

Research Report

Searching for Answers: Information-Seeking by Young People At-Risk for Huntington's Disease

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Abstract.

Background: Health information-seeking is a coping strategy used globally by individuals with a personal or family history of a medical condition, including Huntington's disease (HD).

Objective: We sought to ascertain information-seeking practices of young people who grew up at-risk for HD.

Methods: Participants ages 18–25 were recruited from HD support organizations. An online 96-item survey assessed information-seeking motivations and timing as well as information topics accessed, sources, and needs.

Results: Fifty young adults (mean age 22.2 years) who grew up at-risk for HD responded. HD had been generally kept a secret (35.4%) or talked about but difficult to bring up (43.8%) in many families. Most (78.0%) became aware of HD in their family before age 15. Few (7.1%) received information resources at the time of disclosure. Most (68.1%) first sought information independently online, half within a week of disclosure. Respondents were motivated to understand the potential impact of HD on their personal lives and family members, obtain general information about the condition, and learn about treatments and research. Most sought information on clinical features and inheritance with >80% interested in information on symptoms and personal risk and >70% about having children.

Conclusion: Limited information is provided to young people when first informed about HD in their families leading to independent, mostly online information-seeking. Information is used to build knowledge about HD to facilitate coping and life planning. Healthcare providers can direct young people to reliable resources and guide parents in talking with children to ensure that information needs are met.

Keywords: Adolescents, disclosure of results, Huntington's disease (HD), information seeking, predictive genetic testing, risk communication, young adults

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INTRODUCTION

Huntington's disease (HD) is a dominantly inherited neurodegenerative condition characterized by progressive loss of cognitive and motor function and increased prevalence of psychiatric symptoms. Typical onset occurs in the fourth or fifth decade of life with progression for median 20 years until death [1]. There is no cure for HD. Limited management of symptoms is the only available intervention though clinical trials are in-progress and provide hope for future therapies [2]. Approximately 43,000 individuals living in the United States have manifest HD and an additional estimated 123,000 individuals in the United States are at 50% risk to develop HD [3]. Genetic testing of individuals at-risk for HD who are younger than age 18 is typically recommended against unless manifest disease is suspected [4, 5].

Young people face unique challenges when a parent is manifesting symptoms of HD. Previous studies have reported that teens and young adults growing up in families with HD experience stressors and hardships distinct from their same-age peers. These include assuming the responsibilities of managing home life, caring for loved ones, feeling isolated and helpless, and grappling with their own 50% risk for HD [6]. Even when a parent receives a positive genetic test result for HD but is asymptomatic, children still may face stressors due to the diagnosis in the family and parental anxiety [7].

Families vary in terms of how a diagnosis of HD is disclosed and discussed with children. This can include the age disclosure occurs, who is involved in the conversation, how much and what information is shared, and general openness of communication [7, 8]. Reflecting on their upbringing, some individuals have reported having awareness of HD throughout their life. Others report having a hunch that "something was wrong" before being told about the diagnosis in their family or that HD was kept a secret [7, 8]. Given differences in family communication styles and the diverse experiences of at-risk young people growing up in families impacted by HD, information needs among this population may vary significantly. Some are well-informed about HD and have knowledge about available information or support resources while others have been left with limited guidance and unanswered questions.

Health information-seeking is a globally used coping strategy among individuals with a personal or family history of a medical condition [9–13]. Studies of young people at-risk for HD have reported that

gathering information by "doing reports or research" is a helpful and frequently used coping mechanism and that accessing information about HD is important to them [12, 13]. Few studies to date have examined the process of information-seeking in young people at-risk for HD. This study aimed to characterize information-seeking practices including motivations, timing, and sources used by young people who grew up at-risk for HD as well as expand understanding of the information needs of this population.

MATERIALS AND METHODS

Study design, procedures, and participants

This retrospective study utilized an online survey targeted at young adults who grew up at-risk for HD due to their family history of this condition. Between October and December of 2018, participants were recruited through two major support organizations: the Huntington's Disease Youth Organization (HDYO) and the Huntington's Disease Society of America (HDSA). The survey link was posted on the HDYO and HDSA webpages, sent via three email blasts to the HDYO, HDSA, and HDSA National Youth Alliance (NYA) memberships, and posted six times on HDYO and HDSA social media pages as well as the HDSA research blog.

Eligible participants were aged 18- to 25-years-old, had a family history of a parent or grandparent with HD, and could complete the survey in English. Information about the aims of the study and eligibility criteria were included on the introduction page of the anonymous survey. Individuals provided consent for participation by entering the survey with the option to exit at any time. Participants who completed the survey had an opportunity to be entered into a drawing for a \$25 gift card. Survey responses were not linked with identifiers obtained for gift card distribution. This study was exempt from review by the University of Michigan Medical School Institutional Review Board, HUM00147604.

Survey development

We conducted a review of the literature exploring experiences of teens and young adults at-risk for HD and health information-seeking about HD. This search was also expanded to include health information-seeking for conditions that are inherited and childhood-onset (e.g., 22q11.2 deletion syndrome) or adult-onset and acquired (e.g., cancer).

The online survey was developed by a multidisciplinary team including a genetic counseling student at the time of the study (CLC), a neurologist experienced in clinical and research work with HD (RLA), two genetic counselors with experience in predictive genetic testing for HD and pediatric genetics respectively (WRU, BMY), and the Director of Youth Services for HDYO at the time of the study (CS). Survey items were adapted from validated instruments including the Health Information National Trends Survey (HINTS Survey) and the Huntington's disease quality-of-life battery for carers (HDQoL-C) to explore the experiences of this population [14–19]. Novel questions were also developed by the research team to assess respondents' perspectives of growing up with and learning about HD in their family, information-seeking motivations and practices, and information needs.

The survey consisted of 5 sections eliciting information on 1) experiences growing up with HD in the family, 2) information-seeking timing, motivations, and topics sought, 3) approaches to information-seeking and sources utilized, 4) ranked preferences on how participants obtain information about HD from a support organization, and 5) participant demographics. Participants were asked to answer 39 questions with up to 57 additional questions depending on previous answer choices. Of the total 96 questions, 70 were multiple-choice or multiple-answer, and 26 were open-response. The survey was piloted by four young adults with a family history of HD recruited by the Director of Youth Services (CS) for HDYO. Feedback on readability and time to complete the survey (estimated 30 minutes) was provided by these young adults and incorporated. Survey data were collected and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at the University of Michigan (CTSA: UL1TR002240) [20, 21].

Statistical analysis

Respondents' experiences growing up with and seeking information about HD are reported as descriptive statistics. To assess preferred formats of receiving information about HD from a support organization, respondents were asked to rank their top three of thirteen provided options. Per guidance from the University of Michigan Consulting for Statistics, Computing and Analytics Research (CSCAR) core, a rank score was applied to each item per response (score of 3 for first-choice, 2 for second-choice, 1

for third-choice, 0 for unranked) and the mean score was calculated across participants for each item. One-sample *t*-test was used to compare each mean score to the expected mean if all items were ranked as equal.

Qualitative analysis

A qualitative analysis was conducted to identify common themes related to the information-seeking motivations of young adults growing up at-risk for HD. Specifically, respondents were asked their motivations for information-seeking or attending HD events where information could be obtained. A total of 129 open-ended responses to seven questions were analyzed utilizing inductive coding [22]. The codebook was developed using input from three members of the study team who independently read and analyzed each response to develop codes for the motivations cited by the respondents. Codes were discussed and reapplied to open responses until consensus was achieved.

Analysis resulted in a final set of 19 codes that were organized into four general themes. These represent respondents' motivations to seek information or attend HD events. Definitions for the four themes were developed and agreed upon by the study team:

- **Knowledge:** to gain new knowledge or insight
- **Support:** to use interpersonal relations as a support mechanism
- **Involvement:** to contribute to a goal larger than the self for the HD community
- **Additional drivers:** unique ideas which were not fully represented by the themes above, including internal coping/self-support, lack of communication from purported information sources, and that information needs change over time

As the goal of this study was to explore information-seeking needs and motivations, the presented results focus on themes of *knowledge* and *additional drivers*.

RESULTS

Forty-two individuals completed the survey in full and eight others partially completed two or more sections. Some respondents were not prompted to answer all questions based on previous answers. Demographic information is available for the 42 respondents who completed the full survey. Mean age was 22.2 years with a range of 18 to 25 years. Most respondents identified as female (37/42, 88.1%)

Table 1
Sample demographics

Demographic variables	n = 42	%
Current age (y)		
18	4	9.5
19	2	4.8
20	5	11.9
21	7	16.7
22	3	7.1
23	4	9.5
24	6	14.2
25	11	26.2
Mean: 22.2 y, Median: 23 y		
Gender identity		
Female	37	88.1
Male	4	9.5
Non-binary	1	2.4
Race/Ethnicity		
Caucasian only	34	81.0
Caucasian/Hispanic or Latino	3	7.1
Hispanic or Latino	1	2.4
Other	4	9.5
Education		
Postgraduate	7	16.7
College graduate	12	28.6
Some college	14	33.3
Other post-high school training	1	2.4
High school graduate/equivalent	8	19.0

Some participants chose to not complete all survey questions or were not prompted to answer all questions based on previous answers.

and most had some college education or more (33/42, 78.6%) (Table 1). Notably, nearly all (46/50, 92.0%) had a biological parent with manifest HD, almost a quarter of whom (11/46, 23.9%) were deceased at the time of the study. The remaining respondents (4/50, 8.0%) had a biological parent who was asymptomatic and reported to have a positive genetic test result for HD. Most (40/50, 80.0%) respondents had lived with a symptomatic family member at some point growing up, mean length 10.3 years (Table 2). Nearly half (17/42, 40.5%) had already undergone genetic testing for HD.

Family disclosure and communication about HD

Most (39/50, 78.0%) respondents became aware of HD in their family before age 15 and around half (26/50, 52.0%) before age 12 (Table 2). Most recalled becoming aware when told by a family member about the diagnosis in the family (17/50, 34.0%) or at the time of a parent’s or other family member’s diagnosis (13/50, 26.0%). Some (11/50, 22.0%) “sensed something was wrong” for some time before being told about the diagnosis of HD. Fewer (9/50, 18.0%) reported they were generally aware of the condition

Table 2

Experience growing up with and learning about HD in the family

	N = 50	%
Biological parent with or at-risk for HD		
Mother	27	54.0
Father	23	46.0
Parent status		
Deceased, had symptoms	11	22.0
Living, has symptoms	35	70.0
Living, no symptoms	4	8.0
Age of becoming aware of HD in the family		
Early childhood – age 6 or younger	10	20.0
Later childhood – 7 to 11	16	32.0
Early adolescence – 12 to 14	13	26.0
Later adolescence – 15 to 17	6	12.0
Young adulthood – 18 to 23	5	10.0
Way of becoming aware of HD in the family		
Always been generally aware	9	18.0
A family member disclosed	17	34.0
Sensed something was wrong, but not told for some time	11	22.0
Parent was diagnosed	8	16.0
Another family member was diagnosed	5	10.0
Frequency of contact with symptomatic family members while growing up		
Daily	29	58.0
Weekly or a few times a week	2	4.0
Monthly or a few times a month	5	10.0
A few times a year	5	10.0
Less than yearly	2	4.0
Never	7	14.0
	n = 40	%

Years lived with a symptomatic family member*

2 – 5 years	9
6 – 9 years	9
10 – 13 years	11
14 – 17 years	4
18 – 21 years	7

Mean: 10.3 years, Median: 10 years

*This does not consider that a family member may have died or lived separately

	n = 48	%
HD was . . .		
Openly discussed in my family	10	20.8
Talked about but difficult to bring up	21	43.8
A secret in my family	17	35.4

Some participants chose not to complete all survey questions or were not prompted to answer all questions based on previous answers.

from a young age but were not able to remember a specific disclosure experience or when exactly they learned about the condition. For those who remembered first being informed by a family member, many (15/17, 88.2%) were told by at least one parent and some (6/17) 35.3% by both parents. The at-risk or affected parent was involved in the disclosure around half the time.

Most respondents remembered that when growing up, HD was either generally “kept a secret in [their] family” (17/48, 35.4%) or “talked about but difficult to bring up” (21/48, 43.8%). Fewer reported that HD was “openly discussed in [their] family” (10/48, 20.8%). More than half (29/50, 58.0%) of respondents had attended a doctor’s appointment for HD with a family member in the past. Only some (9/50, 18.0%) remembered receiving a recommendation to speak with a healthcare provider with expertise in HD when they became aware of the diagnosis in the family.

Information-seeking approaches

Information-seeking timing, motivations, and approaches were elicited (Table 3). Of respondents who remembered the time at which they were told about HD, whether as a new disclosure or after sensing something was wrong, very few (2/28, 7.1%)

remembered being provided information resources. Among respondents who became aware of HD at age 12 or older, half (11/22, 50.0%) sought information within a week with most doing so the same or next day. Respondents were asked whether in general they mostly looked for information independently, were given information without asking for it, or both about equally. The majority (34/47, 72.3%) reported mostly looking for information independently and few (3/37, 6.4%) were mostly given information without asking for it. Virtually all (45/47, 95.7%) looked for information for their own use and nearly half (21/47, 44.7%) looked to share with at least one other person. Further, around two-thirds (31/45, 68.9%) report they sought information to “fill in the gaps” in their understanding and another 22.2% (10/45) looked for information out of curiosity.

Most (32/47, 68.1%) respondents first sought information about HD through a general online search for ‘HD’ or ‘Huntington disease’ (Table 3).

Table 3
Seeking information about HD

	N=28	%
Provided information resources at time of awareness		
Yes	2	7.1
No	22	78.6
Do not remember	4	14.3
	n = 22	%
When information was sought after becoming aware (age 12 and older)		
Same or next day	9	40.9
Within a week	2	9.1
Within a month	3	13.6
Within a few months to a year	3	13.6
More than a year later	5	22.7
	n = 45	%
Approach to getting information about HD		
I seek information to fill in the gaps in my understanding	31	68.9
I seek information mostly out of curiosity	10	22.2
I get information that happens to pass my way	3	6.7
I do not look for information	1	2.2
	n = 47	%
Looked for information or was given information about HD		
I mostly looked or asked for information on my own	34	72.3
I looked for information and was given information about equal	10	21.3
I mostly was given information without asking for it	3	6.4
For whom was information sought		
For myself	45	95.7
To share with at-risk family members	14	29.8
To share with friends or significant others	10	21.3
To share with symptomatic family members	6	12.8
To share with teachers	6	12.8
For school projects or presentations	2	4.3
At least one other person	21	44.7

Some participants chose not to complete all survey questions or were not prompted to answer all questions based on previous answers.

In subsequent searching, respondents continued to rely heavily on internet-based resources including HD support organizations (43/45, 95.6%), general online searches (42/45, 93.3%), and social media (25/45, 55.6%). Fewer (17/45, 37.8%) sought information from a healthcare provider. Most (33/45, 73.3%) eventually sought information from family members (on average 2-3 family members per respondent). More than half (28/45, 62.2%) asked at least one parent for information. None sought information from their at-risk or affected parent unless they also sought information from their other parent. Other family members from whom information was sought included a sibling (17/45, 37.8%), aunt or uncle (14/45, 31.1%), cousin (9/45, 20.0%), or grandparent (6/45, 13.3%).

Respondents were asked to rank their preferred method of receiving information about HD from an HD organization from thirteen provided options. The most preferred format was articles ($p < 0.002$) followed by social media posts ($p < 0.006$) which were ranked significantly higher than the expected mean had all items been ranked equal. This was followed by, in order: online support groups, camps or retreats, conferences, emails, in-person support groups, videos about HD, text summaries of information, newsletters, podcasts, “frequently asked questions” pages, or interactive games, none of which were ranked significantly higher than the expected mean.

Information topics

Respondents searched for a wide range of information topics related to HD (Table 4). Most sought information related to clinical features and inheritance of HD with more than 80% interested in

information on symptoms and personal risk for HD. Other commonly desired information topics included process/steps involved for getting genetic testing, having children, age of onset, and expected lifespan. All but two topics (prenatal genetic testing and if insurance will cover testing) were sought by more than half of respondents. Slightly more searched for information about ongoing research (clinical trials, lab research, etc.) than for a cure for HD. Fewer searched for management/treatment information. Of note, 42.9% (18/42) had previously completed a class assignment or paper about HD. Few respondents (7/43, 16.3%) reported having remaining questions for which they have not been able to find answers. These questions included scientific concepts about HD (risk related to intermediate alleles, anticipation, etc.), how to cope or find appropriate support, and how to secure life insurance prior to genetic testing.

Motivations for information-seeking

Qualitative analysis of responses revealed that young people have multifaceted motivations for seeking information about HD. Themes of *knowledge* or *additional drivers* are presented here with excerpts included in Table 5 given the focus of the study on information-seeking. Within the *knowledge* theme four sub-categories emerged: *personal impact*, *general knowledge*, *family impact*, and *treatment, research, or cure*. Information was most often sought to understand the *personal impact* HD could have on the respondent’s life such as what the future may hold if they develop symptoms and how to prepare for that possibility. *Personal impact* also included seeking information about genetic testing to clarify their risk of symptoms and the risk for future children. Many wanted to gain *general knowledge* about

Table 4
Information topics sought

Respondents (n = 47)	Clinical features and inheritance	Treatment and support	Genetic testing and planning for the future
> 80%	Symptoms Personal risk		
70 – 79%	Age of onset Lifespan	Ongoing research	Process/steps involved for genetic testing Having children
60 – 69%	Cause of HD	Cure for HD	What is genetic testing Where to go for testing Impact on future insurance Cost of testing
50 – 59%	Risk for family members	Management/treatment Support groups Caring for family	
< 50%			Prenatal genetic testing If insurance will cover test

Some participants chose not to complete survey or were not prompted to answer all questions based on previous answers.

Table 5
Motivations for information-seeking

Theme and Motivations	Excerpts
Knowledge	Personal Impact “To understand what may happen to me , and how I could best prepare myself .” – Participant 5 “Wanted to get tested for my own knowledge and for the sake of future children .” – Participant 15
	General Knowledge “My motivation for looking for information about HD was wanting to know what [HD] is . I only knew the name and knew what ending results looked like.” – Participant 11
	Family Impact “To try and see if it would explain my mother’s behavior .” – Participant 17 “I want to know if my siblings will be okay . And what might happen to their kids .” – Participant 36
	Treatment, Research, or Cure “To find out more about . . . current ongoing clinical research trials and/or medical advancements .” – Participant 59 “I was looking for a cure .” – Participant 6
Additional Drivers	Internal Coping Mechanism or Self-Support “To learn more and be more understanding about [HD]. Helps to stay more positive in life that way .” – Participant 4 “Sometimes knowledge makes you feel better .” – Participant 28
	Lack of Communication “I felt like the notoriously ‘old school’ clinic . . . was taking a paternalistic approach to revealing only certain things to me .” – Participant 46 “I had this craving for answers of things my parents would never answer .” – Participant 9
	Change Over Time “ When I was 10 the motivation was to understand more of what I had been told and try to really grasp what this all meant. As I grew older the motivation was to understand how I play a part in all of this and how this affects me.” – Participant 3 “ First looking into it , I didn’t feel quite the same connection. After talking to a genetic counselor and seeing my mother get worse , I learned to ask more questions about the people around me.” – Participant 36

the condition including information on the etiology, clinical features, and lifespan of a person with HD. Some aimed to learn about *family impact* of HD for both symptomatic and asymptomatic family members. They expressed wanting to understand the life experience of family members with manifest HD, find information that would explain an affected parent’s behavior, learn what to expect for the disease course, or learn how to provide better care for the affected person. They also wanted to understand the risk for HD in asymptomatic family members who had not yet undergone genetic testing. Finally, respondents made clear their interest in learning about *treatment, research, or cure* for HD. They reported interest in keeping current with ongoing research about HD including clinical trials and other advancements, ultimately hoping for a treatment or cure.

A number of participants identified *additional drivers* that included motivations for information-seeking beyond acquiring knowledge (Table 5).

Sub-categories in this theme included *internal coping mechanism or self-support*, *lack of communication*, and that motivations *change over time*. Several young people acknowledged that the process of information-seeking contributed to their *internal coping mechanism or self-support*, assisting with internal regulation of mood. They expressed that knowledge can improve overall mindset about risk for HD, helping a person adjust or maintain a positive outlook in life. Some noted that *lack of communication* drove their information-seeking. They recalled looking for information that was previously withheld from them, highlighting challenges associated with HD being kept a secret. Further, some respondents indicated that motivations to seek information *change over time*. Specifically, as respondents grew older, learned of new diagnoses in their family, or witnessed symptom progression in loved ones, different amounts and topics of information were desired and sought.

DISCUSSION

This study is the first to take an in-depth look at both how young people learn about HD in their family and subsequently seek information. Results provide insight about approaches to and motivations for information-seeking. This work also highlights gaps in communication about information related to HD in families. Generally, HD was either kept a secret or a difficult topic to bring up in a family. At the time of disclosure, few respondents remember being provided information resources. The majority became aware of the diagnosis shortly before or during the formative years of adolescence, a developmental stage characterized as a time of separation from parents with increased reliance on social contacts and the formation of a personal identity [23, 24]. As earlier studies have shown, the stress associated with growing up at-risk for HD and in a family impacted by the diagnosis can affect young people during this developmental period [6, 7]. Limited family communication about HD or lack of informational guidance has the potential to contribute to these stressors. As half of the respondents sought information within a week of being first informed, the current study suggests that timely access to information is important.

This work finds that young people seek information to facilitate coping with a familial diagnosis or personal risk and actively seek information about ongoing research. This echoes previous literature showing that information is critical to the coping process and research is of interest, especially to those who are asymptomatic and test positive [12, 13, 25, 26]. Strategies for coping highlighted in this study include using knowledge about the condition to empower oneself and learning what the future may hold to guide life planning. Most respondents sought information on ongoing research and finding a cure for HD, demonstrating motivation to stay up-to-date on advancements. The majority of respondents in the current study are connected to HD support organizations and have had their questions about HD answered.

This study identified a major gap in information communication within families impacted by HD. Few respondents remember being provided information at the time of disclosure about HD in their family. After disclosure, most first looked for information through a general online search about HD and subsequently relied heavily on internet-based information resources. Participants who searched for information

more than a decade prior to participation in this study had less access to information relevant to at-risk young people; online content has increased in recent years, with the HDSA NYA Facebook page first emerging in 2010 and the HDYO website going live in 2012 [27, 28]. While a plethora of medical information is currently available online, the process of identifying and evaluating reliable information can be challenging. Previous studies describing information exchange in online HD forums find that information posted may be factually inaccurate [29, 30]. Lack of direction to reliable resources may result in a young person being under- or mis-informed which could exacerbate the challenge of coping with personal risk for HD.

Healthcare providers can give guidance to families in talking with children about a diagnosis of HD in a family member. The first disclosure event is an opportunity for families to provide information about HD and to direct children to reliable resources. Increasing healthcare providers' awareness of the information needs of this population and of available resources is crucial in ensuring that young people connect to relevant and appropriate information. Resources detailing how to talk with children about a diagnosis of HD in the family have been developed by both HDSA and HDYO and can be provided to families [31, 32].

A major limitation of this study involves ascertainment bias. Since respondents were recruited through HDYO or HDSA, they may be more likely to engage in high levels of information-seeking compared to those not connected to HD advocacy organizations. Furthermore, the number of respondents was small, reaching just a small subset of young people who grew up at-risk for HD. Notably, nearly all respondents had a symptomatic or deceased parent which may influence information-seeking behaviors and motivations. Another limitation is the retrospective nature of the information collection. Participants may not accurately recall details of their experiences learning about and growing up with HD or of information-seeking actions taken years prior to this study. Future studies may survey families recruited from testing and treatment centers who may not yet be connected to a support organization. Since the current study focused specifically on experiences of young adults, future studies may address the perspectives of parents, healthcare professionals, or others involved in the disclosure or information-seeking process to gain a holistic understanding of unmet needs in families impacted by HD.

Conclusion

This study is the first to take an in-depth look at the intersection of information-seeking and the experience of learning about HD. The authors explore how learning about and growing up in a family impacted by HD influences information-seeking needs and activities. While information resources were available to at-risk young people who were connected to a HD support organization, information provided by family members at the time of disclosure was limited. Most participants independently sought information about HD. Healthcare providers' awareness of information needs and available resources is important to ensure that young people are provided with accurate information and are supported in adapting to their risk status and familial diagnosis of HD.

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CONFLICT OF INTEREST

Chandler Swope was employed with the Huntington's Disease Youth Organization (HDYO) during the time of study execution.

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