of experiences. Moreover, the support the women gave to each other signified the hope of receiving the same support from other woman whom she directed the support. For online support group the reciprocation is important to show solidarity as a group who face the same ordeal (Beck, Paskewitz, Anderson, Bordeaux, & Currie-Mueller, 2016).

Conclusion

Support group provides a safe haven for people with similar condition. Online support groups, in particular, guarantee the anonymity but also the interactivity of people with the same issue. Trust was established through the retelling of the condition the participant experienced. In the case of complication during or after a pregnancy, online support group serves as the go-to health information and emotional support. Information support comes in the form of medical terms being explained, the obgyn's role, and the steps of recovery. On the other hand, emotional support highlights the topic of possibility of another safe pregnancy, a sense of "others' problem can be bigger than ours", and the feeling of being heard. This particular thread in a pregnancy forum was started by one mother who dealt with preeclampsia and the death of her child because of it. While this thread does not guarantee the post will be read or replied, it comes as a form of sharing and answer seeking for the writer. The thread presupposedly act as a 'cry for help' or in this sense, in search for enlightenment by a mother in dealing with something she could not fathom.

From the perspective of online communication, the mothers using this thread are seen as independently choosing the media and the form of communication. The online forum encourages the participants to share and ask about pregnancy-related issues. The reinforcement pushed further by conditioning the posters for them to be able to contact other posters directly, they need to open a thread and write a specific number of posts. The number of thread inside the forums are more than 100 threads with different topics. For this particular topics the women participated were considered to be aware of how to post a comment and replied the comment. There was no rules about the use of grammatical correct sentences, only warnings about being harsh. Most posters use nonformal Bahasa Indonesia. They shortened the words into only letters, the type of language that is associated with online communication. Besides the grammar, the posters can add or comments any post within the same thread, although the action can disrupt the continuity of the communication flow. However, the policy enables posters to replied on specific posts and ignore other posts. In this way interpersonal communication can turn into group communication and can return to interpersonal communication. The way the level of communication established, showcased the interactivity and perceived anonymity of the posters.

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