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The Experience of Chronic Sorrow among Indonesian Mothers who have Suffered Recent Perinatal Loss Erni Samutri1*, Widyawati2, Wenny A. Nisman2, Joel Gittelsohn3, Hamam Hadi4, Emma C. Lewis3, Lia Endriyani1, Sofyan Indrayana1, Artha Mevia Ruly Afita1 1Department of Nursing, Faculty of Health Science, The University of Alma Ata, Yogyakarta 55183, Indonesia 2Department of Child and Maternity Nursing, Faculty of Medicine Public Health and Nursing, Universitas Gadjah Mada, Yogyakarta, Indonesia 3Center for Human Nutrition, Department of International Health, Bloomberg School of Public Health, The Johns Hopkins University, Baltimore, MD 21205-2179, USA 4 Graduate School of Public Health Department, Faculty of Health Science, The University of Alma Ata, Yogyakarta 55183, Indonesia *Corresponding author: Erni Samutri, Department of Child and Maternity Nursing, Faculty of Health Science, Universitas Alma Ata, e-mail: erni.samutri@almaata.ac.id Competing interest: The authors have declared no competing interest.

Abstract Background: Perinatal death results in physical loss of a child as well as symbolic loss (loss of self, hope and self-esteem) experienced by many parents.

Loss is often expressed via a grief response that can develop into chronic sorrow. Ineffective coping strategies may increase susceptibility to complications associated with chronic sorrow. These complications can include clinical depression, dysthymic disorder, post-traumatic stress disorder, attachment disorder, drug dependence, psychosis, and suicidal ideation. Therefore, it is crucial to understand the barriers and facilitators to chronic sorrow particularly among vulnerable populations. Aim: To explore the experience of chronic sorrow among Indonesian women who have suffered perinatal loss.

Methods: The present qualitative study utilized a descriptive phenomenological approach. Participants included women who experienced chronic sorrow due to perinatal loss within the past seven weeks to three years. Maximum variation sampling was used based on women's current number of children. Data were collected using semi-structured interviews and analyzed using a modified Stevick-Colaizzi-Keen method. Results: Three key themes emerged from the data: (1) recurrent experiences of grief are common particularly when exposed to certain triggers (memories from pregnancy, mementos); (2) adequate coping strategies and emotional support are needed to help treat grief; and (3) specific characteristics of chronic sorrow are associated with perinatal loss, such as grief that feels diminished and the presence of another child serving as both a cure and a trigger of sorrow.

Conclusion: Chronic sorrow as a result of perinatal loss is experienced repeatedly when mothers face certain triggers. We have identified two characteristics (diminished grief, having another child serve to both cure and trigger sorrow) that are specific to the experience of chronic sorrow compared to that of general grief. It is important to understand the experience of chronic sorrow and how coping strategies and a support system can help grieving mothers to overcome their loss.

Keywords: chronic sorrow, perinatal loss, grief, child loss Introduction Perinatal loss is an umbrella term which encompasses the death of a child spanning from fetal death as early as 20 weeks since gestation until neonatal death up to 28 days in early life [1]. Over the last few decades, the perinatal mortality rate has generally decreased worldwide, although more recently it has tended to remain stable [1, 2]. This trend is reflected in Indonesia, where the neonatal mortality rate was gradually decreasing until 2002 when the rate of decrease slowed.

According to Statistics Indonesia, neonatal mortality was at 23 deaths per 1,000 live

births in 2002, then remained at 19 deaths per 1,000 live births in 2007 and in 2012, and most recently was 15 deaths per 1,000 live births in 2017 [3]. Neonatal death is typically associated with high-risk pregnancy and childbirth conditions (such as being pregnant at a younger or older age, birth spacing of less than two years, and living in rural areas) and with labor where there is no healthcare provider present [3]. Perinatal mortality results in the experience of physical loss of the child coupled with symbolic loss that can be felt by parents due to the disparity between the current reality and the desired reality [4, 5].

This loss is expressed through a grief response, which can involve periodic and non-resolution characteristics [6-8]. Periodic characteristics of grief refer to the cyclical and continual process of re-experiencing grief when facing triggers of the loss, which in turn can result in non-resolution of grief when the disparity between current and desired realities remain. The term 'chronic sorrow' was originally coined by Olsansky in 1962 based on his observation of the particular grief response experienced by parents caring for their disabled children.

The concept of chronic sorrow was later expanded upon by Eakes, Burke and Hainsworth in 1998 wherein it was described as a response to significant loss characterized by pervasive, periodic, permanent and potentially progressive sadness [5]. Chronic sorrow is now widely understood to be a normal response to significant loss [5]. However, ineffective coping strategies and inadequate support for those experiencing chronic sorrow may increase susceptibility to complications such as clinical depression [9-11] dysthymic disorder [12], post-traumatic stress disorder, attachment disorder [13], drug dependence, psychosis, and suicidal ideation [14].

Chronic sorrow has been identified as a response to experiencing many conditions in addition to significant loss: disabilities, autism, neurodegenerative disease, cerebral palsy, sickle cell disease, neural tube defects, multiple sclerosis, preterm birth, type 1 diabetes, and drug addiction [9, 15]. Several studies examining chronic sorrow among parents who have lost a child have shown that the sorrow continues to be experienced over the course of the lifespan [16-18]. A quantitative study [10] compared chronic sorrow among infertile participants and perinatal loss participants, and found that chronic sorrow was significantly higher among those who had suffered perinatal loss.

However, a gap in the literature remains regarding an in-depth understanding of chronic sorrow due to perinatal loss and virtually no research has been done in this area among the Indonesian population. The present study sought to explore the experience of chronic sorrow among Indonesian mothers who have recently suffered perinatal loss. Our research questions were as follows: What is the experience of chronic sorrow

among Indonesian mothers who have recently experienced perinatal loss?; and What is the role of the healthcare provider in caring for mothers who have suffered perinatal loss? Methods Participants We conducted a qualitative study using a descriptive phenomenological approach [19]. We chose this approach for its flexibility in leveraging participants' perceptions of the experience of chronic sorrow.

Participants were identified using perinatal mortality records collected between 2015 and 2017 at two community health centers in Yogyakarta, Indonesia. Purposive sampling was used to select participants. The inclusion criteria consisted of: (a) being a mother with chronic sorrow experience due to perinatal loss, (b) meeting variations of the current number of children (a mother who is pregnant and/or already has other child; a mother who is not pregnant and has no children) and (c) having suffered the perinatal loss between seven weeks to three years ago.

Mothers were excluded if their perinatal loss was accompanied by a severe mental disorder (such as major depression, severe physical disorders, chronic illness, or surgery) determined by the perinatal mortality record. The shortest duration since perinatal loss was chosen to be seven weeks because the crisis of acute grief generally ends six weeks after experiencing a loss [20, 21], therefore, parents may enter chronic sorrow experience after this point [22]. The longest duration was chosen to be three years because parents who have suffered from child loss tend to begin to move on with their lives after three years since their child's death [13, 16].

Therefore, we chose this timeframe to most accurately explore the current experience of chronic sorrow and to minimize recall bias. It is important to note that data saturation was reached on the ninth participant. Materials and Procedure Materials. The present study utilized two instruments to (1) screen for chronic sorrow, and (2) explore the chronic sorrow experience. First, the chronic sorrow screening tool was developed based on the Nursing Diagnoses Definition and Classification (NANDA) and The Burke/Eakes Chronic Sorrow Assessment Tool [23].

This screening tool consisted of four questions selected to assess the duration since perinatal loss and the presence of characteristics indicative of chronic sorrow. Second, the interview instrument was developed based on The Burke/Eakes Chronic Sorrow Assessment tool [24]. This instrument consisted of six questions: (1) "How did you experience fetal/baby death?", 2) "How did you feel when you found out that your fetus/baby had died?", 3) "How do you feel right now when you recall the events of your fetal/baby death?", 4) "When do those feelings reappear?", 5) "What situations might remind you of your loss?", and 6) "What actions do you take to overcome the feelings when you remember your loss?". Probing questions were used based on the

participants' answers.

Field notes were taken to record nonverbal responses during the interview. Procedure. Data collection was conducted from January-February 2018. The research team and cadres (community health volunteers) visited eligible participants in their homes to obtain informed consent and administer the chronic sorrow screening tool. Each participant was interviewed at two time points. The first interview was used to explore the chronic sorrow experience, and the second interview was conducted three to eight days later to perform member checking and triangulation.

Member checking was completed by asking the participant about the accuracy of the data collected from first interview during the second interview. The triangulation techniques we chose to use included data triangulation and method triangulation. Data triangulation was conducted by administering an interview to the participant's husband, participant's mother, and the researcher's colleague who had perinatal loss, while method triangulation was conducted by collecting field note observations of participant's nonverbal responses during the interviews. The duration of each interview lasted, on average, 60 minutes and 35 minutes, respectively.

During the interview process, one participant refused to answer a screening question and withdrew from the study. Data Analysis Our data analysis approach used a modified Stevick-Colaizzi-Keen method. This method involves six sequential steps of data analysis [25-27], including: (1) bracketing by writing reflective journals about the researcher's perception before and after the interview, (2) identifying significant statements from the transcribed data, (3) grouping the significant statements into meaningful groups, (4) arranging a textual description of participants' experiences through theme formulation, (5) arranging a structural description from the textual explanation of participants' experiences, and (6) constructing a composite description incorporating both the textual and structural descriptions to represent the overall essence of one's experience. This process was repeated for each participant until no new information was obtained.

The process of translating codes into final themes was conducted through discussion among the research team. Ethical Consideration The present study was approved by the ethics committee of Universitas Gadjah Mada (KE/FK/1244/EC/2017). The participants were informed of the research objectives, data confidentiality, data publication, and their right to withdraw from the study at any time. The chronic sorrow screening was conducted immediately after written consent was obtained. The researcher present offered access to psychological counselors at the community health center for participants due to the sensitivity of the questions being asked, however, all participants stated that they did not need a psychological counselor.

Rigor Trustworthiness of qualitative data is assessed by credibility, dependability, confirmability, transferability, and authenticity [28]. In the present study, credibility was confirmed by member checking, triangulation, and reflective journal writing. Dependability was confirmed by member checking and triangulation. Member checking was conducted by checking the accuracy of data collected with participants, while triangulation was done through data triangulation and method triangulation. Confirmability was assessed by using an inquiry audit procedure. The inquiry audit was completed by consulting the transcript and analysis process with the research advisor.

Transferability and authenticity were strived for by collecting a thick description of the entire study process and citing participant quotations to support the conclusions made by the research team. Results Participants (N=9) ranged from 23 to 43 years old and included mothers who currently had other children (n=6), who already had children and were currently pregnant with another child (n=1), and who were neither pregnant nor had any children (n=2). Researcher-generated codes were used to identify participants. Mothers were identified using P1, P2, P3 and so on (Table 1).

Participants used for data triangulation were identified using T1 for P5's husband, T2 for P9's mother, and T3 for the researcher's colleagues. Table 1. Chronic sorry study participant characteristics Code _Age (years) _Education level _Religion _Age of perinatal death _Number of children _Duration of perinatal loss (months) _Cause of perinatal loss _ _P1 _31 _High school _Islam _6 hours _1 & pregnant _8 _Asphyxia _ _P2 _40 _Elementary school _Islam _3 days _1 _7 _Low birth weight _ _P3 _23 _High school _Islam _3 days _0 _8 _Death on arrival _ _P4 _27 _High school _Islam _IUFD _1 _22 _Intrauterine fetal death _ _P5 _43 _High school _Islam _3 days _2 _2 _Congenital heart disease _ _P6 _39 _Elementary school _Islam _6 hours _2 _19 _Meconium aspiration _ _P7 _32 _High school _Islam _3 days _0 _4 _Premature _ _P8 _27 _University _ Hindu _12 days _1 _25 _Congenital heart disease _ _P9 _30 _High school _Islam _IUFD _1 _26 _Mother with eclampsia _ _ The present study identified three key themes describing the experience of chronic sorrow among mothers who had suffered perinatal loss.

Each theme was comprised of 2-4 sub-themes based on what was shared in the interview (Table 2). Table 2. Themes and Sub-Themes of Chronic Sorrow Themes _Sub-Themes _ _Recurrent grief experience and triggers _Grief experience at the event of fetal/baby death Adapting to loss Recurrent and unforgettable grief experience The trigger of recurrent grief experience _ _Coping strategies and emotional support to treat feelings of grief _Adaptive coping strategies Emotional support from various sources Maladaptive coping strategies _ _Specific characteristics of chronic sorrow due to perinatal loss _Grief that feels diminished The presence of another child can be a cure as

well as a grief-trigger _ _ Theme 1: Recurrent grief experience and triggers.

Theme 1 describes the grief experience of perinatal loss as being felt repeatedly and recurring when the mother encounters meaningful situations or triggers. There are four sub-themes within this theme based on events shared by mothers during their interviews: Grief experience at the event of fetal/baby death The event of perinatal loss caused mothers deep feelings of grief. They mentioned feeling shocked, angry, guilty, regretful, and empty. One mother in particular revealed her shock and that she could not accept the fact that her baby was dead: "…I feel so sad, shocked, I can't believe it.

At first I was excited to get pregnant, but why do it again? I'm really mad, but with who?" (P7, 4 months after perinatal loss). Her response was validated by her husband, who shared that: "...Back then, she did not want to wake up and kept crying. She even stated that "The baby is crying, why you don't want to carry the baby", I said "What are you talking about? The baby is dead but you keep crying." (T1, 50 years old) Adapting to loss by focusing on other children Mothers reported adapting to their loss but that they could not accept it. Certain life stressors influenced mothers' ability to adapt to and accept their loss.

One mother who had a child with special needs reported being physical abused by her husband and subsequently experienced two perinatal losses; yet she felt that she had to stay positive. This mother tried to convince herself to accept the losses as soon as the babies were buried: " I had two losses, the first one (the first baby) and this one (the fourth baby). I feel so sad but I can handle it. The first day after the baby was buried, I thought "OK, maybe I should focus on my other children... I think that was my destiny, I should receive it and look at the bright side." (P6, 19 months after perinatal loss).

Similarly, a mother who had twin births during which one died forced herself to focus on caring for her living baby: "...During labor, the living baby was brought to the NICU. I kept thinking about it. One of them was already dead and I have to let it go. I forced myself though it was difficult. I kept struggling." (P4, 22 months after perinatal loss) Recurrent and unforgettable grief experience Mothers who have adapted to their loss often return to their normal routine. However, grief can recur when a meaningful situation is encountered.

When this happened, mothers reported feeling sorrow, fear, and trauma, which often led to emotional ups and downs. This type of sorrow can be described as a cycle between triggering events, grief, and coping strategies (Figure 1). One mother who had no children after the loss of her baby revealed that the trauma and fear of losing another had stopped her from planning to become pregnant again. In addition, it was felt that

the memory of mothers' babies would never be lost even if they had never spent time together. Some mothers believed that their deceased baby would help them in the next life. Regardless, one mother explained: "...

But the trauma is still there, persists. I am still afraid. I want to hold a baby, have a baby. But, why this feeling is still here" (P7, 4 months after perinatal loss) Triggers of recurrent grief experience Recurrent grief seemed to be most often triggered by seeing a baby of similar age to mothers' deceased babies. Other typical triggers included interacting with the lost baby while alive, pregnancy memories, meaningful days (i.e., the baby's birthday), mementos (i.e., baby clothes, photos), sibling's sadness, and talking about their own sadness (Figure 1).

One mother said: "... When I remember and share about it, I feel hurt, sad..." (P5, 2 months after perinatal loss). Theme 2. Coping strategies and emotional support to treat the grief feeling Mothers tend to use adaptive coping strategies and emotional support to help restore their emotional stability. However, sometimes they reported using maladaptive coping strategies that resulted in a worsening of their grief.

This theme encompasses three sub-themes: Adaptive coping strategies Coping strategies such as keeping busy with another child, being thankful for a current pregnancy, sharing stories, and getting closer to God, have all been reported by mothers as aiding in the management of grief (Figure 1). Mothers with other children especially leaned on those surviving children to help them cope: "...I still do my daily activity and my cure is my child (pointed her living child)." (P4, 22 months after perinatal loss) In addition, turning to religion seemed to help mothers develop positive thoughts related to their loss.

Those who shared religious sentiments often shared that they had chosen to remain patient, restore all things to God's will, accept the destiny of their lives, and think positively: "...Yes I have to be patient, be patient. If we continue to obey our ego, we don't move forward, we must think positively." (P3, 8 months after perinatal loss). "When the memory of the baby came back, the sadness came again. When the arrival of a baby has been expected for a long time, then suddenly God takes it back, it hurts. But, again, I have to be patient. Because everything is destiny, humans only hope, but God determines everything.

I am sure there will be a better one." (P9, 26 months after perinatal loss). "...the experience of losing this baby is the most valuable life lesson, right (P7 starts to cry). Basically I have to be sincere, patient. I always remember that when God gives difficulties, it means that God still loves his people." (P7, 4 months after perinatal loss)

Emotional support from others can be positive or negative Mothers received emotional support from various sources. Their parent's support, such as encouragement to rise from sadness, made them feel more comfortable. On the other hand, husbands tended to cause the mother to feel burdened. One mother's husband exclaimed: "...

I said, "It is better if you pray and do not remember that loss again". I have given more advice to her, but she still remembers it." (S5, 50 years old) Maladaptive coping strategies In certain situations, the coping strategies developed by mothers led to discomfort. Maladaptive coping strategies, such as questioning God's destiny, only made these mothers fall deeper into grief. Efforts to suppress grief often did not help: ".... Now, I can hold my grief. ... It's not relieved. ... But, it can disappear when my other child come." (P5, 2 months after perinatal loss). Theme 3.

Specific characteristics of chronic sorrow on perinatal loss Two specific sub-themes that were identified from our interviews with mothers spoke specifically to the characteristics of chronic sorrow and subsequently shaped this third theme: Grief that feels diminished The first sub-theme describes how mothers have tried to control their feelings and move on from their loss but the result is often a feeling of diminished grief. This sentiment was shared by all nine participants. One mother with a history of three perinatal losses said: "... As time goes by, it used to be felt often, but the longer, it got smaller. So as time goes by, I start a little bit to adapt "(P9, 26 months after perinatal loss).

The presence of another child can be a cure as well as a grief-trigger The second sub-theme pertains to participants who have other children besides the baby that was lost. The mothers who felt that their other child(ren) was a cure for the grief shared that: "...My cure is my child (pointed her living child)."(P4, 22 months after perinatal loss) "...My children make me feel entertained" (P5, 2 months after perinatal loss) Although, sometimes their children's questions about the deceased baby triggered grief: "...If they say, "let's go to my sister's cemetery, mom!", I feel shocked and it triggers me to cry. But I hold it because they are my children."(P5, 2 months after perinatal loss).

One pregnant mother also experienced a similar situation wherein she believed that her pregnancy was a positive substitute for her loss as well as a source of concern. Overall, seven out of nine participants showed emotional responses such as crying (across a spectrum ranging from glazed to tearful eyes). Crying often occurred when they talked about the event of the baby's death and their grief afterwards. This was supported by information provided by their family members who claimed that they typically saw the participants crying when they had remembered the memories of their lost babies. / Figure 1.

The process of experiencing chronic sorrow after perinatal loss Discussion The nature of grief experienced due to perinatal loss among Indonesian women is in line with the characteristics of chronic sorrow proposed by Eakes, Burke, & Hainsworth [5] where the grief felt is pervasive and periodically recurrent. The present study identified specific characteristics of chronic sorrow among mothers who have suffered perinatal loss which help to differentiate the experience from other forms of grief and sorrow: (1) that the grief often feels diminished; and (2) the presence of another child in the home can serve as both a positive cure and a negative trigger.

Firstly, diminished grief refers to the notion that the grief felt when facing a trigger is no more severe than the grief felt at the time of the loss event. This finding supports the chronic sorrow concept analysis conducted by Teel and others [21], in which it was found that although chronic sorrow due to significant loss has no resolution, effective coping strategies can help to make the intensity of the grief felt diminish over time.

Adaptive coping strategies such as being thankful for a current pregnancy, and being grateful for the presence of another child or other positive thoughts, have helped women adapt to loss and minimize the recurrence of their chronic sorrow. This finding is also in line with that of previous studies [28-30]. Secondly, the presence of another child can serve as both a cure and a trigger of feelings of grief. Mothers who had a surviving child typically felt that the presence of their child helped to remedy their grief experience.

On the other hand, when children asked about the whereabouts of their deceased siblings, events like this made mothers recall their loss and triggered grief. This finding is consistent with Üstündag-Budak et al. [30] which revealed that mothers interpreted their living child as a reflection of their deceased child. They were happy to have a living child, but could not deny that they were still grieving their loss. In particular, pregnancy after perinatal loss can cause mothers to feel a mixture of emotions, such as happiness and concern [28, 31]. These conflicting emotions can mean that the pregnancy is both supportive as well as triggering.

In the present study, mothers' adaptation to loss was not accompanied by the resolution of grief. This is consistent with other previous research [5, 10, 17] that has found that the outcome of chronic sorrow is not a resolution, but rather a continuous adaptation. One mother who had suffered two perinatal losses, a history of domestic violence, and had a child with special needs, immediately convinced herself that she needed to adapt to her loss and move on.

Adaptive coping strategies have helped mothers to keep functioning. This is in line with

the case study proposed by Bettle & Latimer (2009) [32] where it was determined that mothers often try to find the strength to adapt to loss in order to maintain their family role. This coping strategy is known as the strength-based approach [32]. It is important to consider culture in this context. All of the mothers in the present study were Javanese.

Therefore, their response to experiencing loss may have been influenced by the life principles instilled in them as a part of the Javanese culture. The life principles cover eling (remembering), sabar (being patient), and nrimo (being submissive). Mothers of this culture typically believe that their loss is the destiny of God and that their deceased baby will be the mother's helper to the next life (hereafter). This finding is in line with one of the Javanese life principles of eling (remembering), which refers to the notion that humans should restore all things to God's will and believe in God's power [33].

Sabar (being patient)[34], pertains to mothers' endurance in facing their loss and attempts to hold back their sadness. In the present study, mothers mentioned developing positive thoughts to help control their grief. In addition, mothers also sought to hold back their overflowing sadness when interacting with their other children. Nrimo (being submissive) can help individuals accept the reality of their lives and develop effective coping strategies that prevent them from experiencing trauma [35, 36].

In the present study, even though the mothers who participated had not yet accepted their loss, they tried to adapt nevertheless, particularly when attempting to feel gratitude for a current living child or current pregnancy. There are a few strengths of the present study worth noting. Our identification of specific characteristics of chronic sorrow after perinatal loss can help to enrich the understanding of chronic sorrow in this particular context. Our findings also provide important data for the planning of effective interventions in this area of work. The main limiting factor of the present study was the small sample size, and the homogeneity of participant characteristics.

Many eligible mothers refused to participate because they did not want to relive the loss and grief. The majority of participants were Islamic and all came from a Javanese background. For this reason, the findings from the present study are not necessarily representative of the chronic sorrow experiences among women of other religious or ethnic backgrounds. Religion and ethnicity both shape how people approach loss and express their grief.

Therefore, research exploring the grief experiences of women while considering different participant's spiritual beliefs and ethnic backgrounds should be conducted to help better understand loss and grief in other settings and contexts [29, 37, 38].

Conclusion To our knowledge, this is the first study of its kind to explore the experience of chronic sorrow in the wake of perinatal loss among Indonesian mothers. We found that chronic sorrow is recurrent and is most often exacerbated when confronted with triggers that remind mothers of their loss.

Two specific characteristics of chronic sorrow resulting from perinatal loss were identified: (1) diminished grief, and (2) the presence of another child serving as both a cure and a grief trigger. Although chronic sorrow often consists of feelings of non-resolution, adaptive coping strategies and positive emotional support can assist those suffering to regain their happiness and reduce their level of perceived disparity in the realities of their loss. This conceptualization of chronic sorrow is crucial for healthcare providers to understand so that they can deliver effective care to patients dealing with chronic sorrow and loss.

Our study findings lay the groundwork for providing evidence-based recommendations. First, healthcare providers should be given the tools to understand the various concepts of grief, including acute grief, the grieving phases, and chronic sorrow, in order to best understand what mothers are going through. Second, it is crucial for nurses to be able to assess life stressors as influences of mothers' ability to adapt to their loss.

Third and finally, helping to correctly identify coping strategies could help mothers to better handle their experience with loss and the grieving process. By providing adequate support during the acute grief phase, mothers may be better equipped to avoid experiencing chronic sorrow and pathological grief in the wake of perinatal loss, lessening their risk of comorbid and life-altering physical, mental, and emotional consequences. Acknowledgments The research presented in this manuscript was generously supported by the University of Alma Ata.

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