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Titi Nur Vidyarini

## Communicating pregnancy complication: a discourse analysis of an online support group

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**Abstract** Support groups are an essential part of health treatment and recovery for pregnancy. An expectant mother may try to find information, solution or solace through an online support group (OSG). Online support groups enabled people from around the globe to communicate, discuss and encourage others with similar conditions. This article delves the question of how mothers use internet-based health support groups to find solace and communication after their pregnancy loss or infant death. The researcher conducted qualitative discourse analysis on an online pregnancy support group and various literature which explores the use of internet-based support group. The findings show, women use online support group because they found lack of support offline, they need information and emotional support regarding their pregnancy loss and the recovery process, how they express the role of medical experts and how the spouses were perceived differently.

**Keywords:** health; communication; online; support; pregnancy

### INTRODUCTION

Health communication, traditionally, was mediated by medical practitioners, administrators and health services organisations. The new development of health communication focuses about multidirectional aspects of the communication process, in which the public actively seek health-related information from the most accessible source around them, such as the internet (Corcoran, 2016). People with issues related to their health found assistance from support groups in that area.

Support group acts for people with similar health issues, problems, and life challenges to find encouragement, solace and exchanging advice, in other words, social support which includes "informational support, emotional support, tangible support, and validation (Wright, 2014)." Additionally, (Wright, 2014) concludes that participation in an internet-based support group increases the health quality of the person, health self-efficacy, well-being, coping and symptom management. People seeking advice on online communities also seek information traditionally through traditional media, their families and friends (Hu et al., 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 fertilisation) 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 women without medical conditions can be the most joyous experience as a woman. However, there are many instances that pregnancy is a difficult moment. A high-risk pregnancy is a condition in which the mother, child or both is in danger before, during or after labour; the condition arose from various causes, such as high blood pressure, infection, injuries and others. In this case, support groups, online support forums, can give the push of encouragement for pregnant women. This article discusses three threads of an online forum for pregnancy-related issues, *pregnantx.com*. Although the forum is an open website, but the real name of the website and the posters are changed to ensure their privacy, because the content might be considered sensitive and triggering for some posters and readers. The issue discussed were fear, worries, trauma, and loss related to pregnancy. Discourse analysis was used to further understand the meaning behind the posted comments, in relations with culture, power, structure and gender.

Social support is a critical 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). In other instances, social support came in many forms; one of them is support groups that specified problems. Howard Rheingold (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 much idle talk." Online support groups 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 communities 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 by people with health issue and some other advantages such as less feeling of being stigmatised, one's contribution to the group is valued more than her physical appearance, it is convenient, social comparison and more diverse information about one's health condition (Wright, 2014). One of the critical elements of online communication is anonymity. However, in the case of online support groups for health issue such as breast cancer, the anonymity of the poster viewed as not trustable for comment or positive comments from visually identifiable members are most likely to be responded (Kang, 2017).

Pregnancy for first time mother can be joyous and challenging. Modh, Lundgren, & 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 broader perspective, in which they sometimes felt happy but also surprisingly unhappy and lonely. Women who were still trying to conceive also facing stigma and difficulty emotionally. In research by Isupova (2011) on women going through IVF procedure, the emotional support from other mothers in online communities with similar endeavour provides a haven of empathy and encouragement to decide on the procedure. Online support systems overcome the hostile environment of negative relatives and friends. Certain health condition can also complicate pregnancy, such as preeclampsia, HELLP syndrome, and the likes. Preeclampsia is a disorder that affects 5-8% of pregnancy, happened during pregnancy and postpartum and affect both the mother and the baby; globally, preeclampsia caused maternally and infant illness and deaths and is characterised by hypertension, swelling, the presence of protein in the urine and sudden weight gain (Preeclampsia Foundation, 2010). However rare the conditions are, the deaths of mothers and/or babies can influence the whole perspective on pregnancy and life afterwards. A bereaved mother may experience culpability. 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 complicated feeling needs to be addressed by medical or psychological practitioners in dealing with the women (Hale, 2007).

## **METHODOLOGY**

Discourse analysis is a qualitative textual analysis which focuses on the analysis of written, verbal and visual language. According to Jørgensen & Phillips, (2012), discourse is "a form of social practise which both constitutes the social world and is constituted by other social practises. As social practise, discourse is in a dialectical relationship with other social dimensions." Discourse analysis by Fairclough (Jørgensen & Phillips, 2012) combines three traditions of linguistic, textual analysis, macro-sociological analysis on social practise, and micro-sociological practice on interpretive tradition. In discourse analysis, the units of analysis include but not limited to, "words, phrases, and sentences to paragraphs or even larger units" (Wood & Kroger, 2000), moreover, discourse analysis breaks down data and assessing the relationships between the components of the data. Gee (2010) 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 recognisable identity." In relations to online communication, the writer in this article highlight the use of discourse analysis from Teun Van Dijk. One of the reasons is the nature of interaction within the communication flow of the online forum. Van Dijk emphasised conversation as a form of text which can be analysed by the speech act as a form of interaction and also the vertical analysis of the accomplished talk by accomplishing other talks (Van Dijk, 1997). Moreover, discourse analysis defines the units or construct of 'language use, cognition and interaction' and formulate the rules of how these aspects used (Van Dijk, 1997).

## **RESULTS AND DISCUSSION**

In this section, the researcher shows and discuss the thread "Can I have a normal pregnancy after preeclampsia" \*, in which several mothers were conveying their ordeal after preeclampsia. However, not all mothers were bereaved parent; some have their kids alive.

### **Communicating Complication and Loss**

Mom1: (translation) Last February I lost my baby in my womb, when it was 7-month pregnancy, I got heavy preeclampsia/PEB. Are mummies out there experiencing healthy pregnancy after preeclampsia? I am scared to conceive again mums; the trauma and fear of losing are still looming.

I am scared I will kill my baby again. It hurts

mom2: (translation) In 2014, I gave birth with preeclampsia mom. In 2016 I had a normal pregnancy. *Alhamdulillah*, the birth was normal

without preeclampsia. My baby is now 16 month, and I am currently nine 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 (I) 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 worried, mom.

Mom1 opens a thread by sentences revealing her traumatic pregnancy loss. She posted the sentence in March 2018, but the content mentioned her actual event occurred in 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 starts by saying that she lost her child before being born, while the gestational age (this information was not clear) of the pregnancy was seven 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 scared to conceive again mums, the trauma and fear of losing is still looming". More so, the consequence of the unnatural death of the child induces guilt in the mom1 four 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 a 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 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 the painful situation with hope. She encouraged mom1 to keep her spirit up because mom1 can have the same ending as hers. In this case, mom2 was 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 contacts. She directed the conversation towards things that can be considered as a physical effort to have another healthy pregnancy. She further informed mom2 about the history of high blood pressure in mom1 family. Here, mom1 tried to find a solution or at least an answer to why she caught preeclampsia. She did not believe in her body's ability

to have a healthy pregnancy. Her first thread portrays the guilt of 'killing' the child inside her body.

mom3: (translation: I have heard there is a big chance of severe preeclampsia in the next pregnancy if we can manage our meal and lifestyle the severe preeclampsia (PEB) can be prevented. Mums let us encourage each other and try not to have severe preeclampsia in the next pregnancy. When I was pregnant, my blood pressure was always good, and my lab results were the same, it turns out I got PEB during birth and got C-section right there and then.)

mom1: (translation: Yes mom, the midwife reminded me to be careful, less salty food and if I got pregnant, I cannot go to a midwife, (I should go) straight to the ob-gyn (gynaecologist) for monitoring, because it might happen again, it also might not. Yes, mom, I hope my next pregnancy will be healthy, let us not repeat it. But I don't know when the trauma will be gone away. I cannot forget what had happened to my child. Your baby was born safely, right? Usually, if the gestational age was enough and the child's weight is sufficed, the c-section can be performed immediately, the hurdle is like my pregnancy, 7 month and small baby, observations were 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 about the next pregnancy because of the chances of recurring preeclampsia. Mom3 traumatised (scared) by the event but focused more on the precautionary measurement, by stating a lifestyle involving healthy and drink to be consumed to hinder herself from recurring event. She emphasised the 'surprise' factor of preeclampsia, by stating that all the medical cheque-up was conducted with a good result, but in the end, the preeclampsia still happened. More so, she must deliver her baby via C-Section to justify the imminent danger she went through. Mom1 responded by agreement to the healthy lifestyle, 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 PEB in my first pregnancy. My baby died two days old. My second pregnancy was blighted ovum and needed to be curettage. I'm still recovering from the procedure. Please pray for me to be given another healthy baby, amen.

mom2: (translation) same with me, mom, after the preeclampsia I got blighted ovum and had to be curettage. One month after the DC procedure alhamdulillah I got pregnant again, and now my baby is 16 months, keep the spirit mums.

Mom5: (translation) Mums, I got PEB and help syndrome. 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 do 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: (translation) Amen mom, thanks for the good wishes. Weirdly, your OB make you feel down like that? You only have one child, by the way, what is Hellp syndrome, 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 successful 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. 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 to stop getting pregnant. However, her doctor statement was contradicted by other mothers' experiences which she perceived as motivation and further surrendering her wishes to her God. The communication happened in the forum which builds medical advice between patients may challenge the traditional healthcare encounter between doctor and patient, in which the doctor provide an opinion from a scientific perspective (Keeling et al., 2013). Mom1 indirectly reprimanded mom5's doctor, who instead of giving motivation, gave a negative closure to mom5. Mom1 further emphasised mom5's only child. This condition ignites sympathy for a non-existent second healthy pregnancy.

The conversation continued between mom1 and mom5. Mom5 explained her complication, her struggle in the hospital and NICU days. She also is seen as explaining her doctor advice in order to correct mom1 judgement. Mom5 retelling her hospital stories and postpartum baby blues and her gratefulness towards her God showed narration of hurdles and hoped at the same time. She was shown as a survivor of multiple struggles and provided comfort to four other women with a 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 a God-given

situation, in which only God who can provide a 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 realisation that they still able to call themselves mother, because of the pregnancy. Mom5 words incite the presence of a husband in the picture. Instead of mom5 hesitance of having another pregnancy, her husband was the one being traumatised and pitying mom5 four experienced the ordeal. In this conversation, the husband was considered as an outsider who 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 participates emotionally was a sign of love by mom1. In the postpartum condition, women expect their husband to be their support system, and currently, many husbands enforce that role (Lindberg et al., 2008). This understanding may not be seen in the dialogue between the women. The husband was considered as a passive support system with only emotional attachment since they do not participate in the labour process.

Based on the extract of the posts on the thread, there are five mothers involved in the conversation. Mom1 was experiencing preeclampsia and loss her baby because of the incident; she still wants to have another baby after the event but was scared and traumatised. Mom1 felt tremendous guilt by stating that she 'killed' her baby because of the preeclampsia. Mom2 joined the conversation by telling her own experience facing the similar health problem, although she experienced 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 her spirit through her words. However, mom1 still felt pressured, especially with the medical history in her family, which might trigger a similar incident. Mom3 came into the conversation by hinting that mom1 history did not necessarily induce the incident, her severe preeclampsia occurred despite her normal pregnancy cheque-up, but she also raises 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, and her story reiterates the complicated process of experience and recovery process. Mom1 stated her fear but also admiration that mom5 was 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 two sides of loss**

The posts indicate the emotional turbulence facing mothers in a specific situation. A pregnancy that supposed 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 receiving salvation and long age." So, despite the situation, they can find something positive from the event.

In the discussion, the position of an OB (obstetrics and gynaecologist) was an advisor but also someone who can induce negative feeling from the consultation. "the OB suggests me that. If it repeated, it would 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 gynaecologist supposed to be the one that decides the procedure and seen as the expert. In the discussion, the revelation of loss also interconnected with the support system available around the parents. 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 the medical solution only before preeclampsia was detected. When the diagnosis was sure, the patient should consult obstetrics and gynaecologist. Here, the midwife considers as useful in a normal pregnancy, but for a high-risk pregnancy, their roles are dismissed. Online support group mediates the emotional side of the participants, even the discussion of death which usually taboos in face-to-face communication is considered normal in a virtual community. This fact underlines the need for 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 & Taylor, 2019).

### **Faith and understanding pregnancy complication**

In all of the conversation, the mention of *Allah*, *alhamdulillah* and *astaghfirullah* kept appearing. *Allah* is the calling name of God in Islam (Qurtuby, 2018), *alhamdulillah* means "praise be to God" or grateful ("Alhamdulillah," 2019), *astaghfirullah* means "I beg four forgiveness from Allah" (Syakuro, 2019). The researcher observed that many times in Indonesia, the latter is said in a surprised tone by something and regretful. Without acknowledging their religious background, their mentions of the three words show their religious belief.

Moreover, it was perceived as normal to repeatedly mention the name of God as the source of what had occurred and the source of comfort after the hurdles. In this discourse analyses, the occurrence of religious words indicates the profound perception that life, death, and birth are outside the power of human or mother in this case. Human only accepts the fate that they supposed to undergo. Nevertheless, the posters did not curse or blame God for their ordeal; they still make an effort to have another pregnancy after the ordeal but also surrender to the course of fate or God's will. Human has no control over their fate. Religious belief can influence the way people deals with grief in terms of the time and acceptance of the loss (Cowchock et al., 2010).

### **Understanding the message through informal language**

Based on the style of language used. All the posters 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 letters is possible in the world of online communication. There are some typing errors, 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 posts used nonformal shortened words and medical terms in shortened mode.

*'Sma' is 'sama' or 'same';*

*'bget' is 'banget' or 'so much';*

*'bo' means 'blighted ovum';*

*'kuret' means 'curettage',*

*'peb' in this forum stands four '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 a complication from PEB mom. Oedema. I gain 14 kg, the 12 kg was liquid. The liquid comes out gradually after C-section."

Although the mother who experiences the complication did not write the correct spelling of the term, she said it in the easiest 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. Participants 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 receive 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 the conversation who like a snowball, gradually revealing the true impact of preeclampsia. Medically, preeclampsia only occurred in 5%-8% of pregnancy, without a diagnosis and happened after 20 weeks of pregnancy (Communication, 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 the recurring situation. From the women's perspective, if the pregnancy is a gift from God, that can easily take by preeclampsia, then the fate of future pregnancy cannot be guaranteed. The uncertain condition mediated by the web community, such as this support forum is to provide a glimpse of what can be understood from various puzzles of experiences. Moreover, the support the women gave to each other signified the hope of receiving the same support from other women whom she directed the support. For online support group, the reciprocation is essential to show solidarity as a group who face the same ordeal (Beck et al., 2017).

## **CONCLUSION**

Support groups provide a haven for people with a similar condition. Online support groups guarantee 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 pregnancy, online support groups serve as the go-to health information and emotional support. Information support comes in the form of medical terms being explained, the obstetric and gynaecologist's role, and the steps of recovery.

On the other hand, emotional support highlights the topic of the possibility of another safe pregnancy, a sense of "others' problem can be bigger than ours", and the feeling of being heard. This 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 presupposed act as a 'cry for help' or in this sense, in search of enlightenment by a mother in dealing with something she could not fathom. From the perspective of online communication, the mothers using this thread are 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 threads inside the forums is more than 100 threads with different topics. For this topic, the women participated were aware of how to post a comment and replied the comment. There were no rules about the use of grammatically correct sentences, only warnings about being harsh to other posters. 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 enabled posters to reply 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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## **ENDNOTE**

\*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 as the original Bahasa Indonesia. The researcher did not write all conversations, only some excerpts from the conversations.

Medical terms were written as the posters wrote them, albeit not in the correct spelling. Those are HELLP syndrome (H-Hemolysis (the breaking down of red blood cells; EL-elevated liver enzymes; LP-low platelet count) (De La Rubia et al., 2001); and also, preeclampsia. PEB or *Pre-eklampsia Berat* is an Indonesian term synonym with severe preeclampsia; PEB can be elevated by HELLP syndrome (Muhani & Besral, 2015).

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