**Clinical Schizophrenia & Related Psychoses**

# Time-Related Circumstances Defining Youths Self-Management: Following the Unexpected Loss of a Family Member to HIV/AIDS

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## Abstract

**Background:** There is a high incidence of depression in youth who are stressed, making them less likely to engage in active self-management strategies such as exercise due to the trauma of losing a family member. Youths visit public hospitals for various reasons, including panic attacks and anxiety, which are often experienced after the passing of a family member. The aim was to explore the lived experiences of youths on managing themselves after losing a family member to HIV/AIDS and develop guidelines for nurses to advise youths on self-management following the loss of a family member to HIV/AIDS.

**Methods:** A descriptive phenomenological design was followed for a study at a Comprehensive Healthcare Clinic in the Western Cape Province of South Africa. The sample was selected through purposive sampling until data saturation was achieved. Individual semi-structured interviews with 11 participants were conducted, after which data saturation was established.

**Results:** Accordingly, based on the findings, the research developed guidelines that nurses can use to advice youths on self-managing themselves after the unexpected loss of a family member to HIV/AIDS.

**Conclusion:** The youths need to practice self-management during unexpected situations to cope with the death of family members with HIV/AIDS. Nurses at the Comprehensive Healthcare Clinic can use the developed guidelines to assist youth on self-management.

**Keywords:** Death • Family member • Youth • Grief • HIV/AIDS

**Abbreviations:** CHC: Comprehensive Healthcare Clinic; HIV/AIDS: Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome.

## Introduction

A family can offer an individual a unique feeling of belongingness and morals that cannot be acquired in other relationships. It is also a frequent source of emotional support, love, security, and protection [1]. Youth who have experienced the sudden death of a family member should receive help in managing their grief and creating a positive outlook on achieving their future. Youth is characterized as 18-25 year olds who are young, active, and inexperienced (The United Nations Educational, Scientific and Cultural Organization [2]. Matthews states that there are no linear patterns, no "normal" behaviours, and no rules to abide by when grieving the loss of a loved one [3]. Families are impacted by the fact of death in a variety of emotional or physical ways, as well as by changes to family structures and spirituality. According to Lekalakala-Mokgele [4], everyone's grief is unique and does not follow a specific pattern or duration. Youth may express their grief in a multitude of ways, such as crying, fear, and rage. However, most bereaved people can get over their loss, but mourning sometimes gets difficult or persistent [5]. Individuals who lose a family member go through various stages of grief which they may not always fully understand. These stages are often time related, and each stage is necessary to reach the following stage. In this process of change, grieving people almost always need the support of others. The common thread for all grieving people is change. Not only do they change inwardly, but changes in daily life and routines change immediately, leading to a measure of adjustment and disruption which can be hard to deal with. This process, too, needs support. Someone who unexpectedly loses a family member goes through specific stages of grief, ranging from emotions such as denial to acceptance. Tyrrell,

Harberger, and Siddiqui describe Kubler-Ross's Five Stages of Grieving as (1) denial, (2) anger, (3) bargaining, (4) depression and (5) acceptance. People who lose a close relative go through different stages of grieving, some of which they may not completely comprehend. It can sometimes be interpreted as a prescription for progress that bereaved individuals must consider to find a way to deal with loss, according to Stroebe, Schut, and Boerner [6]. Conversely, studies pointed out that stages are usually time-related and that each step must be completed before moving on to another [7]. The stages of grief can overlap, and different people experience grief in numerous ways. People do not always go through each step to get over their grief [8]. Grieving individuals, such as young people, often require help from others during this period of transformation. Transformation is the one thing that almost all grievers have in connection [9]. They undergo both internal and external transformation, which causes some adjustments that can be challenging to deal with [10].

A person who has lost a family member unexpectedly may experience a range of emotions, from denial to acceptance, for example [11]. They frequently consider giving up their individual ambitions in the process of assuming responsibility for a new function that involves helping those (who were previously supported by the deceased) in need [10]. The memories of happy moments they shared with the departed could be obscured by sad experiences [12]. It is crucial for everyone to look after themselves while they are grieving as their emotional and physical resources can be completely depleted by the effects of a traumatic experience. One may manage oneself or go through a difficult situation by taking care of one's bodily and emotional requirements [13]. Self-management is the practice

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of constructing to improve, in order to progress through various stages of grieving, grow in strength, and inspire themselves with hope for a better future [14]. Youth could therefore benefit from self-management. Lenzen, Daniels, Van Bokhoven, van der Weijden, and Beurskens define self-management as the degree to which persons have the ability to control their own lives and to cope effectively with adjustment, such as grief [15]. Self-management is shown when those left behind after the death of a family member are dealing with sadness to improve their health [16]. Self-management can reduce the burden of losing a family member. Scientific research shows that self-management by youth employing condition-specific knowledge, beliefs, and self-regulation abilities improve health outcomes. Youth might feel preoccupied, overwhelmed, and helpless during difficult periods and stages of grieving [17]. Youth who lose their parents may raise increased alcohol usage and have strained sibling relationships [18]. An active approach promotes self-management skills through self-reflection, issue solving, and active goal planning [19]. Individuals must continue practicing self-management skills, despite emotional discomfort, because it is an ongoing healing process necessary for developing the ability to detach the self from pain and self-efficacy [20]. Intentional self-management can make family members feel stronger, create calm, and renew hope [14]. In this study, self-management related to the youth's planning, organizing, directing, and controlling. To optimize self-management therapies, it's important to recognize what causes individuals pain and sadness [20]. Youth may suffer dread and despair after losing an HIV-positive family member (HIV/AIDS) (Human Immunodeficiency Virus is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome). When a parent dies, a child in certain households must serve as a parent [18]. Grieving individuals are depressed and less motivated to self-manage [20]. Several youths attending a public Comprehensive Healthcare Clinic (CHC) (Comprehensive Healthcare means healthcare is rendered to all individuals for 24 hours, 7 days a week, with the aim of preserving their state of health. Comprehensive Healthcare consists mostly of outpatient and inpatient treatment care. This includes diagnostic care, preventative care, monitoring, and also emergency and rescue service. The provision of medicines and transport of patients.) Facility in Cape Town had panic attacks, anxiety, and purposelessness after losing a family member. It was unknown how youth managed when a family member died of HIV. Explore the lived experiences of youths on managing themselves after losing a family member to HIV/AIDS, and develop guidelines for nurses to advise youths on self-management following the loss of a family member to HIV/AIDS.

# Methodology

## Study design and setting

The researcher was able to get a thorough understanding of the phenomena of losing a family member to HIV attributable towards the use of descriptive phenomenology. Youth who attended a full-service at the CHC in Cape Town, Western Cape, in February 2020 made up the accessible population. Participants had to fulfil inclusion requirements, which included having lost a close family member to HIV who shared a household with them during the previous six months. Eleven (n=11) semi-structured individual interviews utilizing the inquiry method and a 45-minute interview guide were undertaken. Data saturation was reached by the use of probing inquiries, which also produced insights into the youth's life experiences [21]. According to an agreement with the CHC nurses, participants were recruited between January and February 2020. A banner at the CHC entryway asked patients to participate. After health consultations, staff sent patients (youth) to an interview waiting area. Participants were questioned in a quiet room at the CHC. The researcher asked participants if they allowed him to take notes and record interviews, and informed consent was obtained. Record interviews.

## Data analysis

The researcher spoke both English and isiXhosa, and some transcripts were translated from isiXhosa to English. To guarantee reliable data interpretation, the researcher translated the local language (isiXhosa) into English and had it back-translated by a bilingual editor to ensure dependability. Data transcription begins with establishing the unit of analysis to be studied, as well as choosing the individual to conduct the analysis; in most cases, it is the researcher him/herself. The entry addresses the process by which information is or is not included in a transcription, as well as the types of transcription that may occur. Finally, it situates data transcription within the qualitative research process and details what someone may anticipate from transcription and the transcription process [22]. Qualitative analysis of data involves the integration and synthesis of narrative non-numeric data which is reduced to themes and categories with the help of a coding procedure [23]. Data was organised by the ATLAS.ti programme, Version 8, to explore categories and themes.

## Trustworthiness

The study's reliability was guaranteed in several ways. Triangulation was used to verify the reliability of the results since it included a variety of data gathering techniques, including field notes and interviews. Utilizing an impartial coder who examined the study's data and findings and met with the researcher to reach an agreement helped to ensure dependability. The data represented participant voices, inquiry audit methodologies, reflexivity (fairness in inclusion criteria), and data triangulation to assure validity and reliability (interviews and field notes). Transferability was established in the study by giving a detailed account of the methods and results as proof that the research study's conclusions may be applied to different locations, circumstances, times, and people. The applicability of the findings was limited to female participants (Table 1).

**Table 1.** Demographic information and participants losses.

|          | Race  | Years | Gender | Job                                          | Children | Lost        |
|----------|-------|-------|--------|----------------------------------------------|----------|-------------|
| P1 (pilot) | Black | 24    | Female | Pharmacist Assistance                        | 1        | Mother      |
| P2       | Black | 25    | Female | Not working. college for office administration | 1        | Aunt        |
| P3       | Black | 25    | Female | Administration                               | 1        | Sister      |
| P4       | Black | 24    | Female | Studying grade 11                            | 0        | Sister      |
| P5       | Black | 19    | Female | Matric                                       | 0        | Grandmother |
| P6       | Black | 23    | Female | Health promotion                             | 0        | Sister      |
| P7       | Black | 22    | Female | Matric                                       | 0        | Aunt        |
| P8       | Black | 22    | Female | Municipality                                 | 2        | Mother      |
| P9       | Black | 21    | Female | Study college                                | 0        | Sister      |
| P10      | Black | 25    | Female | Private college                              | 1        | Brother     |
| P11      | Black | 25    | Female | Voluntary work                               | 1        | Aunt        |

# Results

Participants (n=11) were limited to black women aged 18-25 years, including the interviewee in the pilot study. They had lost a close relative to HIV. Their mothers (n=2), grandparents (5), aunts (n=2), sisters (n=1), and a brother (n=1) were the relationships with people they lost. Five participants had to take care of their children left behind by the deceased. Whereas six participants had their own children who had been cared for by the deceased. Five of the participants were uneducated and from the working class, while six were enrolled in school or a college. Four themes emerged. Overall this article will focus on the outcomes and will centre on one of them "Time-related circumstances define youth behaviour on how to manage themselves after the unexpected loss of a family member".

## Overall themes of the study

1. Time-related circumstances define youth behaviour on how to manage themselves after the unexpected loss of a family member

2. Youths go through different grieving stages after the unexpected loss of a family member

3. Managing difficult changes in daily lives of the next of kin following the unexpected loss of a family member

4. Support measures for the next of kin following the unexpected loss of a family member

## The sub-themes of the theme in use are as listed below

1. Consequences of death while siblings are still at school (consequences of death where siblings are of school-going age)

2. Suddenness of death triggers feelings of anxiousness due to the rapid shift in their role

3. Unexpected reality that the deceased family member withheld information

4. Developing unusual behaviour due to detachment from reality

When a terrible, unexpected death occurs, individuals who encounter it face significant disruption, and many may fail to adjust positively [24]. The untimely loss of a family member is shocking and upsetting. Today's youth are subjected to a significant number of traumatic occurrences, including the occurrence of unexpected death [24].

## Consequences of death while siblings are still at school

In this study few of the participants had to take care of school-going siblings following the death of a parent or relative. Children's interests and attitudes toward their education might alter as a result of the death of a family member. Siblings who have lost a family member may grieve constantly and refuse to attend school; in other circumstances, they may go to school but find it difficult to concentrate because of the grief period [25]. As an outcome, these children will almost certainly do worse in school. Participants mentioned teachers saying that children were not handling their sadness well and were not interested in doing their homework [26]. According to research by Ngesa, Tuikong, and Ongaro [27], children who experience sadness may find it difficult to concentrate in class or continue attending. These writers draw attention to the very real potential of diminished academic performance. One of the participants related how his family's oldest brother lost all access to schooling and was forced to drop out at a young age in order to help his younger siblings. This participant clearly felt a sense of pity for her brother:

"My brother had to leave school, drop out, so that he can look for work so that he can then take care of us." (P7, female, 22 years old, matric learner)

The psychological effects on siblings may cause some of them to leave school before they graduate [27]. A participant spoke of her own struggles to continue with schooling after the death of her mother, as her home environment and guardian that previously looked after her, changed to new circumstances:

"And I end up drop off the school then my cousin sister takes me, and I stay with her. She did everything for me. Like, she always talks to me that I can go to school so I can be like other children. But it was so hard." (Sad face reaction.) (P8, female, 22 years old, municipality work).

The abrupt death of a family member and breadwinner forced siblings to leave home and school:

"Since we were living with her, she was the only old person we are living with. We were living with her in Eastern Cape, my mom was here in Cape Town. And, my siblings, my cousin and so on we were just children living with her. She was the old one. We were schooling". (P5, female, 19 years old, matric learner)

Death affected school activities personally.

A participant lost concentration and felt inadequate, perceiving the loss as a personal failure:

"At school I couldn't focus. I couldn't go out with other children. I had a low self-esteem. And, (mmm) I look myself down on others. Ja". (Body shaking, avoiding eye contact.) (P5, female, 19 years old, matric learner)

The psychological and emotional well-being of children is significantly impacted by the death of a parent [28]. When orphans enter school, they may frequently feel inferior to their classmates and perhaps endure unfair treatment there [28]. After the loss of a loved one, poor academic performance is linked to mental health conditions like PTSD and signs of despair [29]. Malizia discovered that people experiencing bereavement have numerous modifications [29]. Substance misuse, guilt and shame, harmful behaviour, interpersonal issues, stress, and sadness are examples of these changes. It was evident from the foregoing that positive attitudes were required to manage the issue.

A participant exhibited bad behaviour changes at school and lacked concern about repercussions:

"I didn't cope at school (takes a deep breath). And one of my teachers noticed that I'm not the same. I am not concentrating at school. I'm careless. And, I ended up to be a disturber, by disturbing other children in the class. I am not listening. I am not doing my homework. I don't care anymore". (Sad face with tears in the eyes.) (P10, female, 25 years old, college student)

Skovdal asserts that a child or young person who has experienced HIV/AIDS-related issues is likely to have low educational achievements [30]. These children struggle to focus in class, which lowers their grades, causes them to miss class frequently, or even quit school altogether. Losing a family member or relative can bring about unpleasant obstacles in life, especially for those who are left behind in terms of connections and education. According to Akard et al. (2019: 81), children who lose a parent have quick changes in attitude toward school and a lack of respect for others, which causes conflicts and disturbance in the family.

## Suddenness of death triggers feeling anxious due to the rapid shift in their role

All family members are impacted by a loved one's death, and many of them experience worry and panic due to the unknown [31]. To control the issue, constructive thoughts that were behaviour-focused were required. It is unusual to suddenly go from being a dependent family member to needing to support oneself and raise children who are not one's own.

One participant took up increased obligations alone:

"Yes, so my worry was that what we are going to do with these two children. Because we are all staying in one house. So, ja. I was very worried about her children mostly". (Sad face.) (P6, female, 23 years old, health promoter)

Family routines and rituals terminated abruptly and evoked emotional reactions, as the departed individual had numerous background roles:

"It was tough. It was tough. Because we benefit to her. She was the one who buys food for us. She was the one who always play a role of being a parent because we don't have mom and we stay with our father.

So, she was having four kids. She was the one who always grocer, pay for TV licence, always do everything when things are going down and up. She always did it well but now we can't do anything". (Praises the sister and looks sad). (P4, female, 24 years old, grade 11 learner)

Family members frequently lose hope and worry that they will not survive after a traumatic occurrence like the death of an important family member. They feel as though their sense of identity has been "shattered," and they doubt their capacity to take care of themselves in a world without the bereaved [32].

The feeling of fear was quite overwhelming for some.

"Okay … aaaah … to be honest, mostly I had fear". (P1, female, 24 years old, pharmacist assistance)

One youngster was unsure of her abilities to financially and emotionally support her siblings:

"I feared that … uh … because my mom is no longer around I may not be able to give the kind of support that she would have given to my siblings. That is supporting them financially, emotionally". (P1, female, 24 years old, pharmacist assistance)

According to research by van der Mark, Conradie, Dedding, and Broerse women who are the primary breadwinners and reside in underdeveloped areas struggle to maintain their siblings needs while still paying for school and groceries [33].

Another participant spoke of feeling shocked about sudden loss:

"So, we were very shocked". (Facial expression of disbelief.) (P6, female, 23 years old, health promoter)

People who are in school have a harder time dealing with loss. Students frequently experience shock at their sudden freedom as well as dread, perplexity, and pressure [34]. Depressive disorders are also present. According to Haravuori, Suomalainen, and Marttunen [35], depression brought on by traumatic experiences has an even greater impact on a person's quality of life in children than post-traumatic stress disorder.

### Unexpected reality that family member withheld information

The realization by family members that the deceased kept their condition hidden, so their death came as a complete shock, is one element of the sudden death of a family member. Many people choose not to reveal details about their health situation. Choosing who to reveal to, where to disclose it, and when to do so is difficult [36]. A participant was disillusioned and sorrowful about the unexpected death of her brother, especially after the medical staff informed her about his health status:

"So, by the time he was sick I didn't realise that he was HIV positive. He didn't tell any family member that he is HIV positive. Not unless my sister went to the clinic by the day he passed away to search how he was sick, to search about his health history. So, they tell my sister that my brother had HIV/AIDS. So, he defaults to the treatment". (Sad face). (P10, female, 25 years old, college student)

Another participant was shocked by the deceased's careless behaviour in hiding her illness and not taking her medication:

"She hides it from us because she didn't tell us that she was HIV positive. She was not doing anything. She was just coming when she feels like to come to the clinic. So, she wasn't taking her medication correct". (Shakes head). (P6, female, 23 years old, health promoter)

One of the most effective ways for someone with a disease, such as HIV/AIDS or TB, to make sure they follow their treatment plan is to disclose it to others [37]. The deceased family member's secrecy may prevent them from being held accountable for properly taking their medication, which led to their deaths when they did not take it as prescribed.

A participant was shocked and angry that the deceased hid her illness and neglected treatment:

"The reason why we were shocked is that she hide it from us that she

was HIV positive. We only found out when saw the pills and asked the doctors, and they told us, "No, this person was HIV positive. And she was defaulting, that's why she passed away". (Angry face). (P6, female, 23 years old, health promoter)

"She could have told us that she was HIV positive". (Calm voice). (P6, female, 23 years old, health promoter)

HIV status secrecy is still a major issue in many areas. HIV-positive individuals frequently struggle with the conflict between their need for privacy and worries about stigmatization. According to research, it is crucial for people to let their loved ones know if they have HIV [38]. Regardless of their right to privacy, people are more likely to follow treatment guidelines if they share their health status [38].

The sharing of an individual's HIV/AIDS status to family and friends offers several advantages, according to the Centre for Disease Control for HIV Basics [39]. Increased adherence to HIV/AIDS therapy is one of the main advantages.

### Developing unusual behaviour due to detachment from reality

A detachment from reality and numerous mental health issues, including post-traumatic stress disorder (PTSD), which includes sadness and anxiety, can be brought on by exposure to terrible life experiences [35]. The results showed that individual's behaviour had changed in ways that were connected to stress and anxiety, panic attacks, and negative thinking.

A participant described her unreasonable ideas and anxieties over upcoming obstacles:

"When you stress, you think stupid things because of, you know that the person that died is a breadwinner at home. You think now where are you going to get the things she used to buy for me. It's about that. You are going to suffer more, because she was a breadwinner". (Strokes the chin). (P7, female, 22 years old, matric learner)

Many participants could not stop thinking about the incident and its aftermath:

"Eish, I was panicking then, I was panicking, and I was depressed. I was thinking all the time that … oohh … I was thinking all the time". (Bites nails), (P8, female, 22 years old, and municipality work).

## Discussion

The youths need to practice self-management during unexpected situations to enable them to cope with the death of family members with HIV/AIDS. Self-management is the ability of an individual to control their feelings and actions. According to Acharyya [40], self-management means being able to oversee unexpected tasks. It also means having the skills, ability and confidence to take charge of yourself and your daily roles and responsibilities.

Nurses should understand the grief of youths who lost a family member to HIV/AIDS for them to provide appropriate guidance to these youths who are experiencing anxiety and fear of the unknown. HIV-related deaths or illnesses affecting the family have a huge impact on the individuals and may lead to experiences of Post-Traumatic Stress Symptoms (PTSS) or Post-Traumatic Stress Disorder (PTSD). Additional mental health problems of depression and anxiety could occur [41]. When parents die, children become the head of the household in some families. They take over responsivities of their parents and must leave their childhood stage of development. This is a huge trauma and stress to them, often leading to mental health problems such as depression, anxiety and post-traumatic stress disorder [42,43].

In the Behavioural-focused approach, the nurse should first acknowledge the youth's sadness about the situation and show empathy and care by using good interrelationship skills. Empathy is commonly known as a need during times of loss [44]. The nurse should be there and assist the youth by listening and helping the youth to understand their own

value in life even after the loss of the loved ones. Youths need to regain their strength after the difficulties and challenges they have faced in their mourning over the deceased. Numerous treatment options can be used to deal with grief. Some of the interventions include grief education, support groups, group therapy, spiritual and religious sessions and individual counselling [45]. A therapeutic session can involve the encouragement of the youth to share ways of dealing with stress and negative thinking. In this way, youths are given solutions to their own situations. The facilitator can direct the discussion towards a positive outcome, while the youth can experience being the problem-solver.

Although the youth will be traumatized due to the passing of their loved one, they should be advised to focus on their future and own life. The youth needs to realise the importance of continuing their professional development of for e.g. their career so that they contribute to the community and support their family. The youth should understand how to be an anchor for their siblings after the loss of a family member in order to provide stability in the family. Youths should organize their time and allocate enough time for the responsibilities they have inherited from the deceased. They should also share their time-management progress, which will help them to keep busy during their handling of their grief. This forms part of the Natural reward approach. As part of the Cognitive behavioural approach, the youth needs to understand and acknowledge that the death of their loved ones has placed them in a different situation now and that they have to accept the responsibilities they have to take over. Many individuals suffer from self-blame and feelings of being stuck in their grief [46]. It is important for the youth to be aware that you act on what you know and that people have different responsibilities in life. They should also know that they must respect and accept the decision of the individual who has died and kept their HIV/AIDS status confidential and that it was not anyone's fault.

## Conclusion

The young person should schedule their daily activities when a family member passes away in order to maintain their pace and focus. Instead of focusing on things they cannot control, this will assist kids in realizing and comprehending their own value in the family and surroundings. According to the research by Carlsson, Bremer, Alvariza, Restedt, and Axelsson, a person's deep relationships with their deceased loved ones would suddenly become meaningless when they were alone, necessitating advance planning for daily activities. One of the most painful occurrences in a person's life is the death experience, especially which of a parent or other close relative. Some individuals feel as though the death was unjustified and shouldn't have occurred. Emotional agony, a sense of being shocked by the loss, difficulties comprehending the loss, and great love for the departed were among the common feelings brought on by loss.

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## Author's Contributions

S.H. developed the proposal with the guidance of K.J., and S.H. conducted the interviews and analysed the data with writing the report. S.H. wrote the manuscript with input from K.J. authors.

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## Data Availability

The data that support the findings of this study are available from the corresponding author, S.D.H, upon reasonable request.

## Declarations

### Ethical approval and consent to participate

The Cape Peninsula University of Technology Ethics Committee accepted the scientific methods and ethics of the study project, namely, Youth requires self-management to manage the difficult stages after the unexpected loss of a family member to HIV/AIDS for the period January 2020 – December 2021.

Approval was granted by the Cape Peninsula University of Technology (CPUT/HW-REC 2019/H2) and the Research and Ethics Committee Western Cape Department of Health (WC 201911 032). Participants got a language-specific information leaflet (English, Xhosa). Their inquiries were responded to verbally. Participants volunteered and knew that they could withdraw without penalty. Transcripts kept interviewees names secret to ensure confidentiality. A psychiatric nurse practitioner was accessible at the CHC in case a participant required psychological assistance and had to be referred. The principal researcher's computer ensured online, password-protected data. Five years after the study's release, all data will be deleted.

### Consent for publication

Not applicable.

### Competing interests

The author declares that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

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