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Perceptions of Wheelchair Users with Spinal Cord Injury on Community Re-integration Following Inpatient Rehabilitation in Rwanda: A Qualitative Study, 2024.

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ABSTRACT

INTRODUCTION: Spinal cord injury (SCI) is a life-altering condition that significantly impacts physical health and community reintegration. Despite the global prevalence of SCI, wheelchair users often face barriers to reintegration, particularly in low-resource settings like Rwanda. This study explored the perceptions of wheelchair users with SCI regarding community reintegration, focusing on facilitators and barriers.
METHODS: A qualitative phenomenological design was employed, with nine participants recruited via purposeful sampling from two Rwandan healthcare facilities. Semi-structured interviews were conducted in Kinyarwanda, transcribed verbatim, and translated into English. Thematic analysis was performed using Braun and Clarke's framework to identify key themes.
RESULTS: Four main themes emerged: (1) Family and societal attitudes, including negative stigma and diminished social support; (2) Environmental accessibility, with challenges such as inaccessible pathways, bathrooms, and public transportation; (3) Activity limitations, particularly in daily living tasks and wheelchair mobility; and (4) Participation restrictions, such as reduced involvement in communal and religious activities. Participants reported dependence on caregivers, social isolation, and environmental barriers as major hindrances to reintegration.
CONCLUSION: The study highlights multifaceted challenges faced by wheelchair users with SCI in Rwanda, emphasizing the need for comprehensive interventions. Recommendations include pre- and post-discharge education, community awareness campaigns, home assessments for accessibility modifications, and policy changes to improve infrastructure. Addressing these barriers is crucial for enhancing community reintegration and quality of life for individuals with SCI.

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INTRODUCTION

According to the World Health Organization (WHO), approximately 15% of the global population, around one billion people, live with some form of disability, including spinal cord

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injury (SCI), physical disabilities, and visual, auditory, communication, cognitive, or learning impairments [1]. The global incidence of spinal cord injuries, both traumatic and non-traumatic, is estimated to range from 40 to 80 cases per million individuals annually [2]. Based on 2012 world population estimates, between 250,000 and 500,000 new cases of spinal cord injury occur each year, an event that is often life-altering and catastrophic [3].

Spinal cord injury (SCI) represents a major global health concern [4], frequently resulting in varying degrees of paralysis, sensory deficits, bowel and bladder dysfunction, and chronic pain [5]. These impairments profoundly affect physical health and contribute to limitations in daily activities and restrictions in social participation [6]. Understanding individuals' perspectives on community reintegration is, therefore, essential for addressing their needs post-injury.

For most people with SCI, wheelchairs are vital for mobility. Selecting an appropriate wheelchair and necessary accessories is crucial for optimizing functionality, fostering independence, and preventing secondary complications [7]. In Rwanda, studies have shown poor community reintegration outcomes among individuals with SCI, with gender and level of injury being significant influencing factors [8]. Effective community reintegration is strongly associated with increased life satisfaction and a sense of competence, which are key determinants of psychological and economic well-being [6].

Evidence indicates that individuals with newly acquired SCI are often discharged from hospitals after relatively short rehabilitation stays, without adequate knowledge or functional skills needed for life in the community. This gap in preparation is linked to poor reintegration outcomes and even higher mortality rates [4]. It is therefore crucial to explore how individuals with SCI perceive their own reintegration into the community.

A recent systematic review and meta-analysis reported that approximately 69% of wheelchair users with SCI experience falls annually and remain poorly integrated into their communities [7]. Community reintegration is a dynamic and ongoing process influenced not only by rehabilitation services but also by family and social support, personal attributes, access to attendants, transportation, housing availability, and broader environmental factors. Although community reintegration is a central goal of SCI rehabilitation, it remains challenging to achieve through clinical care alone [9]. Rehabilitation professionals often assume that improved physical function will naturally result in greater community participation, yet community integration is a multifaceted concept encompassing diverse aspects of societal engagement.

Therefore, the aim this qualitative study was to explore the perceptions of wheelchair users with spinal cord injury regarding community reintegration, identifying facilitators and barriers to active participation in the community and functioning following discharge from inpatient rehabilitation.

METHODS

Study Design

This study employed a qualitative phenomenological design, selected to explore the lived experiences and perceptions of individuals with spinal cord injury (SCI) through rich, descriptive narratives.

Study Population and Setting

The study population included male and female outpatients with spinal cord injury who use a wheelchair as a mobility aid. Participants were recruited from two healthcare facilities in Rwanda: Gahini District Hospital and HVP/Gatagara Orthopedic and Rehabilitation Hospital.

Sampling Strategy

A purposeful sampling technique was used to recruit participants who met the inclusion criteria. This method was chosen to identify individuals with direct experience of community reintegration following SCI, as they could provide in-depth and meaningful insights [10]. This approach is beneficial for studying information-rich cases, which yield greater understanding rather than generalizable data [11]. The sample consisted of individuals with diverse characteristics, including different age groups, education levels, socioeconomic status (homeowners vs. renters), sex, and residence (urban vs. rural), to capture a wide range of perspectives.

Sample Size

The final sample size was nine participants. Recruitment continued until data saturation was achieved—that is, no new themes or insights were emerging that would significantly contribute to answering the research question.

Inclusion and Exclusion Criteria

Participants included males and females aged 18 years and above, with either traumatic or non-traumatic SCI, who use a wheelchair for mobility and had been discharged from inpatient rehabilitation.

Excluded were individuals with SCI who did not use a wheelchair, and those who were still hospitalized and had not yet returned to the community after injury.

Data Collection Tool

Data were collected using a semi-structured interview guide developed based on the study objectives and relevant literature. The guide was designed to explore participants' experiences and perceptions of community reintegration following hospital discharge.

Procedure for Data Collection

The researcher met participants at outpatient rehabilitation clinics, where the study's aim and purpose were explained clearly. Individuals meeting the inclusion criteria were purposively selected, provided with informed consent forms, and interviewed only after obtaining written consent.

Interviews were conducted face-to-face in private rooms to ensure confidentiality and allow participants to speak freely. All interviews were held in Kinyarwanda, the participants' native language, to facilitate expression. A digital audio recorder was used to capture the conversations, and interviews were later transcribed verbatim. This process helped minimize recall bias and preserved the authenticity of participants' responses.

The interviews began with a grand tour question: "Can you please tell me about any challenges you encountered at home and in the community after being discharged from the hospital?"

This approach encouraged open dialogue since probing questions were used to elicit deeper responses [12]. The researcher also took field notes during interviews to complement audio recordings. At the conclusion of each session, participants were thanked for their time and contribution.

Data Analysis

Data were analyzed using thematic analysis with a deductive approach, which allows themes to be identified based on the research objectives and existing literature [13]. Braun and Clarke's six-step framework was followed: Familiarization with the data; Generating initial codes; Searching for themes; Reviewing themes; Defining and naming themes; and Producing the final report [14].

The researcher transcribed the recorded interviews in Kinyarwanda and compared transcripts to the original audio to ensure accuracy. A professional translator then translated the transcripts into English. The translated data were thoroughly reviewed to identify recurring patterns, commonalities, and divergences in participants' responses.

Themes were developed by coding shared impressions and responses. Then, a second round of independent coding was performed one week later to ensure consistency. Discrepancies were resolved through comparison and refinement of emerging themes. Thematic development was grounded in the participant narratives and supported theoretical understanding of community reintegration. Open coding was conducted line by line, followed by a second level of codingto group and conceptualize the findings.

Ethical Considerations

Ethical approval was obtained from the College of Medicine and Health Sciences Institutional Review Board (Ref: CMHS/IRB/132/2024). Permission to conduct the study was also secured from both participating hospitals. The researcher also obtained permissions from Gahini District Hospital and HVP/Gatagara Orthopedic and Rehabilitation Hospital to conduct the study. All participants received a detailed explanation of the study objectives and procedures. Informed consent, including consent for audio recording, was obtained in writing before participation.

Confidentiality was maintained by using codes and initials instead of names. Participation was voluntary, and participants were informed of their right to withdraw from the study at any point without any adverse consequences.

RESULTS

Participant Characteristics

The study involved nine individuals with spinal cord injuries, most of whom were male, with only one female participant. The injuries were broadly categorized as cervical, thoracic, or lumbar, based on the areas of the body affected. Most participants had thoracic injuries, while the remaining had either cervical or lumbar injuries.

Chronicity here defined as the period (in years) a person has been living with a spinal cord injury, ranged from 1 to 6 years. Ages ranged from 18 to 59 years, with an average age of 39.3 years (27-53 years). In terms of education, some participants had completed only primary school, a few had completed high school, and others had attained a bachelor's degree or higher.

All participants used manual wheelchairs for mobility. Regarding marital status, some were married, others were single, and one participant had become separated after the injury. Most participants were unemployed at the time of the study, with only one employed and another still a student. The majority lived in rural or remote areas, while a few resided in urban settings. Table 1 shows the characteristics of the participants.

Perceptions on Community Reintegration

During the in-depth interviews, participants were asked about their perceptions of community reintegration following discharge from inpatient rehabilitation. Four main themes emerged related to the reintegration of spinal cord injury survivors who use wheelchairs: (1) Family members' and societal attitudes and relationships; (2) Environmental accessibility; (3) Activity limitations; and Participation restrictions.

These themes were further divided into subthemes, including: attitudinal environmental barriers, social support challenges, inaccessible pathways, inaccessible bathrooms, public transportation difficulties, limitations in activities of daily living, restrictions in wheelchair mobility, inability to participate in communal and religious activities, and challenges in social interaction.

Family Members' and Societal Attitudes and Relationship Challenges

When participants were asked about the attitudes and relationships of their family members and society at large, many perceived negative attitudes. Two key subthemes emerged: negative attitudes and social support challenges.

Attitudinal Environmental Barriers: The perceived attitudinal barriers involved frequent insults directed at wheelchair users with spinal cord injury, ranging from family members to broader society, as reported by several participants:

"The attitude of my family towards me changed, primarily because their living conditions changed since I am no longer able to provide the financial support I used to before my injury." (P2)

"After the accident, it was very hard for some of my family members to accept me." (P5) He further expressed, "One of my family members discriminates against me, and some have not even checked on me by phone for a year, to the extent that they consider me as if I were no longer alive." (P5)

"After my health condition worsened, I lost all my friends and some family members because they see

Table 1: *General characteristics of participants*

No.	Gender	Age	Marital status	Employment status	Education	Residence	Housing	Chronicity (Years)	Injury level
1	Male	35	Separated	unemployed	A level	Urban	Rent	6	Thoracic
2	Male	42	Married	unemployed	Bachelor	Rural	Rent	3	Cervical
3	Male	39	Married	employed	Masters	Urban	Owner	2	Lumbar
4	Male	34	Single	unemployed	Bachelor	Rural	Owner	3	Thoracic
5	Male	27	Single	unemployed	Primary	Rural	Rent	1	Thoracic
6	Male	18	Single	Student	A level	Urban	Owner	1	Lumbar
7	Male	47	Married	unemployed	Primary	Rural	Rent	2	Cervical
8	Male	59	Married	unemployed	Primary	Rural	Owner	5	Thoracic
9	Female	53	Married	unemployed	Primary	Rural	Owner	3	Thoracic

me as a burden and wish I would die." (P7)

Social Support Barriers: Lack of social support, as a subtheme related to societal attitudes, revealed strong emotions among participants. When asked about their relationships with family and social circles, some reported receiving support, while others described a lack of support from relatives and society. For example:

"…I didn't receive family support. I was living alone, which made it very difficult to perform basic daily activities." (P1)
"Neighboring families discriminate a lot, often saying discouraging things to me." (P7)
"I lost all my friends except for some family members who try to care for me." (P7)

Several participants noted that support from family and friends diminished over time. One participant shared:

"At first, they would reach out to you, but as time passes, they seem to give up on visiting or talking to you." (P2)
He added, *"I can now go up to two months without a visitor, unlike before."*
"My disability has made some relatives tired of my condition. They may not say it openly, but their behavior shows it." (P2)

Environmental Accessibility

Participants regularly reported physical and social barriers affecting their reintegration. Subthemes related to physical barriers included inaccessible pathways, bathrooms, and public transportation.

Inaccessible Pathways: When asked about challenges faced in daily community life, many participants emphasized problems with physical accessibility, such as narrow doorways, uneven ground, and stairs:

"I was renting a place that was not designed for people with disabilities, which made mobility difficult. For example, there were stairs in the house that prevented me from moving easily in my wheelchair." (P1)
"It remains difficult to fully access my home, including the bathroom and kitchen, due to uneven outside ground. The owner built the house without considering wheelchair users." (P2)
"My home environment, especially the walkways and corridors, are too small to accommodate my wheelchair. I often need family members to help transfer me from the wheelchair to a chair, and then pull the chair into the bathroom." (P3)
"Moving inside and outside the house and going to the toilet is a challenge. When the house was built, I did not plan on having a disability. The toilet is far from the house." (P4)
"I live in a house built in 1982, with door widths of about 70 centimeters. It's always hard for me and my caregiver to move around the home. Sometimes, I prefer to stay in the living room to reduce the burden." (P8)

Inaccessible Bathrooms: Some participants described difficulties with bathrooms that were not accessible or suitable for wheelchair users, as illustrated by the following quotes:

"The washrooms in the house were not designed to accommodate a person with a disability like me who uses a wheelchair, as they had pit latrines." (P1)
"I usually need support from family members to transfer me from my wheelchair to a chair, and then they pull the chair into the bathroom. I depend on my caregiver when using the bathroom and toilet. For quick needs, I use a basin after the caregiver locks the children in another room." (P3)

Public Transportation

Participants reported significant barriers when accessing public transportation, which limited their ability to attend important places. Some shared the following experiences:

"Public transport does not accommodate us comfortably; it is difficult to get on, and there is no space for a wheelchair." (P1)

Activity Limitations and Participation Restrictions

When asked about challenges and facilitators encountered at home and in the community after discharge from hospitalization, two main themes emerged: activity limitations and participation restrictions.
Two subthemes related to activity limitations arose: limitations in activities of daily living (ADLs) and difficulties with wheelchair mobility.

Limitations in Activities of Daily Living: Most participants reported dependence on others for self-care activities such as dressing, bathing, eating, and toileting. They emphasized their need for assistance to carry out these daily tasks, as shown by the following quotes:

"I depend on my caregiver when using the bathroom and toilet. For quick needs, I use a basin after the caregiver locks the children in another room." (P3)
"Toileting is difficult because of pain when sitting on the toilet. Dressing is also a challenge due to pain when flexing my legs." (P6)
"When my wife is not around, it's very hard for me to manage basic daily activities." (P8)
"Bathing is a big challenge because the caregiver has to help me while I am sitting in the wheelchair. I cannot reach the bathroom on my own, so someone has to bathe me in the wheelchair." (P9)

Limitations in Wheelchair Mobility: When asked whether their home setup facilitated or hindered their self-care, some participants identified their limited wheelchair mobility as a barrier to performing activities of daily living:

"I did not receive any formal wheelchair training; my caregiver and I taught myself. No one informed me about wheelchair safety precautions." (P3)
"The main problem I face at home is transferring in and out of the wheelchair." (P6)
"The doors are about 70 centimeters wide, making it very hard for my caregiver and me to move around the house." (P8)
"It is very hard for me because I always need someone to propel my wheelchair. At home, I live with my husband and one grandchild, and finding someone to assist me with wheelchair mobility remains difficult." (P9)

Most participants experienced limitations in wheelchair mobility, which increased their dependence on others. To cope, some developed strategies to help them move around, as one participant shared:

"I usually receive support from family members to transfer me from my wheelchair to a chair, and then they pull the chair into the bathroom." (P3)

Participation Restrictions

Regarding participation restrictions, participants' perceptions during the interviews related mainly to the following subthemes: inability to participate in religious and communal activities and reduced social interactions.

Inability to Participate in Communal and Religious Activities: The subtheme of inability to participate in communal and religious activities emerged when participants were asked whether their level of community participation had changed since being discharged from inpatient rehabilitation compared to before their spinal cord injury. This limitation was often linked to inaccessible roads and environments that hindered their involvement:

"Activities like going to the market, church, or other community gatherings are hard to participate in." (P1)
"Activities such as going to the market or church require someone's assistance because the environment is not wheelchair-friendly." (P2)
"Participating in community activities is challenging because the remote area where I live is not accessible for wheelchair users." (P4)
"Community participation stopped immediately after my injury because the village roads are too rough for wheelchair propulsion. Acceptance is the only remaining option." (P7)
"Getting to public places like churches, markets, or community events is still difficult because they are not designed to accommodate people in wheelchairs." (P9)

Some participants expressed a strong desire to engage in community and religious activities but felt restricted by geographical and environmental factors:

"It is something I always want, but my wheelchair cannot manage hills since my arms are weak, and most areas are difficult to reach due to uneven ground." (P8)

Challenges in Social Interaction

When asked about difficulties in interacting with friends and family, participants reported a decrease in social interaction due not only to stigma but also neglect by friends, family, and neighbors, as described below:

"My disability has made some of my relatives tired

of my condition." (P2)

"The first challenge I faced was stigma from friends, family, and even myself." (P3)

"What I cannot do is visit their homes because I worry about how they perceive me, and I feel like I might damage their houses since they are not accessible for persons with disabilities. It's better to stay home." (P3)

"Social participation and leisure with friends is difficult. I never go to church or other community activities because of self-stigma." (P5)

DISCUSSION

This study explored the perceptions of wheelchair users with spinal cord injury (SCI) regarding community reintegration following discharge from inpatient rehabilitation. Community reintegration encompasses multiple aspects, including recreation, occupation, social activities, and relationships with others. Similarly, inclusion aims to provide equitable access to opportunities, resources, and information for all individuals, regardless of ability. The perceived challenges identified in this study include activity limitations, participation restrictions, negative attitudes from family members and society, and environmental accessibility barriers. The findings are discussed under these four main themes.

Activity limitations emerged as a major concern among wheelchair users with SCI after inpatient rehabilitation discharge. Most participants reported difficulties with activities of daily living (ADLs) and wheelchair mobility, which they perceived as significant barriers to community reintegration. Persons with SCI often experience activity limitations due to the increased physical demands associated with their condition [15]. Participants highlighted difficulties with self-care activities such as eating, bathing, mobility, and dressing, especially involving the lower limbs, often requiring assistance to perform these tasks.

These findings align with previous studies. For example, van Diemen et al. reported that poor self-care significantly affects quality of life and self-efficacy among SCI patients [16]. Participants in their study occasionally required help with basic needs such as eating, dressing, and toileting, leading to increased dependency and poorer health outcomes. Similarly, Benedicto et al. found high levels of mobility dependence, particularly in activities such as stair navigation and transfers between the floor and wheelchair [17].

Participation restrictions, especially in social activities, were commonly reported as hindering community reintegration. Numerous studies have demonstrated that increased participation is associated with higher quality of life for individuals with SCI. Greater social involvement enhances community reintegration and fosters feelings of self-worth and confidence [9]. Therefore, promoting participation is a key goal of rehabilitation for people with SCI.

Environmental barriers have been shown to negatively impact social participation. A Swiss study reported that many community-dwelling individuals with SCI experience participation restrictions due to environmental obstacles and limited physical independence [18]. Community reintegration contributes to life satisfaction and a sense of competence, playing an important role in both psychological and economic well-being.

Consistent with the present findings, social interactions with friends and family, alongside feelings of isolation, were highlighted in the study "Patients, Partners, and Practitioners: Interactions and Meaning-Making Following Spinal Cord Injury" by Alexis Bender [19]. Similarly, Mohammadi et al. identified a lack of social support as a significant challenge [20]. Environmental inaccessibility has also been recognized as a primary barrier to social participation and integration among individuals with SCI in South Africa [21].

Joyce Mothabeng's study found that wheelchair users with SCI often experience limited social participation, live in isolation, and feel unprepared for community life, resulting in poor integration [22]. Participants in the current study similarly perceived their environment as unsupportive, which negatively affects the development and maintenance of a positive self-concept. Successful social involvement requires an unbiased assessment of an individual's abilities, irrespective of mobility limitations.

The daily effort required to perform ADLs, the stress related to significant interpersonal relationships and role interactions, and the loss of satisfaction from previously enjoyed occupational and leisure activities have been noted to compound social difficulties among persons with SCI [23].

Social interaction problems were also reported in a study by Serres-Ade et al. in Tanzania where restricted access to home- and community-based activities was highlighted [24]. Overall, these findings are consistent with numerous studies reporting social interaction challenges within families and communities among individuals with spinal cord injury.

Persons with SCI openly shared their experiences and challenges following discharge from inpatient rehabilitation. The most frequently discussed issues were attitudinal environmental barriers and social support challenges. Negative attitudes from family members and society were reported in various studies. For example, Hanass et al. found that people with disabilities often face negative attitudes from their community, friends, and family [25]. Similarly, Halvorsen et al. reported poor relationships with family and friends among people with spinal cord injury [26]. As echoed by participants in this study, such negative social dynamics contribute to a reduced quality of life, highlighting the importance of positive relationships with family and friends for wheelchair users with SCI.

Inadequate social support from family, friends, and colleagues, combined with negative societal attitudes, has been shown to make life more difficult for persons with SCI. This was documented in a Swiss study by Lucian et al., consistent with participant experiences in the current study [15]. A systematic review by Müller et al. demonstrated that social support positively correlates with physical and mental health, pain management, coping strategies, adjustment, and life satisfaction in individuals with SCI [27]. Family support, in particular, has a positive effect on social reintegration [9], and early social support is considered essential during rehabilitation to enhance community integration. Many people with SCI describe their current community involvement as substantially reduced compared to the past, often due to negative attitudes from others, a finding also reflected in this study [28].

A significant number of participants perceived environmental accessibility as impacting their daily lives. The most problematic areas identified were inaccessible pathways, public transportation, and bathrooms. Similar challenges have been documented elsewhere; for example, Joseph et al. reported public transport as a major barrier for persons with SCI in South Africa [28]. Farzana et al. found environmental accessibility barriers among SCI patients in Bangladesh [29]. Rapidi et al. noted that home accessibility is a major challenge and that public transportation often remains unavailable to wheelchair users [30]. These findings align with the current study, where participants reported similar challenges upon returning to the community. Comparable results have also been observed in South Africa, where an inaccessible built environment and insufficient support systems limit participation in various activities [31]. Accessibility is essential for effective community reintegration and plays a crucial role in overall satisfaction for wheelchair users with SCI.

Rehabilitation professionals can benefit from these findings by looking beyond the physical needs of wheelchair users with SCI. Focusing on the individual needs of each client is vital to support successful reintegration into their communities and enable participation in meaningful activities.

This study included only patients attending outpatient rehabilitation services; persons with SCI still undergoing inpatient rehabilitation were excluded. Another limitation is the variability in chronicity (time since injury) among participants, which may affect community reintegration due to differences in adaptability over time. Finally, unequal resource distribution among Rwandans could have influenced the results, as environmental modifications vary and are likely to impact accessibility and participation differently.

CONCLUSION

The findings of this study revealed that wheelchair users with spinal cord injury (SCI), upon discharge from inpatient rehabilitation, face numerous challenges in their communities. These challenges span across environmental accessibility, activity limitations, attitudinal barriers, and participation restrictions. Participants expressed the need for comprehensive interventions both before and after discharge to support successful reintegration into society.

The findings of this study highlight the urgent need for comprehensive and multifaceted interventions to support individuals with spinal cord injury (SCI) in their transition from inpatient rehabilitation to community life. First, education for both SCI clients and their families should be an integral part of the discharge process. Providing information about the challenges of reintegration, self-care techniques, wheelchair use, and available community resources can better prepare individuals and their caregivers to navigate life after rehabilitation.

In addition, raising community awareness about disability is essential. Negative societal attitudes and stigma were consistently reported by study participants, indicating the need for targeted awareness campaigns that promote inclusion, empathy, and understanding of people with disabilities. These efforts can play a crucial role in changing perceptions and fostering a more supportive environment for individuals with SCI.

Home visits should also be incorporated into discharge planning to assess the living conditions of the person with SCI and identify necessary environmental modifications. Personalized home assessments can help ensure that the physical environment is adapted to the user's needs, thus promoting independence and reducing caregiver burden.

Lastly, there is a pressing need for wheelchair accessibility to be integrated into national and local urban planning policies. Ensuring that public spaces, roads, transportation systems, and buildings are accessible is fundamental to achieving full community participation for wheelchair users. Inclusive infrastructure not only supports reintegration but also affirms the rights and dignity of persons with disabilities as active members of society.

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