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Article

## Sharing sensitive health information through social media in the Arab world

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### Abstract

**Background:** Sharing daily activities on social media has become a part of our lifestyle, but little is known about sharing sensitive health information in the Arab world.

**Objective:** The objective of this study is to explore how social media users in the Arab world share sensitive health information through Facebook.

**Design:** A retrospective qualitative analysis was used in the study.

**Settings and participants:** A total of 110 Facebook groups, related to HIV, sickle cell and depression were screened between 5 June and 1 December 2014.

**Results:** Forty four Facebook groups met the inclusion criteria. 28 471 posts were extracted, of which 649 met inclusion criteria. Forty two percent of health information exchanged were related to HIV, 34% to depression and 24% to sickle cell diseases. The majority of postings were from Egypt 21.1%, Saudi Arabia 20%, Algeria 10% and Libya 9.2%. Male posts were 54.2% while 45.8% were posted by females. Individuals utilized Facebook groups to share personal experiences of their disease 31%, in addition to being used for seeking queries 13.6%, offering explicit advice 8.3%, reporting signs and symptoms of the disease 7.3% and posting their communication with the health-care provider 6.6%.

**Conclusions:** Users in the Arab world use social media to exchange sensitive health information, which could have serious implications regarding the privacy of the information shared with other members of the group. On the other hand, sharing health information could have positive effects for patients, such as sharing disease experiences and peer support. However, more work is needed to ensure that Facebook users in the Arab world are aware of the potential consequences of sharing sensitive health information through social media.

**Key words:** social media, internet, Arab world, diseases, sensitive health information, Facebook, privacy issues

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## Introduction

The use of social media platforms is growing with Facebook alone constituting over 800 million users [1]. These enable users to interact in a variety of ways, functionalities and capabilities. In the United States, 74% of internet users utilize social media [2]. Furthermore, the internet has become a major source of health-related information and users are expected to significantly increase over the coming few years [3]. With the growing use of social media in healthcare, concerns are mounting over how health information is being shared.

The purpose of this study is to examine how social media users in the Arab World share sensitive health information through Facebook. The Arab World consists of 22 countries which combined have a population of ~422 million people, with over half of them under the age of 25 years [4]. The study will focus on the analysis of Mental, Genetic and Sexual forms of sensitive health information. Due to some special characteristics in the Arab world, such as high level of consanguinity, genetic disorders are common such as sickle cell anemia, with a rate of 4.20% having sickle cell trait and 0.26% having sickle cell disease [5, 6]. The Arab world continues to be perceived as a region with very limited HIV epidemiological data. The general pattern in different countries points towards emerging epidemics in high-risk populations with a general prevalence rate of 25–30 cases per 100 000 populations [7, 8]. Depression is the second among the top 10 causes of early death and disability in the Arab world, affecting females of the middle to high income population groups, more than males, with an increasing prevalence rates varying from 4% to 11% in different countries [9].

Although various laws have been enacted to protect health information, patients still fear that their information will be violated and used by unauthorized individuals or organizations [10]. A recent study on sharing sensitive health information through Facebook found that users openly sought and shared information related to behavioral, mental and genetic information without realizing the potential consequences of doing so [11]. According to the Australian National Health and Medical Research Council, sensitivity of information is difficult to universally assess and standardize [12]. Sensitivity of health information is rather based on the nature of the information, the context in which it is handled or the views of the person to whom the information is related [13]. Improper disclosures could result in embarrassment, social stigma, discrimination, or even physical harm in certain cases related to reproductive health or domestic violence [14].

Of the several studies done on sharing sensitive health information online, only few agree that issues related to patient privacy is crucial in understanding the threat towards the privacy of patients and their families. Lober *et al.* and Flowers *et al.* have shown that patients of different ages find privacy to be a primary concern when using social media for health-related information [15, 16]. Roblin *et al.* [14] while testing a social media system for its usability, reported issues related to concerns in sharing private health information. With the use of social media platforms, such as Facebook, the sharing of sensitive health information is becoming more widespread. For example, Facebook users need to consider a vast array of privacy settings available on Facebook accounts (i.e. private versus public), an account set to ‘public view’ would enable a large audience of Facebook users to have access to all information posted by the user [17–19].

Privacy violation is also a major concern when dealing with private health information. Recently, studies showed that numerous

privacy violations were carried out by medical residents and students, where they posted photographs of sensitive patient caregiving scenarios [20, 21]. As a result, there has been a call for the protection of patient privacy through the implementation of various laws to protect health information [22]. Even so, post-privacy movement advocates argue even though laws protect how information is shared and used by an organization, there are no laws to prevent individuals from sharing their own information [23]. The concept of privacy and confidentiality within the healthcare system amongst Arab societies, as discussed by Househ *et al.* [11], is of minimal concern [11]. Genetic diseases due to their chronic nature impose heavy medical, financial and emotional burdens, these may contribute patients who suffer from genetic disorders to look for information and seek support through social media [24, 25].

Other patients who also use social media for a variety of reasons are HIV patients. Obermeyer *et al.* [26] elaborated how the Arab world societies view HIV elicited contradictory expectations and responses such as denial ‘Not in our region’ and how it is difficult to break the silence around issues of sexual behavior, especially those that deviate from religious norms. Furthermore, religious magazines and doctrinal pronouncements (fatwas) have conducted an analysis of the past decade and proclaimed the illness of HIV to be a divine punishment for deviating from religion, whereas closely abiding to religious practices served as protection [27]. Another study found that the patients tend to manipulate their virtual image and be untruthful by exaggerating their life experience to be more appealing [28]. All these factors impact on why and how HIV patients share their sensitive health information via social media [29].

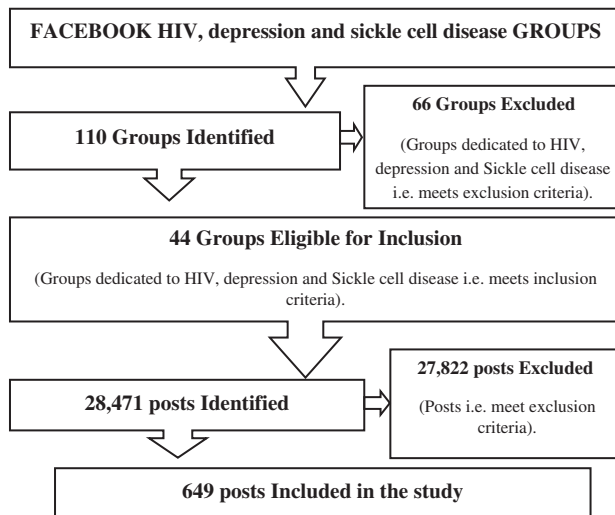
## Method

The study used retrospective methods to determine concept, content and analysis of publicly available posts in Arabic language on Facebook groups. The Social networking (SN) website Facebook was selected since it is the leading SN platform used in the Arab world [29]. Between June 5 and 1 December 2014, the Facebook search function was used through key terms in relation to HIV, depression, and sickle cell anemia in the search field for titles of Facebook groups. We identified groups focused on the diseases of interest and used content analysis to classify and analyze posts on their walls.

Inclusion criteria were that posts written only in Arabic, posts related to the three disease conditions, between 1 December 2010 and 1 December 2014. The study excluded news, promotional, marketing campaigns, repeated/spam posts, groups dedicated to other disease conditions, and those with relatively very few postings, less than 50, very short activity, less than one year or postings out of study period. The required sample size was estimated between 286 and 370 posts.

After conducting the content analysis, we identified 110 Facebook groups in Arabic language dedicated to depression, HIV and sickle cell diseases. Of those 110 groups, 44 were eligible to participate in the study because they met our inclusion criteria. From 44 included groups for analysis, there were a total of 28 471 posts, therefore, the calculated required sample size was 380, at 95% level of confidence, while the actual number that met our inclusion criteria was 649 posts, which were all included for further analysis, instead of including only the sample size, as shown in Fig. 1.

After the posts were translated from Arabic to English, using a professional translation service, the selected 649 posts were downloaded



**Figure 1** The processes of data inclusion and exclusion.

to NVivo, which is a qualitative data analysis software tool. Next, we developed a coding scheme to classify posts into categories. The coding scheme was adapted and modified based on the work of Osman *et al.* [31]. This was used to independently extract and analyze core information from the postings to determine major content themes. The study used the predetermined themes, adopted from Osman's work, and developed further inductive ones. The predetermined themes were sharing personal information or situation, seek explicit query, offer explicit advice, seeking or clarifying personal status, reporting signs and symptoms, inferred management, group stimulation and negative comments on disease. The inductive themes that were developed by the researchers are medical history, communication with provider, scheduled appointments, medication list, and laboratory or study results, providing spiritual support.

A pilot was done on six selected Facebook groups to develop the coding scheme. This initial analysis led to the identification of two main types of Facebook groups for these three conditions, i.e. HIV, depression and sickle cell. 'Support Groups' were created to meet the emotional and informational needs of people with such conditions, inclusive of their relatives, such as family members and friends. 'Awareness Raising Groups' were created to draw attention to the importance of these three conditions, or to promote a charitable organization, support a program or a fundraising event.

Posts were reviewed and analyzed individually and in isolation to any previous analyzed posts to ensure consistent application of codes and themes. We conducted a primary analysis by generating frequency counts for each theme, and each of the posts was evaluated and classified according to the dominating theme based on the highest frequency of matching with the key words and expressions of the theme. An example of the posts which illustrate the selected codes were extracted, translated to English and added to the table of codes frequency counts. Frequency and percentage of each theme with examples are shown in Table 2.

## Results

The largest geographical distribution of postings were from Egypt with ( $N = 137$ ; 21.1%), Saudi Arabia ( $N = 130$ ; 20%), Algeria ( $N = 65$ ; 10%), and Libya ( $N = 60$ ; 9.2%). Postings by male users were ( $N = 352$ ; 54.2%), while females were ( $N = 297$ ; 45.8%). The

**Table 1** Demographic details of the 649 posts

S/N	Gender	No.	%
1	Males	352	54.2%
2	Females	297	45.8%
S/N	Geographic location	No.	%
1	Egypt	137	21.1%
2	Saudi Arabia	130	20.0%
3	Algeria	65	10.0%
4	Libya	60	9.2%
5	Sudan	42	6.5%
6	Syria	41	6.3%
7	Yemen	29	4.5%
8	Iraq	25	3.9%
9	Morocco	16	2.5%
10	Tunisia	14	2.2%
11	Jordan	14	2.2%
12	Palestine	13	2.0%
13	Kuwait	13	2.0%
14	Oman	12	1.8%
15	Bahrain	2	0.3%
16	Ethiopia	2	0.3%
17	Mauritania	2	0.3%
18	Somalia	1	0.2%
19	United Arab Emirates	1	0.2%
20	Not determined	30	4.6%
Total		649	100%

age of Facebook users was not available publicly. Table 1 shows frequency distribution of posts by gender and by country in details.

The results show that 42% of postings were related to HIV, 34% to depression and 24% to sickle cell diseases. Within the themes, patients tend to share their personal health information or disease related situations ( $N = 402$ , 31%). Patients seek explicit query about their disease ( $N = 176$ , 13.6%), offer explicit advice related to the disease ( $N = 107$ , 8.3%), report signs and symptoms ( $N = 94$ , 7.3%) and post their communication with health care providers ( $N = 85$ , 6.6%). The frequency and percentage of each theme with examples of some of the posts are illustrated in Table 2.

Regarding HIV, there were a total of 70 Facebook groups but only 26 groups met the inclusion criteria for this study. From a total of 15 923 posts, we included only 271. The purpose behind Facebook group ( $N = 103$ , 38%) posts from users who were also HIV patients was mainly to share their personal information or experience. Patients posted on Facebook to seek explicit query ( $N = 31$ , 11.4%), to offer explicit advice related to the disease ( $N = 23$ , 8.5%), post their communication with the health care provider ( $N = 20$ , 7.5%), to infer management ( $N = 15$ , 5.5%), and posts for other reasons ( $N = 79$ , 29.1%) (Table 3).

Regarding depression, there were a total of 14 Facebook groups, 11 of them were included. The data showed a total of 9142 posts, of which we included only 225. The purpose of posting for depression patients was mainly to share personal information or situations relating to their disease ( $N = 68$ , 30.2%), to seek explicit query about the disease ( $N = 38$ , 16.9%), patients reporting their signs and symptoms ( $N = 29$ , 12.9%), and patients offering explicit advice related to the disease ( $N = 26$ , 11.6%), and posts for other reasons ( $N = 64$ , 28.4%).

Regarding sickle cell diseases, there were a total of 26 Facebook groups, of which we included 7. The data showed a total of 3414 posts, of which we included 153. The purpose of posting for sickle cell

**Table 2** The frequency and percentage of each theme with examples

Purpose of posting	Number (Percent of postings per code)	Example of posts (Translated from Arabic To English)
Sharing personal information/situation	402 (31.0%)	I am HIV patient since five years now and no one in my family nor my relative knows about my condition because I am from a well-known family and my life will be in danger if they now. I can't even go to the doctors and take medications because of my fear of being known as HIV patient...they might even kill my.
Seek explicit query	176 (13.6%)	I am taking cipralex since five years. Is it really good for depression?
Offer explicit advice	107 (8.3%)	AIDS test should be conducted between 3 weeks to 3 months so don't be afraid and do the test. I am an HIV positive since 1996 and I am doing well in my life and my health is good because I take my medication regularly. So I don't worry and do the test.
Seeking or clarifying personal status	43 (3.3%)	My age is 32 years old and I have this disease. Both, my brother and sister died because of this disease. Can you tell me how you are able to live with it? I can't tolerate this anymore. I am dying.
Reporting signs and symptoms	94 (7.3%)	After a long suffering with my disease, I finally found the solution and that is Wellbutrin. Since I took this medication my episodes stopped, but after only 4 days, severe signs appeared in the form of severe headache, insomnia and my depression symptoms worsened but I get those symptoms with other mood stabilizers.
Inferred management	61 (4.7%)	I have this disease since 2001, I didn't inherit it and I don't know what the cause of my illness was but I thank god for his blessings. After the Dr. diagnosed me as being bipolar he prescribed Depakin to control my depression and psychosis. However, within the past 10 years I only had 3 episodes. The last episode was in 2004.
Medical history	65 (5.0%)	
Communication with provider	85 (6.6%)	
Scheduled appointments	31 (2.4%)	
Laboratory or study results	54 (4.2%)	I have this disease since 2001, I didn't inherit it and I don't know what the cause of my illness was but I thank god for his blessings. After the Dr. diagnosed me as being bipolar he prescribed Depakin to control my depression and psychosis. However, within the past 10 years I only had 3 episodes. The last episode was in 2004.
Medication List	62 (4.8%)	
Group stimulation	57 (4.4%)	Thank you for your courage and positive comments and I hope you will stay a source of inspiration for everyone. However, I think that instead of telling everyone that you are an HIV patient, you should start with the people you trust and explain the disease nature to them. Maybe by doing so, we will win another soldier in our war against HIV and against the discrimination we face from the community. Again, I really admire your courage.
Providing spiritual support	46 (3.5%)	Since my diagnosis on 2008, I stayed away from sexual intercourse and adopted a spiritual lifestyle that keeps me close to god. I believe that if I stay close to God he will never leave me and I will find a cure for my disease. I also adopted healthy lifestyle. As a result whomever sees me knows he will never believe that I am an HIV patient since 2008. So, I don't lose hope and stay close to god
Negative comments on disease (downplay)	13 (1.0%)	Let's talk frankly. Most HIV patients brought this on themselves when they committed sins and illegal sexual relationships.
Total	1296 (100%)	All Types of Posts

patients was mainly to share personal information or situations ( $N = 37, 24.2\%$ ), posting to seek explicit query about the disease ( $N = 20, 13.1\%$ ), posting their laboratory or study results ( $N = 14, 9.1\%$ ), and posting their communication with the health care providers ( $N = 13, 8.5\%$ ), and posts for other reasons ( $N = 69, 45.1\%$ ).

HIV patients showed strong support and trust among group members, to the point that some group members revealed their real identities to one another. On the other hand, it was noted that once a patient requested other group members not to write anything about his/her disease on his official Facebook page. A few patients in this category reported misconduct by healthcare providers. Some patients reported violations done by charitable organizations forcing them to attend activities for fundraising in exchange for their required healthcare and medications. In one incident, that did not need to be included in a separate category, a counselor (non-member) threatened and posted the personal information, social and health status of a patient on the wall of one of the Facebook groups included in this study in retaliation to accusations lodged by the patient against the counselor's healthcare institution.

It was noted that patients would openly share details about their life, social/economic status, disease status, medical history, medication and healthcare management to other Facebook group members and mostly to people who identified themselves as doctors and counselors. Patients also compared their medications and gave advice on which drug or dose was better. Furthermore, several disturbing posts were noted in which a patient asking for advice on how to induce manic episodes which are characterized by elevated moods enabling patients to free themselves from depression.

Sickle cell disease patients frequently updated each other with their health status, scheduled appointments, affiliated organizations they seek treatment from, order tests and/or study results, medication name, dose and time to be given all as a form of showing support for each other. The patients also reported feelings of stigma as some patients stated they have been called addicts by healthcare providers when they ask for their morphine dose i.e. a narcotic given to the patients when they have severe pain. Patients stated their inability in paying their medical bills due to the chronic nature of their disease; as a result, they tried to reach out to doctors who offered

**Table 3** Search terms used and their translations

Disease	English term	Arabic translation
Disease 1	HIV	الأيذز
Disease 2	Depression	متلازمة نقص المناعة المكتسبة الإكتئاب
Disease 3	Sickle Cell Anemia	فقر الدم المنجلي أنيميا الخلايا المنجلية

free consultations on Facebook. More importantly, many patients in this category scanned their laboratory or study results and posted it on the Facebook group wall to get a free consultation from a doctor in the group. Some doctors asked patients to send their laboratory and study results in private messages to review it, but a few patients posted their results on the group wall instead. One patient claimed that he “was not good at using technology”. He only created a Facebook account to gain communication to specialized doctors abroad as his country’s political issues barred doctors from abroad to enter the country.

## Discussion

Five main findings could be identified for discussion. The first is that sensitive health information is exchanged in the Arab world to primarily discuss experiences about diseases. This is shown through the higher frequency of posts classified as ‘sharing personal information/situation with others’ in all of the three conditions. This is consistent with the results of another study on diabetic communities who mostly use Facebook to share personal clinical information and diabetes management strategies [32].

The second finding is that Facebook in the Arab world is used to receive free health consultations. This situation has also been associated with an increased penetration rate of Facebook users with an average, in May 2014, of over than 21.5%, 81 302 064 users, compared to 15%; 54 552 875 users in May 2013 [33–35].

The third finding is that some Facebook users are sharing sensitive health information to express their feeling of social stigma. For instance, sickle cell patients have been called addicts by their health-care providers when they ask for their morphine dose. Depression patients also, described their experience as being stigmatized for being psychiatric patient. Even more, HIV patients requested that their disease information should not be disclosed on their official Facebook page. This is understandable if we consider how HIV is viewed in the Arab world as a divine punishment for actions against religion, and therefore, many patients with this disease suffer from discrimination and societal stigma [36].

However, as there have been not many studies in this regard compared with other areas or domains [37], we are still in the listening phase, where we should collect as much information as possible to be able to make evidence-based interventions that can help the users of such platforms. We should also focus on health-related discrimination and stigma that many people with different conditions are facing. This is one of the five levels that strategies and interventions, identified by Heijnders *et al.* can be implemented in interpersonal, intrapersonal, organizational/institutional, community and governmental/structural levels, which can empower patients and help in educating the community about conditions and how to treat patients with more decency [38].

The fourth finding is that the inability of some users to use SN technology properly caused some to unintentionally share sensitive health information to a broader audience. Not many users know

how to use Facebook effectively in terms of privacy. Many updates and complicated features have been added to privacy settings, which lead to more confusion. There are always tradeoffs between providing comprehensive and precise granular controls and offering simple tools that may be broad and blunt [39]. Despite not being analyzed in this study different levels of education could be linked to the ability of some users to manage privacy settings on social media applications and websites appropriately [40]. Incidents that violate the privacy of the user, like the ones reported in this study, can always occur and one of the reasonable remedies to this issue, for the unintentional violation of privacy, is to make privacy settings more user-friendly.

The fifth finding is that Facebook is used as a social support system. Facebook members support each other in different forms and countless occasions such as updating each other about their conditions and sometimes sharing non-health-related life events. Many members of these groups post their health and social status details to be able, for example, to find a wife for marriage as what can be seen as a coping or compensation mechanism against the way they are being treated by others and being stigmatized with the previously mentioned views.

In addition to these five main findings, poverty and political turmoil might have encouraged Arab Facebook users to seek health information on an internationally open platform [41]. The political circumstances forced many physicians to leave their country, along with the subsequent poverty, which forced some patients to seek free information and consultation through Facebook.

We found that there are two main types of Facebook groups for these three conditions i.e. HIV, depression and sickle cell, which are: ‘Support Groups’, which were created to meet the emotional and informational needs of people with such conditions and their relatives such as family members and friends; and ‘Awareness Raising Groups’, which were created to draw attention to the importance of these three conditions in general, or to promote a charitable organization, support program or a fundraising event. This result is consistent with previous studies that used content analysis as well and evaluated user engagement in the representation of the most 20 searched for health conditions on Facebook and found out that a large number of these pages’ content was marketing/promotion, followed by information/awareness. Additionally, only a small number of pages were dedicated to social support and there were six conditions that were ‘not represented by any support pages (i.e. HPV, diarrhea, flu symptoms, pneumonia, spine, HIV)’ [33].

The study also revealed that engagement, which was measured by the number of the likes, was less in patient support and information/awareness pages than it was for pages that contain general support and marketing/promotion [33]. Having said that, it should be noted that the researchers in this study excluded the marketing/promotional content from the analysis. However, our findings do not concur with the results of another study on breast cancer Facebook groups which reported that, among the study population, the awareness groups had the most members even though other groups such as fundraising and product or service promotion related to fundraising or awareness were identified [43].

We should help to translate this healthy and supportive atmosphere noticed in the virtual world into actual programs to educate the public about the effects the current ways treatment of people with these conditions would affect them, which could result in an improved quality of life, including the services provided to them socially and medically. Patients could be victims of privacy violations that occur intentionally or accidentally due to many reasons

such as the complexity of the SN privacy settings versus the lack of knowledge many users have.

Regarding study contributions to the current state of knowledge, this is the first study that examines the role of social media and healthcare in the Arab world. This study expands on the work of Househ, conducted in 2010, which calls for further study about sharing sensitive health information through Facebook. This study helps in understanding the role of social media and healthcare in the Arab world and how people are using it to exchange health information. This study should pave the way as well for more comprehensive studies on medical conditions that can for example adapt a multi-level intervention program and test its effectiveness in the awareness of these diseases in the Arab region. The study showed that people with these conditions openly exchange information with other Facebook members.

Here we can also mention some limitations regarding our study. When it comes to the internal validity issues, our study is prone to selection bias since that we are targeting patients with these only three conditions i.e. HIV, depression and sickle cell disease. In order to overcome this weakness, the researcher should randomly choose posts from different groups to ensure that they are sufficiently representing the population. Furthermore, since that a single researcher solely rated the posts, human bias can affect the internal validity of this study. The personal bias of the researcher in interpreting the results can be present as well in this study since that a single researcher was responsible for conducting manual data analysis. To overcome this obstacle, a panel of researchers should verify this process. Due to the fact that there is no way of authenticating the posting of the Facebook user's, content validity can be compromised. In addition, cultural sensitivity that varies considerably around the Arab World can play a role in how users share their sensitive information, and therefore, the result of the study cannot be generalized for the entire population which differs in its culture and ethnicity.

## Conclusion

People in the Arab world are increasingly sharing their personal information on social networks such as Facebook. Patients in particular, join online support groups for specific conditions to get support and share their experience with other members of a social media group with similar condition.

Health privacy laws need to be revised in light of the current protocols for exchange of health information using social media. There is an increased need for laws and legislations that protect and empower patients with regards public access and misuse of sensitive information through social media platforms.

There is a need for the existence of ongoing awareness in the form of educational campaigns, conducted in collaboration between healthcare providers and social media groups on the impacts of sharing sensitive health information through social media platforms. This study can be used later on as a benchmark for intervention-based studies in the future.

The main implications of this study is to highlight the privacy issues in the Arab world and keep it from being underestimated because people tend to share their information openly with those who have the same conditions and to those expected to offer support and help while treating them with compassion at the same time. On the contrary, they hide the truth of their disease, even from their family because they are afraid of the social stigma usually associated with these conditions in our Arab society.

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